

# A systematic review of the qualitative literature on older individuals' experiences of care and well-being during physical rehabilitation for acquired brain injury

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## Abstract

**Aims:** To acquire an in-depth understanding of how older individuals diagnosed with acquired brain injury (ABI) experience their well-being and care when undergoing physical rehabilitation.

**Design:** Systematic literature review.

**Data sources:** The electronic databases of PubMed, CINAHL, APA PsycInfo, ASSIA and SCOPUS were searched from 2005 to 2020. Extensive reference checking was also conducted.

**Review methods:** A systematic review was conducted following PRISMA guidelines, including predominantly qualitative studies. Studies' quality was appraised using the critical appraisal skills programme (CASP) tool.

**Results:** Seventeen studies met the inclusion criteria. Following methods of thematic synthesis, four overarching interpretive themes were identified: (a) Rehabilitation processes and their impact on older individuals' well-being; (b) Identity and embodiment concerns of older individuals during rehabilitation; (c) Institutional factors affecting older individuals' care and well-being experiences; and (d) Older individuals' participation in creative activities as part of rehabilitation.

**Conclusion:** Organizational and structural care deficiencies as well as health disparities can adversely impact older individuals' autonomous decision-making and goal-setting potentials. The discrepancy between older individuals' expectations and the reality of returning home along with the illusionary wish to return to a perceived normality, can further negatively affect older individuals' sense of well-being. Constructive communication, emotional support, family involvement in rehabilitation and creating a stimulating, enriching social environment can humanize and facilitate older individuals' adjustment to their new reality following ABI.

**Impact:** There is a lack of qualitative research on older individuals' ABI rehabilitation experiences, especially traumatic brain injury incidents. Further study should consider patients' concerns over their involvement in decision-making and goal setting about

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their care. Overall, this review reveals the need to examine further the significance of humanizing care and the factors that affect older individuals' sense of well-being.

#### KEYWORDS

acquired brain injury, nursing, older individuals' experiences, physical rehabilitation, stroke, systematic review, well-being

## 1 | INTRODUCTION

Acquired brain injury (ABI) is one of the most common neurological diseases, afflicting around 939 per 100,000 individuals worldwide (Dewan et al., 2019), with older people (65 years and above) being one of the most affected age groups (Jones et al., 2011; Yates et al., 2006). ABI is a chronic condition that pertains to mild or severe brain damage occurring after birth, which can entail serious life-changing ramifications and a potential high probability of mortality (Chan et al., 2013; Corrigan & Hammond, 2013; Giustini et al., 2013; Oyesanya, 2017). The literature further distinguishes between two types of ABI: traumatic brain injuries (TBIs) and nontraumatic brain injuries (nTBIs), mainly stroke. Essentially, the main difference between the two types concerns the cause of the brain damage, with the former referring to brain damage caused by an external force, whereas the latter to damage caused to the brain by internal factors (BIAA, 2020).

ABI's resulting consequences may be mild, moderate or severe (temporary or permanent) impairments and functional changes in one or more areas, leading to personal and psychosocial difficulties for individuals (Giustini et al., 2013; Jones et al., 2011). Common consequences experienced by people living with ABI range from physical to cognitive, emotional and behavioural difficulties, such as headaches, memory loss, depression and aggression (Giustini et al., 2013). Moderately to severely injured individuals may receive specialized rehabilitation care, including physical, psychological and/or neurological therapy, occupational therapy, speech/language therapy and social work (Giustini et al., 2013). The overall goal of ABI physical rehabilitation is to improve an individual's functional abilities and emotional state to live independently at home and in society in the face of the injury's residual effects (Giustini et al., 2013). Given the impending increase in ageing populations (United Nations, 2020) and the fact that ABI is often a life-changing condition, physical rehabilitation for older individuals needs to focus more on these people's potential to live well.

There are different approaches related to well-being in the literature, including psychological, physical, socio-economical, mental and philosophical (Diener, 2009; Galvin & Todres, 2013). The current review will approach well-being from a philosophical perspective and based on the humanizing framework of care, as developed by Galvin and Todres (2013). Their definition captures the subjective, experiential and dynamic nature of well-being, emphasizing its positive and strength-based potential of enabling and empowering individuals to move forward, evolve and adapt to any potentially difficult life changes (Galvin & Todres, 2013). From this perspective, well-being can be considered a much deeper and more complex phenomenon

than the mere absence of illness and suffering. Under the prevailing conditions, the concept of well-being during the physical rehabilitation of older individuals with ABI becomes quite salient deserving greater consideration, especially in improving ABI treatment programs (Jones et al., 2011).

### 1.1 | Background

Studies of the last two decades identify an increase of ABI incidents on 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 (Gardner et al., 2018; Grigorakos et al., 2016; Peterson & Kegler, 2020). Also, stroke is the most common nTBI, with the risk of having a stroke doubling for every decade of life after 55, and with approximately 50% of all strokes occurring in people over age 75 and 30% over age 85 (Lui & Nguyen, 2018; Michael & Shaughnessy, 2006).

