#### **REVIEW ARTICLE**



# TEAM-BASED REHABILITATION AFTER TRAUMATIC BRAIN INJURY: A QUALITATIVE SYNTHESIS OF EVIDENCE OF EXPERIENCES OF THE REHABILITATION PROCESS

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Objective: To synthesize and explore experiences of the rehabilitation process for adults with traumatic brain injury receiving team-based rehabilitation.

Data sources: A qualitative evidence synthesis was conducted according to the "Enhancing transparency in reporting the synthesis of qualitative research" (ENTREQ) Guidelines, of qualitative studies published in 5 databases in 2000-21.

Study selection and data extraction: Screening, selection of relevant studies, assessment of methodological limitations, systematic qualitative content analysis and assessment of confidence with Grading of Recommendations Assessment, Development, and Evaluation- Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) were carried out by independent researchers.

Data synthesis: The 10 included studies revealed how people with traumatic brain injury perceived that they struggled on their own for a long time to adapt their daily life. They experienced that access to team-based rehabilitation was scarce and that the interventions offered were neither individually tailored nor coordinated. A respectful attitude from professionals and individually adapted information facilitated their rehabilitation process.

Conclusion: This qualitative evidence synthesis indicates areas for improvement and a need to develop person-centred team-based rehabilitation for adults with traumatic brain injury, in terms of accessibility, coordination, continuity, content and participation. Given the limited opportunities for team-based rehabilitation after hospital discharge, further research is needed to understand how rehabilitation can support the adaptation of everyday life.

*Key words:* brain injury; evidence-based practice; rehabilitation; review; qualitative research; qualitative evidence synthesis.

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Traumatic brain injury (TBI) affects millions of people worldwide of all ages (1, 2), and the outcome of the injury varies from complete recovery to life-long disability or death (3). TBI can be either severe, mo-

### LAY ABSTRACT

The aim of this study was to review scientific publications about experiences of the rehabilitation process from the perspective of adults with traumatic brain injury who had received team-based rehabilitation. Several established databases were searched, yielding 10 relevant qualitative studies. The experiences described in these studies overlapped, and showed that people with traumatic brain injury struggled on their own over a long period of time to adapt to their new situation in everyday life. They experienced that access to team-based rehabilitation was limited and not adapted to their needs at different time-points. As many people with traumatic brain injury had limited experience of teambased rehabilitation after hospital discharge, this study indicates a need to develop person-centred team-based rehabilitation over a longer period of time. Further research is needed regarding experiences of how rehabilitation can support adaptation in everyday life after traumatic brain injury.

derate or mild (4), and many people need to undergo prolonged rehabilitation to adapt their daily life after injury, as they may have various long-term physical, cognitive, and psychosocial impairments (5, 6). Given the individual and multifaceted consequences, the rehabilitation process must be managed by a multiprofessional rehabilitation team throughout all phases (3, 7–9). Commonly, coordination also needs to take place between professionals and teams at different levels and organizations of care (8, 10). In addition, rehabilitation needs to be individualized, e.g. person-centred, due to the complexity of TBI (8). Consequently, multiprofessional team-based rehabilitation plays a crucial role in rehabilitation outcomes following TBI (8, 9, 11). Systematic reviews show some evidence of the effects of specific and team-based rehabilitation after TBI (12–14). However, no qualitative evidence synthesis (QES) of people with TBI has addressed how adults receiving team-based rehabilitation experience the rehabilitation process. Existing QESs have focused on the experience of losses and recovery (15) and the experiences of rehabilitation approaches using music and poems (16). More comprehensive knowledge of the lived experiences of the rehabilitation process, from the perspective of people with TBI, is important

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in evaluating whether team-based rehabilitation meets their needs and expectations to inform improvements in rehabilitation.

The aim of this QES was to explore the experiences of the rehabilitation process for adults with TBI receiving multi-professional team-based rehabilitation, with a focus on the experiences of relationships with professionals, coordination between professionals in rehabilitation, and the importance of rehabilitation for daily life.

## **METHODS**

This QES is part of a governmental health technology assessment of TBI rehabilitation commissioned by the Swedish agency for health technology assessment and assessment of social services (Statens bredning för medicinsk och social utvärdering (SBU)) (17) and includes an updated search using the same search strategy. The QES was conducted by 3 researchers according to the "Enhancing transparency in reporting the synthesis of qualitative research" (ENTREQ) Guidelines (18). The protocol for the full assessment of rehabilitation after TBI was registered with the International Prospective Register of Systematic Reviews (PROSPERO) (number CRD42018102822).

## Literature search and inclusion and exclusion criteria

A literature search of the following databases was performed: PubMed, EMBASE, Cochrane Library, CINAHL and PsycInfo, from 2000 to 24 March 2021. The search was comprehensive, and a broad strategy, aimed at capturing studies on TBI and using qualitative methods, was applied. Studies addressing rehabilitation according to the selection criteria were identified in the screening. The full search strategy is published at SBU (17), and an exemplar search in 1 database is shown in Appendix 1.

Inclusion criteria were: qualitative studies based on individual interviews or focus groups with adults (>16 years) with any severity of TBI concerning their experiences of the rehabilitation process after team-based rehabilitation. Only peer-reviewed articles in English and Scandinavian languages were included.

Exclusion criteria were: articles that only included experiences of rehabilitation of specific symptoms or experience of the adaptation process without specific reference to team-based rehabilitation. Studies of experiences of rehabilitation services provided by 1 profession were excluded. In addition, studies of rehabilitation that involved a specific component or a specific focus, such as music therapy, a technical solution, or vocational rehabilitation, were excluded. Studies that involved other types of brain injuries were excluded if those with TBI were approximately less than half of the sample, or if their proportion of the sample was unclear. Studies that involved both participants with TBI and others were excluded if it was unclear which the results were based on.

