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“Going under the radar”: barriers to continuity in the rehabilitation trajectories of adults with acquired brain injury in North Norway

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ABSTRACT

Purpose: Acquired Brain Injury (ABI) is a major cause of disability, but rehabilitation services for adults with ABI discharged home remains deficient. This study explores barriers to continuity in the rehabilitation trajectories of this population in North Norway.

Materials and methods: Data were generated from focus groups consisting of individuals with ABI and family caregivers ($n=5$) and healthcare professionals ($n=14$). Purposeful sampling of participants (total $n=19$) ensured diverse perspectives. A reflexive thematic analytical approach was applied to identify recurring themes.

Results: This study reveals significant misalignment between the support needs of home-dwelling adults with ABI and the existing healthcare system in North Norway. Four themes were identified: (1) A lack of awareness of patient rehabilitation needs in hospitals, (2) individuals with ABI slipping through the cracks during transitions, (3) constraints in municipal healthcare services' capacity, and (4) unclear rehabilitation pathways for individuals with ABI.

Conclusions: Individuals with ABI need assistance navigating complex healthcare systems, gaining insight into their functional problems, and expressing needs and goals. The findings support calls for a paradigm shift in ABI rehabilitation, advocating for a transition from impairment-focused to reengagement-oriented practices as individuals with ABI transition from inpatient to home settings with increasingly stable residual impairments.

► IMPLICATIONS FOR REHABILITATION

- Rehabilitation needs in home-dwelling adults with Acquired Brain Injuries (ABI) often go unnoticed, leading to this population “going under the radar.”
- Individuals with ABI require assistance in navigating complex healthcare systems, gaining insight into their functional challenges, and expressing their needs and goals.
- Fostering collaborative relationships among individuals with ABI, their families, and healthcare professionals can enhance care continuity.
- Emphasising community integration and participation is essential as individuals with ABI adapt to home settings.

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Introduction

Acquired Brain Injury (ABI), which includes conditions such as stroke and Traumatic Brain Injury (TBI), ranks among the leading causes of disability in the adult population worldwide [1–5]. Depending on the extent and location of the injury, individuals with ABI may experience a multifaceted array of deficits extending across functional domains, encompassing motor, sensory, cognitive, perceptual, and emotional aspects. These deficits often lead to long-term activity restrictions, complicating the individuals' return to valued roles and community reintegration [6–9].

ABI injury severity is typically classified during the acute and subacute phases using medical imaging and clinical assessments. Standardised assessments such as the Glasgow Coma Scale (GCS)

[10] and the National Institute of Health Stroke Scale (NIHSS) [11] are used to classify injury severity on scales ranging from mild to severe. The course of rehabilitative care following ABI varies depending on the severity and nature of the injury, time since injury, and individual needs. This care can include acute and subacute rehabilitation in hospital, subsequent inpatient rehabilitation, and rehabilitation programs that are focused on supporting individuals in living independently in the community or returning to work [12, 13]. Depending on injury severity and long-term impairments, some individuals require continuous care (e.g., institutionalised care), while others are able to live independently at home.

There is a growing awareness that even individuals who can live independently at home after experiencing ABI frequently face

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challenges resulting from their condition [14–16]. Although reduced motor control and mobility often contribute significantly to disability, less tangible difficulties related to cognitive impairments, fatigue, depression, and psychosocial issues tend to exert a more detrimental influence on the daily lives of these individuals [8,17,18]. Furthermore, it is widely recognised that even milder ABI can yield substantial and lasting consequences [19–25]. Despite this knowledge, the provision of adequate professional support from healthcare services for individuals with ABI who are discharged to their homes remains deficient [7,15,17,26–34]. This highlights the urgent need to improve care for this population throughout the rehabilitation trajectory.

When designing and delivering rehabilitation services, it is crucial to consider the life circumstances that influence support needs. The adult population typically faces responsibilities and desires such as pursuing economic activities, being financially independent, parenting, nurturing family relationships, maintaining a healthy sexual life, engaging in social activities, and performing tasks such as driving a car [35]. However, the functional difficulties experienced after an ABI can hinder this [36,37]. Notably, adults with ABI have voiced that the greatest long-term threats to their dignity and overall quality of life are social isolation, inactivity, exclusion from the workforce, and limited access to recreational activities [38–41].