Research has shown that older individuals with TBI can achieve similar rehabilitation results regardless of the severity of the injury compared with younger patients (de Bonis et al., 2010; Lilley et al., 2016; Mak et al., 2012; Taussky et al., 2012). Hence, age and severity are insufficient indicators of accurate TBI prognosis (Peters & 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 et al., 2008; Wood, 2008). Jones et al. (2011) conclude that changes in individuals' well-being after ABI are greatly affected by personal and social changes due to the injury. Boosting self-confidence and gaining more support from relatives can also play a crucial role in reducing the injury's negative impact (Jones et al., 2011).

Various qualitative and quantitative studies have investigated stroke individuals' experiences of rehabilitation, focusing either on their experiences about their daily lives after their discharge from the hospital or on their physical rehabilitation experiences during their hospitalization (Almborg et al., 2010; Barbour & Mead, 2012; Taule et al., 2015). Previous research also focused on individuals' experiences of poststroke fatigue (Barbour & Mead, 2012; Eilertsen et al., 2013), on individuals' involvement in their rehabilitation goal setting (Brown et al., 2014; Lloyd et al., 2014; Wressle et al., 1999) and on age-related perspectives with particular emphasis on older individuals (Andersson & Hansebo, 2009; Pound et al., 1994).

Beyond empirical research studies, there are literature reviews exploring stroke individuals' inpatient physical rehabilitation experiences.

Luker et al. (2015) reviewed 31 studies, and all reported negative experiences of rehabilitation, including disempowerment, boredom and frustration, lack of control, lack of understanding and lack of effective communication. Rosewilliam et al. (2011) also indicate negative experiences and various barriers that hinder applying 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.

Still, there seems to be a scarcity of literature that identifies links between 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. Qualitative studies dealing with this subject area are also quite limited, as most recent literature mainly adopts quantitative methods.

## 2 | THE REVIEW

### 2.1 | Aim

The purpose of this review is to acquire an in-depth understanding of the available literature on how older individuals diagnosed with ABI experience care and well-being during rehabilitation for ABI.

### 2.2 | Design

The current review focuses on the systematic investigation of primary qualitative research studies that explore the experiences of older individuals with ABI about their well-being and physical rehabilitation. We used the process outlined by Bettany-Saltikov and McSherry (2012) to review the available literature systematically. The first author carried out the search, screening, data extraction and quality appraisal of the studies. All authors assessed and approved the search, screening and data extraction processes, thus avoiding any inconsistencies. All authors carried out the analysis, synthesis of results and writing up of the manuscript.

The PEOT (Population, Exposure, Outcome, and Type of studies) format was used to identify the significant components of the review's question (Khan et al., 2003). Subsequently, we used the Preferred Reporting Items for Systematic Review and Meta-analyses (PRISMA) guidelines to comprehensively display the identified records' selection process and report the findings (Moher et al., 2009).

### 2.3 | Search methods

Specific keywords and synonyms were identified and developed for each PEOT question component. Truncations and abbreviations of the keywords were also used with specific Boolean

TABLE 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*

operators to obtain as many relevant results as possible (Watson, 2020). Table 1 presents the search terms and keywords used to conduct the electronic search. The first column lists the PEOT components and the second column presents all the keywords, truncations and abbreviations that we identified. Table 1 represents the final refined search version of this systematic literature review that includes the keyword 'stroke'. The inclusion of the keyword 'stroke' in the search strategy was important since stroke constitutes one of the most common ABIs in older populations, and at times studies use the terms 'stroke' and 'ABI' interchangeable (Lui & Nguyen, 2018).

A comprehensive search was conducted from April to May 2020, using the electronic databases of PubMed, CINAHL, APA PsycInfo, ASSIA and Scopus. Further refinement of the literature search included filtering by the language (English), the age of informants (65 years and older), and the period of publication (2005–2020). The results from the databases' search are presented in Table 2.

### 2.4 | Eligibility criteria

The current review developed specific eligibility criteria to guide the overall screening process and selection of studies. The review included qualitative studies that focused on the experiences of care and well-being of individuals aged over 65 years (or mean age over 65 years), living with ABI and undergoing/underwent physical rehabilitation, which takes/took place in a formalized care setting or at home. Furthermore, for studies to be eligible for inclusion in the current review, their emphasis needed to be on caring.

The review excluded articles that focused on individuals who received rehabilitation more than once and for another reason apart from ABI and studies researching people diagnosed with brain injury as part of a drug trial. Studies whose participants were only family members, carers or health professionals were also excluded. Lastly, the review excluded studies that referred to hospitalizations in intensive care units, coronary care units or high dependency units because they provided rehabilitation of critically unwell people (NHS, 2019).