## Selection of studies

Titles and abstracts were screened based on the inclusion and exclusion criteria by 2 independent researchers to identify relevant abstracts. Thereafter, 2 researchers (MLL, TS) read these abstracts independently, and potentially relevant studies were read in full text. The researchers made an individual assessment of whether the studies fulfilled the criteria and then made a

final decision in consensus. The risk that the study findings were affected by limitations in the design and conduct of the study was assessed in a quality appraisal, based on a review protocol available at SBU (Appendix 2). This assessment was first performed independently by the researchers and thereafter discussed jointly before a final decision was made in consensus. Only studies with minor or moderate levels of limitations were included. The selection process is shown in Fig. 1. The excluded studies and reasons for exclusion are listed in Appendix 3.

## Qualitative evidence synthesis

Systematic qualitative content analysis (19) was chosen to inductively analyse and synthesize the content of findings across the studies. The method is a knowledge-building qualitative systematic review that generates new evidence based on multiple qualitative studies to support evidence-based practice. Two researchers (MLL, TS) worked independently with each step of the QES, followed by a discussion and consensus. First, the texts were read to gain an understanding of the whole. Data segments with content relevant to the aim were extracted from the results sections of the studies. The segments were transferred to a matrix and were assigned preliminary codes close to the text. The codes were combined with reflective notes to preserve the understanding of the data. Thereafter, codes and notes were synthesized across studies. Because the studies focused on experiences from different phases of the rehabilitation process, the codes were sorted according to a time perspective, from the acute phases in hospital to post-acute rehabilitation at home, and the late phase (>6 months after admission). Codes with similar contents were abstracted to preliminary categories, and these were later grouped into preliminary subcategories. The preliminary subcategories were then abstracted and refined to final categories with subcategories. An example of the synthesis process is shown in Table I.

The second researcher (AP) validated each step in the process. A reflective approach was adopted throughout to ensure the fit of the synthesis, meaning that the findings should be grounded in the data and inter-related to form a systematic whole (19).

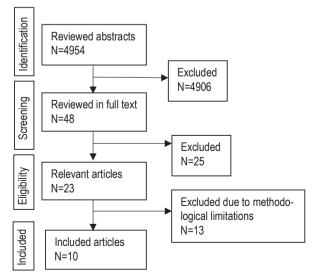


Fig. 1. Flow chart for selection of studies.

Table I. An example of the qualitative evidence synthesis (QES)

Data segment	Code	Subcategory	Category
The practical organization of rehabilitation after returning home was described as deficient. A participant with a moderate traumatic brain injury described how poorly organized rehabilitation impeded reintegration to practical and social daily life:	Lack of coordinated support influence reintegration negatively	Being in a gap of insufficient coordination of rehabilitation between the hospital and continued actions during the	Finding hospital rehabilitation to be poorly organized, with insufficient support and participation
"I have been missing some information and notice about what is going to happen and when. Because very often things happen simultaneously and that is very frustrating when you have a traumatic brain injury."		transition	

## Confidence in the findings

The confidence in each of the subcategory findings was assessed with Grading of Recommendations Assessment, Development, and Evaluation- Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) (20–22) by joint discussions between the authors. The discussion was based on consensus regarding the quality appraisal of the items in Appendix 2 for each of the included articles (i.e. the specific articles that built up a subcategory). Confidence in each subcategory was assessed separately by the 4 domains (in the GRADE-CERQual framework): methodological limitations, relevance of the data, coherence and adequacy of data. The confidence was categorized into 4 levels: high, moderate, low, and very low.

## **RESULTS**

The search retrieved 10 studies that met the inclusion criteria. (Table II): 6 from Australia (23–28), 2 from the UK (29, 30), and 2 from Scandinavia (31, 32). The

studies included a total of 138 persons, of whom 52 were women. Each study included between 6 and 20 persons. Participants were mostly of working age (<65 years), and 3 studies (24, 29, 30) included participants over 65 years. The time since injury varied between one month and 6 years in most of the studies. A majority of the participants had moderate or severe TBI.

The synthesis formed 3 categories:

- Struggling with adapting to life with new conditions;
- Facing limited access to individually tailored and coordinated team-based rehabilitation over time; and
- Interacting with rehabilitation personnel and close persons influenced the rehabilitation process.

These 3 categories each consisted of 3–4 subcategories (Table III).

The participants' experiences of the rehabilitation process showed that they went through an "inner"

Table II. Included studies

Reference	Aim	Setting	Participants	Data collection	Data analysis
Abrahamson et al. (64), 2017	Explore experiences from the transition from in-patient rehabilitation to the community	Specialist inpatient neurorehabilitation unit in an NHS teaching hospital. UK	Adults with severe TBI Age range 48–89 years $n=10$	Interview and field notes	Thematic analysis, data driven
Copley et al. (65), 2013	Describe experiences of care and the factors that impacted upon participants' ability to access services	Former patients at 2 metropolitan acute trauma hospitals. Australia	Adults with moderate to severe TBI Age range $18-65$ years $n=14$	Interviews and guided oral history	Thematic analysis
D'Cruz et al. (66), 2016	Explore the client perspectives of client- centred occupational therapy	One occupational therapy practice in metropolitan area. Australia	Adults with moderate to severe TBI Age range 20–71 years $n=6$	Semi-structured interviews. Memos and reflective journals	Constant comparison
Fleming et al. (67), 2012	Describe the in-patient rehabilitation experiences prior to discharge	One rehabilitation unit at a large metropolitan hospital. Australia	Adults with TBI/ABI Age range 24–65 years $n=20$	In-depth interviews	Manifest content analysis
Graff et al. (68), 2018	Explore the living experience from hospital discharge up to 4 years post-injury	The trauma centre for severely injured patients at a university hospital. Denmark	Adults with TBI Age range 25–63 years $n = 20$	In-depth interviews and field notes	Thematic analysis
Lexell et al. (69), 2013	Describe the experiences of an outpatient group rehabilitation programme	Community. Sweden	Adults with TBI/ABI Age range 25–62 years $n=11$	Semi-structured interviews	Qualitative content analysis
Mueller et al. (70), 2017	Explore how medical and social services support community-based patients	A newly established pilot clinical service for TBI. UK	Adults with TBI Age 18 years and above $n=10$	Semi-structured interviews and field notes	Thematic analysis
O'Callaghan et al. (71), 2012	Explore experiences of healthcare of adults with moderate to severe TBI	Community. Australia	Adults with TBI All age groups $n = 14$	Unstructured interviews based on guided oral history	Thematic analysis
Turner et al. (72), 2007	Explore the lived transition experiences of individuals with ABI and their caregivers	One outpatient and 1 case management service. Australia	Adults with TBI Age range 19–53 years $n=13$	Semi-structured interviews	Qualitative content analysis
Turner et al. (73), 2011	Study the experience during the transition phase from hospital to home and the perceived factors influencing the service and support needs during the transition phase	One metropolitan- based in- patient rehabilitation unit. Australia	Adults with ABI/TBI Age range 17–63 years $n = 20$	Semi-structured interviews	Thematic analysis