Professional support in the community following ABI may encompass a diverse range of services and interventions designed to facilitate the transition from hospitalisation and inpatient rehabilitation to community living. The evidence base for various approaches to providing professional support for community integration and participation are well-documented in several literature reviews spanning the last two decades [28,42–56]. These reviews display a heterogeneity in interventions and organisational models, including multidisciplinary team approaches [45,46,50], the use of individual navigators [45,52], educational and self-management initiatives [28,43–54,56], exercise and physical activity programs [28,49–51,53,55,56], and supported participation in everyday life situations, including work and leisure activities [42,49,50,52,55]. Although these service models and interventions offer tailored care to facilitate the community integration and recovery of individuals with ABI, evidence suggests that our current healthcare systems are ill-equipped to provide the support needed by this population over the longer term [29,57,58]. Consequently, adults with ABI who are discharged to their homes often experience a sharp decline in professional support [17,20,26,30,59].

The current study is a part of a research and service design initiative centred around enhancing rehabilitation services for home-dwelling adults with ABI in North Norway. This region, with its arctic climate and rural landscape, is characterised by a dispersed population, lengthy travel distances, and demanding weather conditions, making it a challenging context for healthcare service delivery. The impetus for the project arose from a string of studies that exposed shortcomings in care continuity, multidisciplinary collaboration, and cross-sectoral coordination in North Norway's rehabilitation services [60–64]. More specifically, these studies identified considerable gaps in professional support for cognitive impairments, psychosocial issues, the transition to everyday life, and community integration among adults with ABI after hospital discharge [60–64].

Norwegian healthcare services, which are founded on ideals such as public funding, equal access, and individualised care [65], are structured with a two-level system. The specialist healthcare level, encompassing hospitals, is organised into four regional entities governed by The Ministry of Health and Care Services. Primary healthcare, including postdischarge rehabilitation, is

managed by local authorities across 356 relatively autonomous municipalities.

Over the past 15 years, Norwegian authorities have demonstrated an enduring commitment to improving neurorehabilitation services, with various governmental documents emphasising the importance of enhancing continuity across specialist and primary healthcare, adapting services to individual needs, and engaging users in service design [66–72]. However, despite these ideals and aspirations, recent nationwide organisational changes, including the transfer of responsibilities from specialist to primary healthcare [69,73,74], have failed to enhance rehabilitation services for people with ABI in Norway [75–77]. Notably, there has been a significant decline in the average hospital stay duration, and the extent of rehabilitation provided at the specialist healthcare level has diminished [75,78,79]. Recent reports indicate that little has been done to increase the rehabilitation capacity at the primary healthcare level correspondingly and that the rehabilitation sector in Norway remains fragmented, marked by an unclear distribution of responsibilities and a lack of national-level leadership [75–77]. Furthermore, numerous evaluations and policy documents have identified the same system deficiencies for decades, leading to the conclusion that substantial change in rehabilitation services is unlikely unless future reforms are approached differently [75].

To foster the development of novel approaches to service delivery, this study adopts a collaborative knowledge generation framework, according to which researchers work with a range of stakeholders to align research efforts and service development [80]. Although previous research has identified gaps in professional support for adults with ABI worldwide, current approaches to collaborative knowledge generation and service design stress the importance of framing challenges within their local context [81,82]. Furthermore, suggestions for improvement must begin with a clear understanding of the barriers to continuity. Therefore, to create a foundation for subsequent service improvements, the aim of this study is to identify and explore barriers to continuity in the rehabilitation trajectories of home-dwelling adults with ABI within the context of North Norway.

Materials and methods

Study design

The study design was inspired by the principles of Experience-based Co-design (EBCD) [83,84], which is one of several possible approaches to collaborative knowledge generation [80]. EBCD is characterised by recognising the crucial role of service recipients' experiences in guiding improvement. In accordance with the EBCD approach, preliminary fieldwork was conducted to lay the groundwork for a subsequent series of three all-day workshops to be held with individuals with ABI, family caregivers, and Healthcare Professionals (HCPs). The workshops progressed from identifying existing service shortcomings (workshop 1) to generating ideas for future services (workshop 2) and conceptualising a coherent new service model (workshop 3). Refer to [Figure 1](#) for an outline of the process. This article reports the findings from workshop 1. The preparation of this manuscript was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) [85] and the Standards for Reporting Qualitative Research (SRQR) [86].