## 2.5 | Search outcomes

In total, 2746 records were retrieved from the databases' initial search. The number of results was adjusted to 2464 after removing the duplicates. The inclusion/exclusion criteria were then applied by screening each of the remaining studies' title and abstract. This reduced the number of results to 217. A second screening took place by carefully reading each of the 217 studies' full text to assess which ones met the inclusion criteria. Ultimately, 14 studies were found to meet the eligibility criteria fully. The reference lists of these 14 studies and the lists of previous relevant literature reviews were then hand searched thoroughly to discover any potentially valuable resources, yielding three additional studies. In total, 17 studies were selected for this review. Figure 1 displays the PRISMA flow diagram, which provides an overview of the review search's selection process.

## 2.6 | Quality appraisal

The included studies were assessed for their methodological quality by applying the critical appraisal skills programme (CASP) tool to strengthen further the review's internal validity (Critical Appraisal Skills Programme, 2018). The quality appraisal produced no studies of insufficient quality. All articles scored with high methodological quality: seven studies met all 10 criteria of the CASP checklist, while the remaining 10 met 9 out of 10 criteria, as they did not explicitly examine or reflect on the researchers' potential biases and/or influences. The lack of reporting

of this specific item in some studies did not impact the articles' quality. The methodological quality score of each study is presented in Table 3.

## 2.7 | Ethical considerations

The current study is a systematic review, and therefore it was not required to be submitted for an ethics committee approval. Nonetheless, extra care was taken to ensure that all studies included in the review confirmed they had approval from ethical committees and maintained ethical principles.

## 2.8 | Data extraction and study characteristics

Data extraction captured the necessary information about the individual studies' key characteristics and results (Centre for Reviews & Dissemination, 2009). Overall, selected studies were published between 2005 and 2019 and provide comprehensive qualitative data from 211 participants from 8 different countries. Table 4 presents the characteristics of the included studies.

## 2.9 | Synthesis

The synthesis of the selected studies' content was based on the *thematic synthesis approach*, as developed by Thomas and Harden (2008), by taking the form of three stages. First, all studies' outcomes and results were coded using the NVivo software. The codes were assessed and reviewed to ensure their meaning remained consistent without misinterpreting and misrepresenting key ideas (Creswell, 2009). Overall, 85 preliminary codes were developed. Secondly, codes were categorized according to similarities and differences, forming nine descriptive categories. Lastly, from these categories, four overarching interpretive themes were identified: (a) Rehabilitation processes and their impact on older individuals' well-being (b) *Identity and embodiment concerns of older individuals during rehabilitation*; (c) *Institutional factors affecting older individuals' care and well-being experiences*; and (d) *Older individuals' participation in creative activities as part of rehabilitation*. An overview of the developed themes and categories is presented in Table 5.

TABLE 2 Results from the databases' search

Database	Search results (filters applied)	
	Filters (Language: English; date range: 2005–2020; age of informants: 65+ years)	Results after duplicates were removed
PubMed/MEDLINE	218	216
CINAHL Plus	389	330
APA PsycInfo	253	93
ASSIA	1062	1024
SCOPUS	824	801
Total results	2746	2464

## 3 | RESULTS

### 3.1 | Reported findings

#### 3.1.1 | Theme 1: Rehabilitation processes and their impact on older individuals' well-being

Theme one focuses on older individuals' experiences about their adaptation to physical rehabilitation and how rehabilitation processes impact on their sense of well-being. In the work of Bennett et al. (2015) and Galvin et al. (2009), older individuals focused on their