ABI: acquired brain injury; TBI: traumatic brain injury.

**Table III.** Findings from the qualitative evidence synthesis (QES) of experiences of the rehabilitation process in persons with traumatic brain injury (TBI), based on 10 qualitative studies, and the confidence of the results expressed according to GRADE-CERQual

Category	Subcategory	No. of studies (no. of study participants) that the subcategory was based on	Confidence of the subcategory according to CERQual
Struggling with adapting to a life on new conditions	Becoming aware of the injury and being emotionally vulnerable during the hospital stay.	3 (43)	Low <sup>a</sup>
	Being challenged with an increased understanding of the long-term consequences on everyday life following the transition to the home	5 (77)	Moderate <sup>b</sup>
	Struggling on one's own to adapt to daily life after formal rehabilitation had ceased	6 (88)	Moderate <sup>b</sup>
Facing limited access to individually tailored and coordinated team- based rehabilitation	Finding hospital rehabilitation to be poorly organized, with insufficient support and participation.	4 (63)	Low <sup>a</sup>
	Being stuck in a gap of insufficient coordination of rehabilitation between the hospital and home	5 (67)	Low <sup>a</sup>
	Experiencing limited access to a rehabilitation supporting reintegration into society evoked feelings of powerlessness	6 (71)	Moderate <sup>b</sup>
	Engaging in individually tailored rehabilitation over time was crucial for the adaptation process	3 (30)	Very low <sup>c</sup>
Interacting with rehabilitation personnel and close persons	The way one was treated influenced whether the rehabilitation was experienced as person-centred	4 (51)	Low <sup>a</sup>
influenced the rehabilitation process	Impersonal and scant information on the course of rehabilitation and future possibilities were experienced as an obstacle in the rehabilitation process	4 (55)	Low <sup>a</sup>
	The involvement of close persons was crucial for the rehabilitation process	7 (121)	Moderate <sup>b</sup>

<sup>a</sup>Very serious uncertainty in Data adequacy (-2) due to few studies and few participants. <sup>b</sup>Serious uncertainty in Data adequacy (-1) due to relatively few studies and participants. <sup>c</sup>Very serious uncertainty in Data adequacy (-2) due to few studies and few participants, and serious uncertainty in Relevance (-1) as participants had other types of ABI than TBI. GRADE-CERQual: Hidradenitis Suppurativa International Online Community: Patient Characteristics and a Novel Model of Treatment Effectiveness

struggle (first category) that was integrated and parallel to their experiences of formal team-based rehabilitation (second and third categories).

Struggling with adapting to life with new conditions

Participants experienced the rehabilitation to be a demanding process of adapting to a new life with new conditions, characterized by an inner struggle, ranging from onset of the injury to several years later (25–31). Becoming aware of the injury and being emotionally vulnerable during the hospital stay. Rehabilitation at the hospital was initially associated with an overwhelming experience when participants became aware of their brain injury (25, 27, 30). When their condition stabilized, they slowly realized that many functions were affected, such as balance, coordination, vision, and memory, and they experienced extensive fatigue (27, 30). As they experienced a loss of activities of daily life, different emotions arose, such as frustration, sadness, and worries:

"What I find more frustrating than anything, is, at this present moment in time, I cannot do what I want to do and what I used to be able to do" (30) (p. 1689).

Being challenged with an increased understanding of the long-term consequences on everyday life following transition to the home. After the transition from hospital to home, previously unknown consequences of TBI in everyday life became evident for the participants (26–28, 30, 31). They had expected that everyday life would return to normal, but life became everything else but normal (27, 30, 31). The transition was described

as overwhelming, as the participants became aware of changes that they had not realized before (26–28, 30, 31):

"Yeah, when you come home it is a bit of a shock because all of a sudden you're at home and like I say, I found it hard because I couldn't do all the things that I used to do and that's what upset me. I wasn't prepared for how much shock I got." (27) (p. 1124).

Struggling on one's own to adapt to daily life after formal rehabilitation had ceased. After the rehabilitation had ceased, an even more vulnerable life situation than before the transition from hospital was experienced (26–29, 31). The participants had to continue with the adaptation without professional support. In this process, they re-evaluated their life and realized the importance of finding new goals and meaning in their changed life situation (26–29, 31). This was experienced as a traumatic process, including grieving the loss of their former self to be able to accept the new self (26). They struggled with their changed abilities in daily life (26, 31), finding it difficult to perform activities and uphold routines (27). Some of the participants were worried about the future (31). Meaningful activities and hobbies were important, as they gave meaning to life (27), as illustrated:

"It gives me a bit of passion back. I thrive in that environment, I really do." (27) (p. 1125).