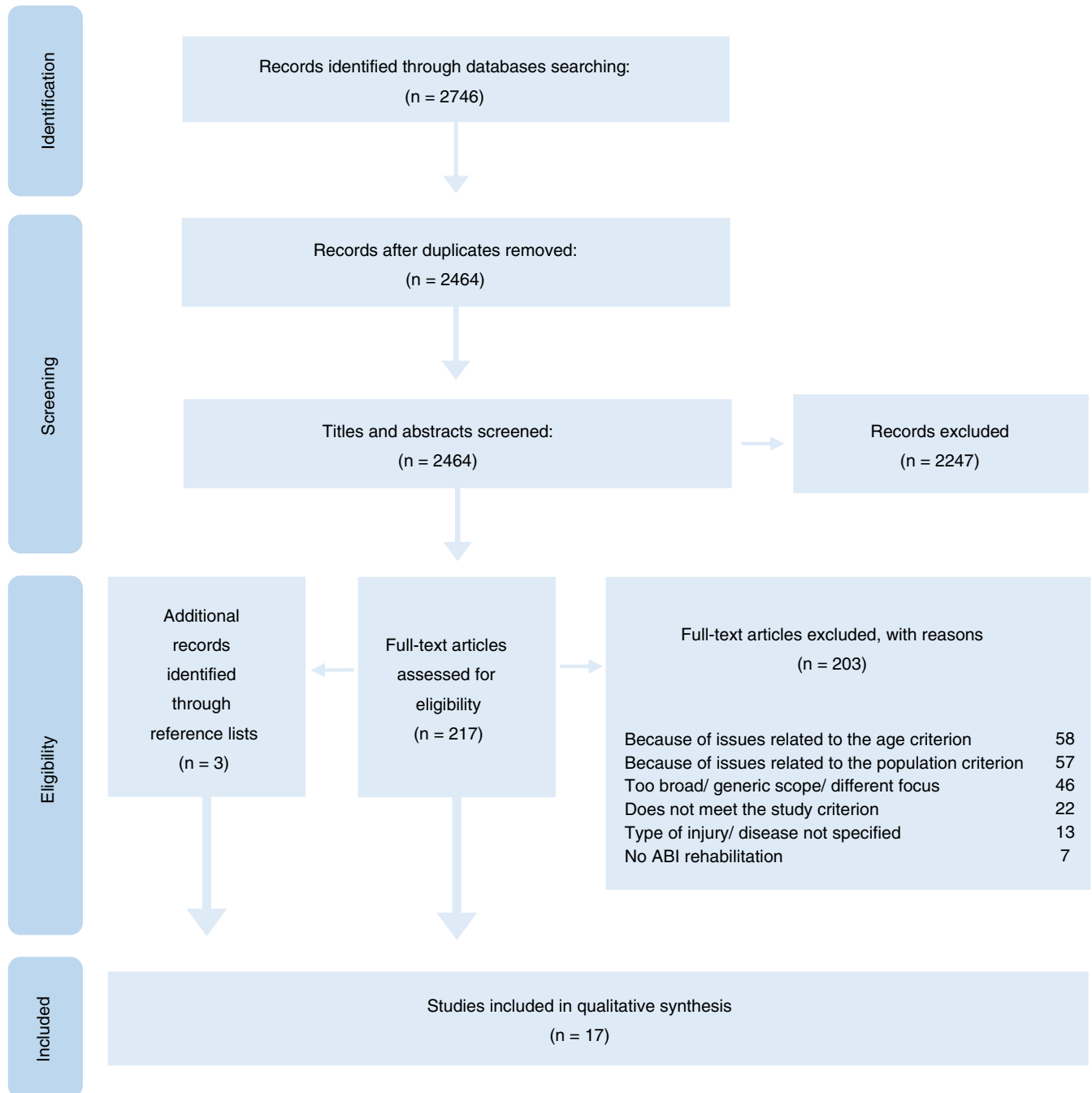


FIGURE 1 PRISMA flow diagram

physiotherapy duration expressing their wish for more sessions during the week and arguing that additional physiotherapy can benefit their recovery. In a similar vein, participants in Tholin and Forsberg (2014), reported that they preferred a more intense and varied inpatient rehabilitation programme provided by knowledgeable and encouraging professional staff. Family involvement in rehabilitation was another salient topic, with studies indicating the beneficial effect of family engagement on older individuals' physical and emotional recovery (Galvin et al., 2009; Loft et al., 2017; Poltawski et al., 2015; Tholin & Forsberg, 2014). Motivators for engaging in the rehabilitation process, including a de-medicalized approach to care

and an emphasis on lifestyle modifications, were found to promote a sense of well-being in older individuals (Poltawski et al., 2015).

Olofsson et al. (2005) study claim that older individuals associate discharge with 'coming home' inciting positive experiences and feelings of relief and joy. Furthermore, as presented in Wray et al. (2019), the transition from hospital to returning home created feelings of happiness and relief for older individuals. Nevertheless, this initial sense of satisfaction for coming home is short-lived or even constitutes an illusion, as individuals experience a significant change concerning their self-realization. In some cases, older individuals experienced difficulties during their transition from hospital to home,

TABLE 3 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. (2015)	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
Galvin et al. (2009)	Y	Y	Y	Y	Y	Y	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 et al. (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
Olofsson et al. (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 et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High

Y, yes; N, no; U, unclear/cannot tell.

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.

requiring great physical and emotional effort (Wray et al., 2019). Furthermore, when returning home, older individuals quickly realized that they were not the same persons as before, perceiving themselves as ABI (stroke) survivors and feeling anxious about becoming ill again (Olofsson et al., 2005).

An additional issue that can intensify older individuals' disillusionment and dissatisfaction is that their opinions are not taken into consideration after hospital discharge, and they may also have no choice about where they would go after their acute rehabilitation phase (Krishnan et al., 2019; Tholin & Forsberg, 2014). As Krishnan et al. (2019) conclude, older individuals are usually not involved in selecting their post-acute care setting, with medical staff mainly choosing on their behalf. Overall, with regards to their discharge experiences, older individuals were mostly concerned about whether the information they had about post-discharge rehabilitation was adequate and also whether the discharge was successful or not (Ellis-Hill et al., 2009; Krishnan et al., 2019; Morris et al., 2007).

### 3.1.2 | Theme 2: Identity and embodiment concerns of older individuals during rehabilitation

The existential concerns of older individuals with ABI during rehabilitation and how these concerns affect older individuals' recovery also emerged as a salient theme during the review. Wray et al. (2019) reported older individuals' desire and need to preserve a sense of autonomy during their rehabilitation and maintain hope and progression towards recovery; this empowered many participants to move forward and cope with their rehabilitation.

According to Mangset et al. (2008), the sense of well-being for individuals with ABI undergoing rehabilitation links to their perception of the quality of rehabilitation they receive and to a felt sense of dignity and humanity in their treatment. Mangset et al. (2008) argue that older individuals' need for autonomy and dignified care derives from the vulnerability and dependence that many feel because of their diagnosis and the rehabilitation process.

TABLE 4 Characteristics of included studies

#	Reference details (author(s), year, country)	Study design	Purpose/Aim of study	Study setting	Population characteristics (sample size, age, sex, type of disease)	Data collection methods & data analysis techniques
[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 setting (stroke rehabilitation ward)	5 females and 5 males with stroke; between 66 and 75 years old	Semi-structured interviews Content analysis
[2]	Bennett et al. (2015), Australia	Qualitative study	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	Semi-structured interviews Thematic analysis
[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
[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
[5]	Galvin et al. (2009), Ireland	Qualitative study	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	Hospital setting (acute stroke inpatient wards)	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 and Focus groups with senior physiotherapists (n = 2) Transcripts were analysed using the grounded theory approach

(Continues)



TABLE 4 (Continued)

#	Reference details (author(s), year, country)	Study design	Purpose/Aim of study	Study setting	Population characteristics (sample size, age, sex, type of disease)	Data collection methods & data analysis techniques
[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 provider and with regards to rehabilitation goal setting; and to examine their discharge recommendations for stroke survivors	Home environment Location where support group meeting was held Health care facility where some individuals were residing	18 stroke survivors; mean age = 68 years	Semi-structured interviews Thematic analysis
[7]	Löfmark and Hammarström (2005), Sweden	Qualitative follow-up study	To analyse from a gender perspective how older females and men responded to treatment after stroke in the acute care setting, characterized by a medical hierarchic structure	Hospital setting (stroke ward)—1st interview Home environment—2nd interview (4–6 weeks later)	12 stroke patients; between 75 and 83 years old	Semi-structured interviews Grounded theory analysis Participants were interviewed twice. Regarding the second interview, 2 participants refused to be interviewed again
[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	Semi-structured interviews Content analysis
[9]	Mangset et al. (2008), Norway	Qualitative study	To identify factors contributing to elderly stroke patients' satisfaction with poststroke rehabilitation	Hospital setting (university hospital stroke rehabilitation unit) Followed by home environment, nursing home environment, or at the outpatient clinic of the hospital	12 stroke patients; mean age = 77 years	Semi-structured interviews Analysis was based on Giorgi's (1985) phenomenological method
[10]	Morris et al. (2015), Scotland, UK	Qualitative study	To explore stroke survivors' and artists' beliefs about participating to visual arts programme during inpatient rehabilitation and identify potential benefits and mechanisms of action	Home environment or a place of participants' choosing Artists were interviewed in their workplace or the local university	11 stroke survivors; mean age = 73 years 3 artists	Semi-structured interviews Framework approach was used to identify themes and develop conceptual schemes

(Continues)



TABLE 4 (Continued)

#	Reference details (author(s), year, country)	Study design	Purpose/Aim of study	Study setting	Population characteristics (sample size, age, sex, type of disease)	Data collection methods & data analysis techniques
[11]	Morris et al. (2007), UK	Qualitative study	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	Focus groups of patients, carers and staff following a semi-structured format Thematic analysis
[12]	Nimrod and Hutchinson (2010), Canada	Qualitative study	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	Home environment (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 Qualitative analysis techniques along with cross-case analysis and comparison strategies
[13]	Olofsson et al. (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 after their stay in hospital	Home environment	9 stroke patients; mean age = 72 years	In-depth interviews Qualitative data analysis
[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 age (range) = 67 (53–77) 6 stroke survivors in group 2 (2 females and 4 male); median age (range) = 68 (42–74) (+2 partners) 2. 6 stroke survivors (1 female & 5 males); median age (range) = 67 (57–72) (+1 partner)	1. Focus groups 2. Semi-structure interviews. Thematic analysis of transcribed discussions and interviews. ↓ Extraction and synthesis of themes (thematic descriptive approach)
[15]	Tholin & 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	Home environment Nursing home environment	11 participants (5 females & 6 males); mean age = 73 years (range 49–90)	Semi-structured interviews Content analysis

(Continues)

TABLE 4 (Continued)

#	Reference details (author(s), year, country)	Study design	Purpose/Aim of study	Study setting	Population characteristics (sample size, age, sex, type of disease)	Data collection methods & data analysis techniques
[16]	White et al. (2015), Australia	Qualitative study	To 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 utilized to collect and analyse data
[17]	Wray et al. (2019), UK	Qualitative study (cross-sectional)	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 seven participants were also interviewed	Semi-structured interviews Thematic analysis