Facing limited access to individually tailored and coordinated team-based rehabilitation

The participants in all studies described insufficient access to team-based rehabilitation, especially to reha-

bilitation that was individually tailored and coordinated during all phases of the recovery (23–32).

Finding hospital rehabilitation to be poorly organized, with insufficient support and participation. The experiences of rehabilitation at the hospital were mixed (25, 27, 28, 30). The participants considered that medical treatment and rehabilitation were of high quality (25, 27), although the rehabilitation was not as intense as expected (25, 27, 28). Other participants experienced that they did not receive the support they needed and that their participation in the planning of their rehabilitation was restricted. The rehabilitation was seen as disorganized when it was delayed (30) or when there was a lack of coordination between staff (25, 30):

"You'd ask someone one thing and you might not see them again. And they wouldn't tell me anything that was going on. They wouldn't answer my questions, you know?" (30) (p. 1688).

Aside from the rehabilitation sessions, the participants were referred to few activities on the ward (25, 30). This experience evoked feelings of meaninglessness or boredom, with participants seeking opportunities to use their time in a more purposeful way.

Being stuck in a gap of insufficient coordination of rehabilitation between the hospital and home. The preparation, planning and coordination of rehabilitation and other support both before and during the transition to the home were experienced as insufficient (26–28, 30, 31). Upon reflection, participants wished that they were better prepared for going home and that the planning of the continued rehabilitation had been more clearly outlined (26–28, 30, 31):

"Nobody prepared me for home... Nobody said, "Well, what are you going to do when you get there?... I just needed a bit more guidance on how it was going to be" (30) (p. 1688).

In the home, the participants often did not know who to contact when new needs arose (27, 30, 31). The participants described that rehabilitation was delayed for weeks up to months and was provided less frequently than expected (27, 28, 30). They felt that the rehabilitation had a short time perspective, while they wanted to focus on future long-term goals for reintegration in society, such as return to work and transport (30). Some participants experienced that they had only a few follow-ups after discharge (26) or that the services they received were not coordinated (27, 30). They also had unanswered questions about their medical condition and medical care (30). All these experiences led to feelings of being in a service gap and of being abandoned (26–28, 30, 31).

Experiencing limited access to rehabilitation supporting reintegration into society evoked feelings of powerlessness. In the later phase, when striving to reintegrate into society, the participants described that it was difficult to understand and find their way in the complex support system. This included all kinds of services. They described a continuous struggle to obtain access to rehabilitation (23, 26–29, 31), including knowing whom to contact, what kinds of interventions were available and if they had the right to access them (23, 27, 28, 30). They felt dependent on close persons or case managers to help them navigate the system and request support (23, 27, 28, 30). The participants experienced that their own initiatives were crucial to obtaining access to services (23, 27, 28, 31). The lack of coordinated rehabilitation and other forms of services evoked feelings of powerlessness, frustration and abandonment (23, 26-29, 31). A common view was that the rehabilitation was more effective and resulted in better outcomes when individually tailored and coordinated services were given at the right time:

"I think they should focus on the best rehabilitation plan to optimize the patient's potential, this is my only complaint. They have offered me rehabilitation in a gym on an exercise bike, which can be great for some people, but not for a young person with a traumatic brain injury. I want a good life later, and I have more cognitive problems than physical. Then, it's not enough" (31) (p. 931).

Engaging in individually tailored rehabilitation over time was crucial for the adaptation process. The participants emphasized that it was important that the rehabilitation was tailored to individual needs that varied over time (23–32). However, only 1 of the included studies had investigated the actual experiences of rehabilitation programmes in depth (32), and 2 other studies to some extent covered experiences of actually having received rehabilitation (24, 26). The participants stressed that the rehabilitation should support adaptation of activities of daily life, roles and identity (24, 26, 32):

"I have benefitted a lot from this [group rehabilitation], it has been absolutely crucial [to come here]. If you don't get the help you need, it can get really difficult... without the group rehabilitation I doubt that I had managed it by myself." (32) (p.534). An essential part of the rehabilitation, according to the participants, was to facilitate an acceptance that life was different from before but could be good anyway (24, 26, 32). As the adaptation process took place over a longer period time (24, 26, 32), it was seen as essential to receive cohesive rehabilitation over time with recurrent follow-ups (32). The participants described that rehabilitation had been crucial to help them adapt and become more satisfied with their life (32). The adaptation was facilitated by learning strategies to solve problems in activities of daily life, including the use of assistive devices and the support of other persons. Strategies for managing changes in social relations and knowledge about TBI were also helpful in the adaptation process.

Rehabilitation that enabled peer sharing with others in the same situation (24, 26, 32) gave perspectives on their own situation and enabled the participants to identify new opportunities. The participants emphasized the importance of taking responsibility for their success with the rehabilitation (24, 26, 32) by, between the rehabilitation sessions, processing and practising skills learned (32).

Interacting with rehabilitation personnel and close persons influenced the rehabilitation process

The participants' experiences showed the importance of relations and collaborations throughout the whole rehabilitation process (23–25, 27–32).

The way one was treated influenced whether the rehabilitation was experienced as person-centred. The participants described that their relationship with the professionals influenced to what degree rehabilitation was felt as person-centred (24, 25, 30, 32). They expressed the need to be seen as the person they were and not only as a patient (24, 25, 30). A professional relationship combined with competences about the specific needs of persons with TBI was described as important for how they were treated as well as for the outcome (24, 32):

"She ha(s) fantastic knowledge ... to help me... She really understands [how] to operate with sick people. She understands me, my sickness and understand(s) my problem." (24) (p. 33).

A person-centred relationship was described as a process of joint engagement and collaboration between the participant and the rehabilitation personnel. This included good communication regarding planning and implementation of the rehabilitation (24, 30), which was motivating (24). When shortcomings in treatment and communication occurred, experiences of being neglected or treated disrespectfully arose (25, 30).

Impersonal and scant information on the course of rehabilitation and future possibilities were experienced as an obstacle in the rehabilitation process. Participants described a lack of individually tailored information as an obstacle to rehabilitation at all phases (23, 29, 31). They had expected information about their individual condition, future possibilities and long-term consequences, but they mostly received standardized information (29, 31). This was experienced as stressful and as an obstacle for reintegration (23, 31). In addition, the limited information about rehabilitation options made it difficult for the participants to advocate for their needs (23, 29, 31). It was often up to the participants to ask for information:

"I asked a lot of questions. I delved. I persisted. I argued. I often got my way, but that's through a lot of persistence and a lot of battling red tape and administration" (23) (p. 443).

The involvement of close persons was crucial for the rehabilitation process. Engagement and support from relatives, friends and colleagues was described as important for the rehabilitation process (23, 25, 27–29, 31, 32). Emotional support from close persons was important throughout all phases (25, 27–29, 31, 32). Practical support from close persons in activities of daily life and in contacts with authorities was invaluable (25, 27–29, 31, 32). The role of close persons became even more important when the expected services did not function as expected:

"My husband has supported me all along, and I have my sisters who have kept up with the rehabilitation services in our municipality. Not all people have a social network like mine, and if you also have had brain injury, it is difficult to find out where to go. That's probably one of the greatest obstacles" (31) (p. 930).

The participants' experiences show how close persons often take on a burden, to some extent related to limited access to coordinated rehabilitation (23, 25, 27–29, 31, 32). This burden often became difficult to handle (23, 25, 27, 29, 31, 32), and returning home was stressful and difficult for the whole family. Tasks and roles needed to change, and the family needed support to manage their changed life situation together (23, 25, 27–29, 31, 32). The participants felt that the rehabilitation should include close persons through all phases.

## Confidence in the findings

The confidence of the evidence, in each subcategory, was, in most cases, rated as low or moderate (Table III), and the overall considerations for the 4 domains in GRADE-CERQual were as follows:

- There was a low risk for findings being flawed by methodological limitations, although many studies had insufficient information about the reflexivity of the researchers.
- The synthesis method chosen for the QES included steps to ensure coherence.
- Data adequacy was problematic for all subcategories as the numbers of studies and participants were low.
- Relevance was partially affected for 1 subcategory in which a single study contributed the most information, and this study included a large proportion of persons with other types of acquired brain injury.

## **DISCUSSION**

This review synthesized the evidence from qualitative studies of the experiences of the rehabilitation process after TBI. The findings show that the participants with TBI experienced limited access to multi-professional team-based brain injury rehabilitation after hospitalization and that the rehabilitation was insufficiently individually tailored and coordinated. Many felt that the services came at the wrong time, had the wrong content, or were not offered. This meant that the participants experienced that they struggled on their own with adapting their daily life, often several years after their injury. The findings from the studies included in the OES reported that participants felt that the rehabilitation would result in better outcomes if they had received the right support at the right time. Thus, the review indicates the importance of enhancing person-centred content as well as access to coordinated team-based rehabilitation over time. This is also in line with current recommendations of person-centred team-based rehabilitation after TBI (7, 8). Similar to an earlier review (15), the QES confirmed the need for support in adapting activities of daily life in recreating a meaningful life and a new positive view of the self in the late phases after TBI. As rehabilitation after TBI commonly focuses on recovering, i.e. restoring functions (3, 7, 33), this review indicates a need for shifting focus in the late phase to organize rehabilitation programmes enhancing peoples' skills in self-management in daily life (34). The findings reported across the retrieved studies indicates that improved support for a longer time than offered to the participants is important to meet their needs and enhance their skills to manage daily activities and process changes in life during the adaptation process.

The lack of coordinated team-based rehabilitation after hospitalization could lead to haphazard rehabilitation that largely depended on whether the injured persons themselves, or their close persons, knew their options and requested rehabilitation. This can be seen as problematic from an equality perspective and, in accordance with other literature (9, 10, 35), stresses the need for improved information, participation and coordinated team-based rehabilitation throughout recovery. Case management, which was reflected upon by a few participants in the QES, has been suggested as a potential resource to improve the coordination of services, even if the scientific evidence for the method needs further evaluation (36). However, this demands that there are rehabilitation services and other forms of services available to coordinate. As the participants did not perceive that the rehabilitation was individually tailored and that they lacked information, this impacted their relationships with professionals and their participation in the rehabilitation. Consequently, many elements of importance for person-centred care (37) were not met. By acknowledging preferences and needs, the relationship between patients and professionals can become more transparent, and continuity of rehabilitation is better supported.

The findings show, in accordance with previous research (10), that transition from hospital is a vulnerable phase. One explanation may be that planning at the hospital lacked opportunities to fully anticipate long-term needs arising in daily life after transition. This suggests that team-based rehabilitation should be developed to better identify needs that arise after the transition. Another vulnerable phase arose when the rehabilitation efforts in the late phase ceased, and people with TBI were required to continue the recovery process on their own. This process can extend many years after formal rehabilitation has ceased (15, 16). Similar to other reviews (15, 38), the QES confirmed that close persons were important and provided both emotional and practical support during this time In addition, the importance of involving close persons in rehabilitation after TBI was confirmed. However, as the QES was limited to the injured persons' experiences, reviews are needed of close persons' perspectives to better inform about their needs.

The QES followed international guidelines (18) to ensure a transparent and systematic process. To ensure a high-quality synthesis, the researchers had different educational backgrounds and research experiences, integrating various perspectives. The process included continuously going backwards and forwards and questioning the evolving findings (19). Confidence regarding the evidence in the findings was downgraded according to GRADE-CERQual, mainly because data were based on few studies with few participants. Therefore, confidence regarding the subcategories ranged between very low and moderate. In addition, almost all participants in the dataset were of working age, which affects the transferability to older persons with TBI. This is surprising, as many of those who sustain a TBI are older persons (39). Women were in the minority (38%), and potential differences and similarities related to sex were not a focus. Another aspect that can affect transferability is that experiences may vary in relation to the person's need for rehabilitation, which depends on the severity of the disability and life context. This indicates a need for qualitative research with a purposive selection of participants with respect to the severity, sex and age to enhance confidence in the findings. Moreover, few of the participants in the studies had experienced team-based rehabilitation as access to rehabilitation after discharge from hospital was limited. Further research is therefore needed on the content and significance of rehabilitation, especially in the later phase.