TABLE 5 Themes and categories developed by the synthesis of the selected studies

Themes	Categories
1. Rehabilitation processes and their impact on older individuals' well-being	<ul style="list-style-type: none"> <li>Experiences of inpatient rehabilitation and physiotherapy for older individuals living with ABI</li> <li>Hospital discharge experiences of older individuals living with ABI</li> </ul>
2. Identity and embodiment concerns of older individuals during rehabilitation	<ul style="list-style-type: none"> <li>The felt need for autonomy, dignity, humanity of older individuals living with ABI</li> <li>Gender influences on older individuals' conceptualization of ABI condition and rehabilitation process</li> </ul>
3. Institutional factors affecting older individuals' experiences of care and well-being	<ul style="list-style-type: none"> <li>Treatment burdens and organizational healthcare factors impacting on older ABI survivors' treatment</li> <li>Older individuals' negative perspectives and interactions with healthcare service and medical staff</li> <li>Older individuals' positive perspectives and interactions with healthcare service and medical staff</li> </ul>
4. Older individuals' participation in creative activities as part of rehabilitation	<ul style="list-style-type: none"> <li>Art participation and rehabilitation of older individuals living with ABI</li> <li>Older individuals' experiences of rehabilitation and participation in innovation, new activities</li> </ul>

Loft et al. (2017) mention that older individuals feel shocked at how the stroke altered their understanding of their bodies and self-awareness. Participants felt restricted and trapped during their inpatient rehabilitation and hospitalization in a clinical setting, further highlighting their concerns of losing their independence (Loft et al., 2017; Tholin & Forsberg, 2014). Older individuals undergoing rehabilitation are overwhelmed with sentiments of passivity, docility, subordination and dependency in their struggle to (re)define their identity and regain a sense of autonomy (Löfmark & Hammarström, 2005; Olofsson et al., 2005).

Two studies adopt a gender perspective to explore older individuals' experiences and conceptualizations with stroke during their rehabilitation. Andersson and Hansebo (2009), assert that in the aftermath of a stroke, traditional gender roles equally influence both women and men, but in different ways, in their goal setting and identity (re)construction. Therefore, older women undergoing rehabilitation aim to regain more traditionally feminine roles, such as being housewives and independently carrying out household activities. In contrast, older men aim to regain more traditionally masculine roles, such as independently carrying out outdoor and leisure-time activities (Andersson & Hansebo, 2009).

Furthermore, Löfmark and Hammarström's (2005) study purport that older individuals' interactions with staff in part aims to negotiate the opportunity of regaining their autonomy in a traditional gendered context. Women chose to negotiate with nurse assistants, as they felt being in a subordinate position in the medical context. In contrast, men perceived themselves to be equal with nurses and physiotherapists, hence making efforts to negotiate a type of alliance with them (Löfmark & Hammarström, 2005).

### 3.1.3 | Theme 3: Institutional factors affecting older individuals' care and well-being experiences

Theme three examines the older individuals' experiences of care and sense of well-being in healthcare institutions and organizations. Gallacher et al. (2018) demonstrate the treatment burden experienced

by stroke survivors and the factors that influence their capacity to implement rehabilitation processes. Treatment burden refers to the healthcare workload that stroke survivors experience during their long-term rehabilitation and their impact on individuals' sense of well-being, with excessive treatment burdens adversely affecting their sense of well-being (Gallacher et al., 2018).

Gallacher et al. (2018) concluded that increased treatment burden in stroke survivors resulted from the lack of interpersonal interactions with healthcare professionals due to increased workload or multiple enduring care deficiencies in the way care is delivered. The reviewed literature emphasizes care deficiencies that include lack of information; lack of psychosocial support; misdiagnosis; paternalism; poor communication with healthcare providers; low staffing levels; and long waiting times, being critical for increased treatment burden (Morris et al., 2007; Olofsson et al., 2005; Tholin & Forsberg, 2014). Morris et al. (2007) expand by suggesting that older individuals understand care and service deficiencies as a contributing factor to insufficient therapeutic schemes.

The above institutional and organizational hindrances adversely impact older individuals' ability to set rehabilitation goals and take part in planning their care (Krishnan et al., 2019; Loft et al., 2017; Tholin & Forsberg, 2014). Furthermore, goal setting in rehabilitation is also negatively impacted by the medical model's approaches to care for older individuals and its dominance in the organization of care and rehabilitation (Löfmark & Hammarström, 2005; Loft et al., 2017; Tholin & Forsberg, 2014). On the contrary, older individuals' rehabilitation based on constructive relations, positive communication and person-centred care, increases older individuals' satisfaction and encourages them to move forward with their recovery (Galvin et al., 2009; Mangset et al., 2008; Morris et al., 2007).

### 3.1.4 | Theme 4: Older individuals' participation in creative activities as part of rehabilitation

Theme four focuses on older individuals' participation in creative activities as part of their rehabilitation process. Morris et al. (2015)

refer to stroke survivors' psychosocial benefits of participating in artistic activities during their rehabilitation. Art participation addresses important psychosocial issues that other rehabilitation approaches have not addressed and is beneficial for stroke survivors to enhance their rehabilitation experiences (Morris et al., 2015). For example, producing a completed piece of artwork provided stroke survivors with a sense of empowerment and control. Similarly, in Nimrod and Hutchinson's (2010) study, all participants reported that new activities during rehabilitation made them feel better about themselves and improved their capacity for maintaining a sense of well-being despite their health condition. Many in the study also expressed a sense of pride and usefulness as they felt capable and active members due to their new activities (Nimrod & Hutchinson, 2010).

White et al. (2015) study link older individuals' participation in creative activities in the hospital setting with the concept of creating an enriching rehabilitation environment. An enriched environment provides space for performing arts activities and enhancing the recovery phase. Through participation in new artistic and creative activities, older stroke patients reduce their sense of unfamiliarity with the rehabilitation ward. Additionally, an enriched communal environment enhances social interaction among older participants (White et al., 2015).

## 4 | DISCUSSION

The current review's findings demonstrate variations about older individuals' ABI rehabilitation experiences that impact on their sense of well-being. Participants had an initial positive view of their inpatient rehabilitation, but this was tampered with by 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. The literature studying the impact of long waiting times for patients concludes that this can 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 (Cooper et al., 2008; Leddy et al., 2003). A set of other sources further suggest that more days of care or physiotherapy and additional sessions can benefit their care and the rehabilitation process leading to better functional recovery (Kinoshita et al., 2017; Leddy et al., 2003; Luker et al., 2015). However, extending the rehabilitation session duration and prolonging the rehabilitation process impinges on the appropriate staffing levels of health services which are currently critically understaffed (Buerhaus et al., 2007; Marć et al., 2019; Oulton, 2006; WHO, 2020).

Moreover, according to other research studies, the limitations of the physiotherapy sessions' content and shortened duration adversely impact older individuals' autonomous decision-making and goal-setting potentials. Bamm et al. (2015) and Peoples et al. (2011) highlight the detrimental effect that caregiving's passivity has on older individuals where voices on preferences about their caring process usually remain silent, and health professionals' opinions

overpower older individuals' views. 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 et al., 2015; Shilts et al., 2004). Furthermore, such goal-setting limitations can become restrictive for older individuals' sense of autonomy and lead health professionals to assume more controlling roles by limiting the provision of information and setting (or influencing) goals on behalf of the older individuals (Barnard et al., 2010; Levack et al., 2011; Stevenson et al., 2000). The condescending treatment that older individuals feel they receive can amplify their mistrustfulness towards health professionals and aggravate the risk of failure in dealing with lifestyle modifications effectively (Jonsen et al., 2015; Zolkefli, 2017).

The current review identifies that the above limitations in autonomy are not merely a result of the interaction with healthcare professionals and the dominance of health professionals voice but is part –or possibly the consequence– of the broader organizational structure of rehabilitation care and the current ideological conceptualization of health provision. Factors such as older individuals' insurance coverage, the quality of the available facilities, and the affordability of post-acute care setting have a central role in older individuals' decision-making in choosing their post-acute care. These findings concur with the literature asserting that rehabilitation choices depend not only on health needs, but also on socio-economic factors, with poorer people having greater limitations of choice, especially when the affordability of private rehabilitation services is not feasible (Hakkennes et al., 2011; Magdon-Ismail et al., 2016; Putman et al., 2007). In addition, the effects of neoliberal policies on healthcare issues can partly explain the limitations in older individuals autonomy and decision-making capacities as free-market and individual financial mismanagement can lead to widening disparities in the level, and quality of care people receive (Harvey, 2005; McGuigan, 2014; Sakellariou & Rotarou, 2017).

The review's findings also highlight a dissonance between expectations and the reality of returning home from acute hospitalized rehabilitation for older individuals who suffered an ABI. The initial joyful anticipation and sense of delight for returning home and going back to the perceived normality proved to be an unfulfilled wish or an illusory expectation as the perceived normality before the rehabilitation process due to the ABI incident no longer existed. Similarly, other sources identify that the transition period from acute hospitalization to homecoming is not an easy one and considers it a weak point, as significant changes occur in their capacity to carry out daily activities and in encountering for the first time the consequences of their functional limitations (Jönsson et al., 2017; McCabe & Kennelly, 2015; Nordin et al., 2015). Moreover, gendered imperatives further intensify the dissonance between expectations and the homecoming reality as traditional gender roles pressurize men and

women to meet expectations and goals not able anymore to achieve (Kvigne et al., 2004; McCormick & Bunting, 2002).