In conclusion, this QES shows that those with TBI undergo a demanding rehabilitation process that requires multi-professional team-based rehabilitation over a longer time than is usually offered. The findings

indicate a need to improve access to coordinated teambased rehabilitation in the long term and enhance the person-centeredness of services to address the complex needs of persons with TBI. The findings had low to moderate levels of confidence of evidence that largely can be explained by the shortage of research exploring the experiences of people receiving team-based rehabilitation after TBI.

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Appendix 1. Example of search strategy. PubMed via National Library of Medicine, 24 March 2021

Number	Search terms	Items found
Population	n: traumatic brain injury	
1.	"Brain Hemorrhage, Traumatic" [Mesh] OR "Brain Concussion" [Mesh] OR "Brain Injuries/rehabilitation "[Mesh] OR "Brain Injuries, Traumatic" [Mesh] OR "Brain Injury, Chronic" [Mesh] OR "Craniocerebral Trauma/rehabilitation" [Mesh] OR "Contreccup Injury" [Mesh] OR "Craniocerebral Trauma" [Mesh] OR "Craniocerebral Trauma" [Mesh] OR "Head Injuries, Penetrating" [Mesh] OR "Intracranial Hemorrhage, Traumatic" [Mesh] OR "Subarachnoid Hemorrhage, Traumatic" [Mesh]	57198
2.	(acquired brain injur*[tiab] OR brain concussion[tiab] OR brain contusion*[tiab] OR brain damage[tiab] OR brain injured[tiab] OR brain injur*[tiab] OR brain rehabilitation[tiab] OR brain trauma[tiab] OR brainstem injury[tiab] OR cerebral contusion*[tiab] OR cerebral damage[tiab] OR cerebral injur*[tiab] OR cerebral trauma*[tiab] OR concussi*[tiab] OR cranial injury[tiab] OR cranial trauma[tiab] OR cranial trauma[tiab] OR cranial trauma[tiab] OR cranial trauma[tiab] OR post-concussi*[tiab] OR post-concussi*[tiab] OR severe brain contusion[tiab] OR severe brain injuries[tiab] OR severe brain injury[tiab] OR severe TBI[tiab] OR TBI rehabilitation[tiab] OR TBI Model Systems[tiab] OR traumatic encephalopath*[tiab] OR traumatic brain[tiab] OR traumatic cerebral*[tiab] OR traumatic head[tiab] OR traumatic injur*[tiab]) NOT medline[sb]	20108
3.	1 OR 2	77299
Perspectiv	ve: patients experiences and attitudes	
4.	"Adaptation, Psychological" [Mesh] OR "Attitude" [Mesh:NoExp] OR "Attitude to Health" [Mesh:NoExp] OR "Communication" [Mesh] OR "Communication Barriers" [Mesh] OR "Expressed Emotion" [Mesh] OR "Health Communication" [Mesh] OR "Thterpersonal Relations" [Mesh] OR "Nurse-Patient Relations" [Mesh] OR "Patient Acceptance of Health Care" [Mesh] OR "Patient Participation" [Mesh] OR "Patient Participation" [Mesh] OR "Patient Satisfaction" [Mesh] OR "Personal Satisfaction" [Mesh] OR "Physician-Patient Relations" [Mesh] OR "Professional-Patient Relations" [Mesh] OR "Quality of Life" [Mesh] OR "Resilience, Psychological" [Mesh]	1148611
5.	(attitude*[tiab] OR belief*[tiab] OR embodied[tiab] OR emotional[tiab] OR experience*[tiab] OR health care consultation[tiab] OR interpretation[tiab] OR meaning[tiab] OR nursing encounter*[tiab] OR perception[tiab] OR perspective*[tiab] OR professional consultation[tiab] OR nursing consultation[tiab] OR psychological[tiab] OR relation[tiab] OR resilience[tiab] OR satisfaction[tiab] OR self-report[tiab] OR stigma[tiab] OR trust[tiab] OR view[tiab]	645434
6.	4 OR 5	1793959
7	3 AND 6	7384
Studv tvn	es: qualitative research <sup>1</sup>	
8	"Qualitative Research" [Mesh] OR "Grounded Theory" [Mesh] OR "Interviews as Topic" [Mesh] OR "Interview, Psychological" [Mesh] OR "Nursing Research" [Mesh] OR "Health Services Research" [Mesh] OR "Epidemiologic Methods" [Mesh] OR "Personal Narratives as Topic" [Mesh] OR "Anecdotes as Topic" [Mesh] OR "Video Recording" [Mesh] OR "Tape Recording" [Mesh] OR qualitative *[Title/Abstract] OR interview *[Title/Abstract] OR focus group *[Title/Abstract] OR phenomenograph *[Title/Abstract] OR ethnolog *[Title/Abstract] OR ethnolog *[Title/Abstract] OR ethnolog *[Title/Abstract] OR ethnolog *[Title/Abstract] OR focus grounded theory [Title/Abstract] OR narrat *[Title/Abstract] OR grounded theory [Title/Abstract] OR focus grounded theory [Title/Abstract] OR grounded theory [Title/Abstr	7400164
	sets/Limits: publication year, language	
9	7 AND 8 /Filters activated: Publication date from 2020/01/01, Danish, English, Norwegian, Swedish	2682

<sup>&</sup>lt;sup>1</sup>No validated or evaluated filter used.

The search result, usually found at the end of the documentation, forms the list of abstracts.