From the review it can be seen that efficient communication, emotional support, partaking in decision-making and family involvement are essential elements during the rehabilitation process, which can ease older individuals' transition from the acute rehabilitation phase to returning home and managing to come to terms with the new reality. The literature conceptualizes effective nurse-patient communication as a marker of quality care, indicative of greater treatment compliance and a prerequisite for individualized and person-centred care (Ali, 2017; Sibiya, 2018; Skär & Söderberg, 2018; Vennedey et al., 2020). Furthermore, high-quality communication is significant for successfully involving individuals in their care processes, and effective communication strategies and plans are emotionally powerful for ensuring dignified care (Skär & Söderberg, 2018; Vennedey et al., 2020). Finally, family members involved in the rehabilitation process constitute a necessary confidence-building and motivating element for improving older individuals' physical and motor functioning while also providing the practical psychosocial support needed for older individuals to adhere to the rehabilitation regime (Haines, 2018; Lawler et al., 2015; Waller et al., 2019; Winstein et al., 2016).

Lastly, the review's findings indicated that a creative, stimulating and enriching social environment could facilitate more easily older individuals adjusting to their new reality following ABI and rehabilitation. Other sources also confirm that participation in creative activities, such as art, singing, drama therapy and expressive writing, can improve mood, self-esteem, physical performance, and their expressive abilities, (re)creating older individuals' social identity and leading to a greater sense of well-being (Howie et al., 2004; Kongkasuwan et al., 2016; Lo et al., 2018; Tamplin et al., 2013). Similarly, an enriched environment with the increase in the variety and amounts of sensory stimulation, on the one hand, can increase cognitive plasticity and learning abilities, and on the other hand, can reduce stress, anxiety and enhance learning and memory mechanisms, hence contributing to the easing of the rehabilitation process and leading to a sense of well-being (Ball et al., 2019; Sampedro-Piquero & Begega, 2016).

#### 4.1 | Limitations

Including only English language articles in the review may have restricted the range and amount of data retrieved. Also, ABI is an umbrella term that has resulted in certain types of ABI, such as stroke, being more prevalent in the reviewed studies than other ABI types, potentially impacting the review results. However, this limitation indicates the need for more studies concerning types of ABI that go beyond stroke. Also, most studies included in their sample both older and younger individuals, with just three studies focusing exclusively on older individuals. This could inadvertently impact this review's results, as there may be discrepancies in the experiences of care and well-being between older and younger individuals living

with ABI. However, this limitation also indicates the need for more studies focusing exclusively on older individuals living with ABI. Finally, this qualitative review cannot produce representative or predictive results on individuals living with ABI undergoing physical rehabilitation. Nonetheless, it can provide significant insights into their experiences that would be useful for practitioners and researchers in understanding the linkages between ABI, well-being, and physical rehabilitation.

## 5 | CONCLUSION

This systematic review provides an overview of the literature relating to older individuals' experiences of well-being and of the care they receive during their ABI physical rehabilitation. Long waiting times between physiotherapy sessions, disconnecting rehabilitation from individuals' daily reality, and shortening the physiotherapy duration, adversely impacts older individuals' autonomous decision-making and goal-setting potentials. Furthermore, inadequate and ineffectual interaction between health professionals and older individuals who suffered ABI undergoing rehabilitation, the dominance of health professionals' voices in decision-making, and health disparities further impede older individuals' decision-making in the post-acute care phase. Also, the dissonance between expectations and the reality of returning home from acute hospitalized rehabilitation, and the illusionary and unfulfilled returning to a socially constructed normality added another layer of difficulty for older individuals with ABI undergoing rehabilitation, that negatively affected their sense of well-being. Efficient and effective communication, emotional support, family involvement in the rehabilitation process, and creating a stimulating and enriching social environment can ease, humanize and facilitate older individuals' adjustment to their new reality following ABI and the need for rehabilitation.

As there are few qualitative studies published that deal with older people's ABI rehabilitation experiences with most of them focusing solely on stroke, future research should consider shifting focus towards both TBI and nTBI rehabilitation experiences and the older population's perspectives. The review reveals the need to examine the significance of humanizing care and further explore the factors affecting older individuals' emotional condition and their sense of well-being. In addition, the current review identified that while ABI services for younger people follow a more patient-centred approach, this is not equally reflected in the rehabilitation of older people diagnosed with ABI. Future studies should also consider patients' concerns over their involvement in decision-making and goal setting about their care. Overall, the current review lays down the path for further study on how dignified care for older individuals with ABI can be achieved or enhanced in formalized healthcare systems.

#### CONFLICT OF INTEREST

We have no known conflict of interest to disclose.

## AUTHOR CONTRIBUTIONS

PL: made substantial contributions to the conception and design of the review, carried out the search, screening, data extraction and quality appraisal of the studies. PL, CH, MG, AP and SM: assessed and approved the search, screening, and data extraction processes; PL, CH, MG, AP and SM: carried out the analysis and synthesis of results; PL, CH, MG, AP and SM: were involved in writing up and revising the manuscript; All authors gave final approval of the version to be published.

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## DATA AVAILABILITY STATEMENT

Data sharing not applicable – no new data generated.

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