[MeSH]=Term from the Medline controlled vocabulary, including terms found below this term in the MeSH hierarchy

[MeSH:NoExp]=Does not include terms found below this term in the MeSH hierarchy

[MAJR]=MeSH Major Topic

[TIAB]=Title or abstract

[TI]=Title

[AU]=Author

[OT]= Other term

[TW]=Text Word

Systematic[SB]=Filter for retrieving systematic reviews

<sup>\*</sup>Truncation

# Appendix 2. Assessment of methodological limitations, studies with qualitative methodology

Author: Year:			
Reviewer: Included in the synthesis:	•	*	
Questions	Yes	No	Unclear
1. Was there an agreement between philosophy/theoretical underpinnings and design and conduct of the	e study?		
What theory or philosophical approach did the authors use?  Can a lack of agreement between theory/philosophical approach and study design affect the findings?			
Comments:			
2. Context			
What was the context?			
Support question for assessing the choice of context:			
Is the context reasonable for investigating the phenomenon of interest?  Can the selected context affect the findings?			
Comments:		_	
3. Participants			
How was the selection made?			
Support questions for assessing deficiencies in the selection procedure:			
Is the selection appropriate for the phenomenon in question?  Is the recruitment method appropriately selected and implemented?			
Are there deficiencies in the selection that can affect the findings?			
Comments:			
4. Data collection			
What methods were used for data collection?			
Support questions for assessing deficiencies in data collection:  Is the form of data collection appropriate to clarify the phenomenon in question?			
Are there flaws in data collection that can affect the findings?			
Comments:	_	_	_
5. Analysis			
What methods were used for analysis?			
Support questions for assessing deficiencies in the analysis phase:  Is the chosen method of analysis suitable and carried out in an appropriate way?			
Were the researchers reflexive in interpreting data?			
Were the interpretations validated?			
Are there flaws in the analysis that can affect the findings?			
Comments:			
6. Researcher  How many researches were involved in the study and what were their field of competence?			
Support questions for assessing problems with related to the researchers:			
Did the researchers have any relation to the study participants that may influence data collection?			
Had the researchers handled their pre-understanding in an acceptable way?			
Were the researchers independent of financial or other conditions that could influence the analysis?  Are there deficiencies that can affect the findings?			
Comments:			
Overall risk that results are flawed by methodological limitations:			
Insignificant or low			
Moderate			
High the study is not included in the synthesis.			
High, the study is not included in the synthesis			
Comments:			
Questions used for assessment of CERQual (only applied on included studies)			
7. Coherence			
Support questions for assessing coherence:			
Were the main body of the data used in the analysis?			
Were conflicting data handled appropriately?			
Did the data support the findings?  Overall, are there weaknesses that could lead to a lack of coherence in the synthesised scientific evidence?			
Comments:	ш	ш	
8. Adequate data			
Support questions for assessing adequacy of data:			
Were the number of participants in the study enough for the results to be representative (e.g., whether satu	ıration reach	ed)?	
Is the range of participants sufficient to cover all perspectives of the phenomenon in question?  Has the form of data-collection been sufficient to allow rich and necessary data?			
Overall, are there weaknesses that may lead to a lack of coherence in the overall scientific evidence			
Comments:	_	٠	

## Appendix 3. Excluded studies.

Article	Reason for exclusion
Aitken L, Chaboyer W, Jeffrey C, Martin B, Whitty J, Schuetz M, et al. Indicators of injury recovery identified by patients, family members and clinicians. Injury 2016; 47: 2655–2663.	Not team-based rehabilitation
Braaf, S., Ameratunga S, Christie N, Teague W, Ponsford J, Cameron PA, et al. Care coordination experiences of people with traumatic brain injury and their family members in the 4-years after injury: a qualitative analysis. Brain Inj 2019; 33: 574–583.	Not team-based rehabilitation
Dams-O'Connor K, Landau A, De Lore JS, Hoffman J. Access, barriers, and health care quality after brain injury: Insiders' perspectives. Arch Phys Med Rehab 2016; 97: e129.	Not peer-reviewed article
Dams-O'Connor K, Landau A, Hoffman J, St De Lore J. Patient perspectives on quality and access to healthcare after brain injury. Brain Inj 2018; 32: 431–441.	Methodological limitations
Darragh AR, Sample PL, Krieger SR. "Tears in my eyes 'cause somebody finally understood": client perceptions of practitioners following brain injury. Am J Occup Ther 2001; 55: 191–199.	Methodological limitations
Doig E, Fleming J, Cornwell PL, Kuipers P. Qualitative exploration of a client-centered, goal-directed approach to community-based occupational therapy for adults with traumatic brain injury. Am J Occup Ther 2009; 63: 559–568.	Not team-based rehabilitation
Eliacin J, Fortney S, Rattray NA, Kean J. Access to health services for moderate to severe TBI in Indiana: patient and caregiver perspectives. Brain Inj 2018; 32: 1510–1517.	Not team-based rehabilitation
Fadyl JK, Theadom A, Channon A, McPherson KM. Recovery and adaptation after traumatic brain injury in New Zealand: longitudinal qualitative findings over the first two years, Neuropsych Rehabil 2019; 29: 1095–1112	Not team-based rehabilitation
Foster M, Legg M, Hummell E, Burridge L, Laurie K. Right people, right time? A qualitative study of service access experiences of adults with acquired brain injury following discharge from inpatient rehabilitation. Brain Impair 2021; 22: 92–107.	Too low proportion TBI
Gill IJ, Wall G, Simpson J. Clients' perspectives of rehabilitation in one acquired brain injury residential rehabilitation unit: a thematic analysis. Brain Inj 2012; 26: 909–920.	Methodological limitations
Gravell R, Brumfit S, Body R. Hope and engagement following acquired brain injury: a qualitative study. Brain Inj 2017; 31: 721–722.	Not peer-reviewed article
Haag HL, Caringal M, Sokoloff S, Kontos P, Yoshida K, Colantonio A. Being a woman with acquired brain injury: challenges and implications for practice. Arch Phys Med Rehab 2016; 97: S64–70.	Not team-based rehabilitation
Harrison AL, Hunter EG, Thomas H, Bordy P, Stokes E, Kitzman P. Living with traumatic brain injury in a rural setting: supports and barriers across the continuum of care. Disabil Rehabil 2017; 20: 2071–2080.	Methodological limitations
Hoogerdijk B, Runge U, Haugboelle J. The adaptation process after traumatic brain injury an individual and ongoing occupation struggle to gain a new identity. Scand J Occup Ther 2011; 18:122–132.	al Not team-based rehabilitation
boson JM, Coetzer R, Stew G, Moore A. Patients' experience of return to work rehabilitation following traumatic brain injury: a phenomenological study. Neuropsych Rehabil 2013; 23: 19-44.	Methodological limitations
Jumisko E, Lexell J, Soderberg S. The experiences of treatment from other people as narrated by people with moderate or severe traumatic brain injury and their close relatives. Disabil Rehabil 2007; 29: 1535–1543.	Not team-based rehabilitation
The control of the co	Not peer-reviewed article
Fig. and then partners in making decisions about the area injury. Brain Impair 2015, 14, 109–170.  Knox L, Douglas JM, Bigby C. "I've never been a yes person": decision-making participation and self-conceptualization after severe traumatic brain injury. Disabil Rehabil 2017; 39: 2250–2260.	Not team-based rehabilitation
A prescribing and injecting model of care in a public rehabilitation setting. Aust Health Rev 2013; 37: 624-631.	Not team-based rehabilitation
Lannin N, Roberts K, D'Cruz K, Morarty J, Unsworth C. Who holds the 'Power' during goal-setting? A qualitative study exploring patient perceptions. Int J Stroke 2015; 10: 68.	Not peer-reviewed article
Larsson Lund M, Lovgren-Engstrom AL, Lexell J. Using everyday technology to compensate for difficulties in task performance in daily life: experiences in persons with acquired brain injury and their significant others. Disabil Rehabil Assist Technol 2011 6: 402–411.	Not team-based rehabilitation;
Lefebvre H, Levert MJ. Breaking the news of traumatic brain injury and incapacities. Brain Inj 2006; 20: 711–718.  Lefebvre H, Pelchat D, Swaine B, Gelinas I, Levert MJ. The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. Brain Inj 2005; 19: 585–597.	Methodological limitations Methodological limitations
Journey after traumatic brain injury. Neuropsych Rehabil 2020: E-pub 2020/07/15.	Methodological limitations
Leith KH, Phillips L, Sample PL. Exploring the service needs and experiences of persons with TBI and their families: the South Carolina experience. Brain Inj 2004; 18):1191–1208.	Methodological limitations
cardina experience. British 19 2004, 18):1191–1200. Lindstad MØ, Andelic N, Sveen U. Living with cognitive challenges after traumatic brain injury. Experiences of developing coping strategies-A qualitative study. Brain Inj 2016; 30: 584.	Not peer-reviewed article
Lundqvist A, Samuelsson K. Return to work after acquired brain injury: a patient perspective. Brain Inj 2012; 26: 1574–1585.	
Morris PG, Prior L, Deb S, Lewis G, Mayle W, Burrow CE, et al. Patients' views on outcome following head injury: a qualitative study. BMC Fam Pract 2005; 6: 30–36.	Not team-based rehabilitation
Nalder E, Fleming J, Cornwell P, Shields C, Foster M. Reflections on life: experiences of individuals with brain injury during the transition from hospital to home. Brain Inj 2013; 27: 1294–1303.	Not team-based rehabilitation
O'Callaghan A, McNamara B, Cocks E. 'What am I supposed to do? Cartwheels down the passageway?' Perspectives on the rehabilitation journey from people with ABI. Brain Inj 2014; 28: 577–578.	Not peer-reviewed article
O'Callaghan AM, McAllister L, Wilson L. Experiences of care reported by adults with traumatic brain injury. Int J Speech-Lang Pa 2010; 12: 107–123.	Not a qualitative study
Patterson F, Fleming J, Doig E. Clinician perceptions about inpatient occupational therapy groups in traumatic brain injury rehabilitation. Brain Inj 2017; 31:1077–1087.	Not client perspective
Soeker MS, Van Rensburg V, Travill A. Are rehabilitation programmes enabling clients to return to work? Return to work perspectives of individuals with mild to moderate brain injury in South Africa. Work 2012; 43: 171–182.	Methodological limitations
Stergiou-Kita M, Mansfield E, Sokoloff S, Colantonio A. Gender influences on return to work after mild traumatic brain injury.  Arch Phys Med Rehab 2016; 97: S40-45.	Methodological limitations
Talbot LR, Levesque A, Trottier J. Process of implementing collaborative care and its impacts on the provision of care and rehabilitation services to patients with a moderate or severe traumatic brain injury. J Multidiscip Healthc 2014; 7: 313–320.	Methodological limitations
van Velzen JM, van Bennekom CAM, van Dormolen M, Sluiter JK, Frings-Dresen MHW. Factors influencing return to work experienced by people with acquired brain injury: a qualitative research study. Disabil Rehabil 2011; 33: 2237–2246.	Too low proportion TBI
White BP, Brinkman A, Kresge BP, Couture L. Quality of life, stress perception, and quality of social networks in persons living with brain injury: an exploration of the effectiveness of a community-based program. OJOT 2018; 6: 1–14.	Not team-based rehabilitation
Ylvisaker M, McPherson K, Kayes N, Pellett E. Metaphoric identity mapping: facilitating goal setting and engagement in rehabilitation after traumatic brain injury. Neuropsych Rehabil 2008; 18: 713–741.	Methodological limitations

TBI: traumatic brain injury.