Participants

To ensure the relevance and depth of the data collected, we employed a purposeful sampling strategy to recruit workshop

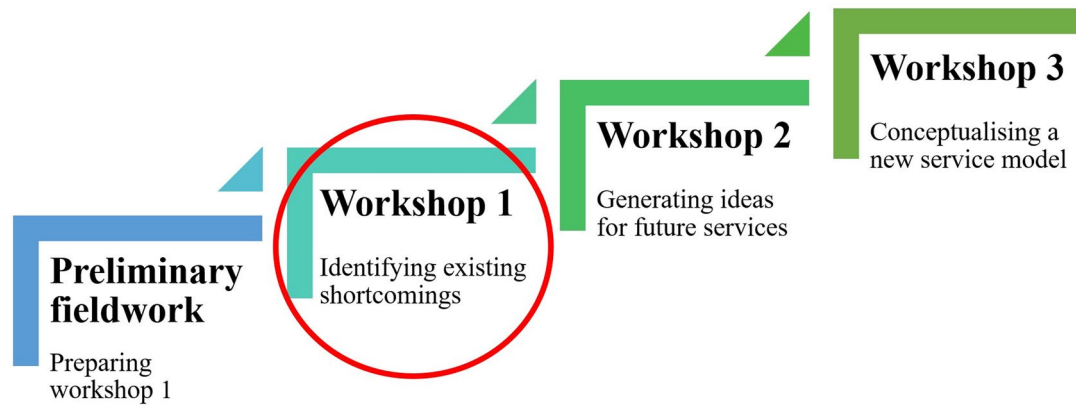


Figure 1. Outline of phases in the collaborative knowledge generation process of the project. This article reports findings from workshop 1, circled in red.

participants with diverse knowledge, experiences, and perspectives regarding the subject matter. Recruitment took place between February and May 2021 *via* healthcare and patient organisations. A total of 19 participants, consisting of individuals with ABI and family caregivers ($n=5$; 3 females, 2 males) and HCPs ($n=14$; 11 females, 3 males), were involved in the workshop. The higher number of HCPs compared to that of individuals with ABI and family caregivers was prioritised to ensure a comprehensive representation of diverse organisational settings and varied professional experiences from different phases of the rehabilitation trajectory. The time since injury for the participants with ABI ranged from four to 11 years. Unfortunately, only one of the four family caregivers who were recruited attended the workshop.

The HCP participants included occupational therapists ($n=4$), nurses ($n=4$), and physiotherapists ($n=6$). Six HCPs were employed at the municipal level, another six were employed at the specialist level, and two were working in intersectoral teams involved in coordinating care across the municipal and specialist healthcare levels. Combined, the HCP participants worked in diverse organisational settings and had varied experience from different phases of the rehabilitation trajectory. Further details about the participants can be found in Tables 1 and 2 (individuals with ABI and family caregivers and HCPs, respectively).

Workshop preparations

To prepare for the workshop series, authors LF and MN conducted preliminary fieldwork in April and May 2021. This fieldwork involved visiting and conducting video-recorded interviews with home-dwelling adults with ABI and healthcare professionals involved in ABI rehabilitation in both specialist and primary care settings. The primary objective of the fieldwork was to explore and capture these individuals’ experiences with long-term ABI rehabilitation, with a particular focus on the interactions between individuals with ABI and the healthcare system. The settings visited included the homes of individuals with ABI, the office of a patient organisation, a hospital, and a rural municipality. Video-recorded interviews were conducted with a total of five persons, all of whom were female, comprising two individuals with ABI and three healthcare professionals.

While the fieldwork notes and video-recorded interviews were not analysed as a part of the primary data for this study, this information still played a crucial role in informing the structure and focus of the subsequent workshop series. The first workshop, from which data for this study was generated, was introduced by a 30-min presentation incorporating 14 video clips, each of which lasted between 30s and three minutes. These films included

Table 1. Characteristics of the individuals with ABI and family caregivers who participated.

Participant number	Category	Size of home municipality	Time since brain injury	Age at time of workshop
1	Individual with ABI	Small (<5.000 inhabitants)	4 years	40–49 years
2	Individual with ABI	Large (>75.000 inhabitants)	6 years	40–49 years
3	Individual with ABI	Large (>75.000 inhabitants)	6 years	50–59 years
4	Individual with ABI	Small (<10.000 inhabitants)	6 years	50–59 years
5	Family caregiver	Small (<3.000 inhabitants)	11 years	60–69 years

individuals with ABI discussing their struggles after hospital discharge, such as feeling abandoned by services, having difficulties related to returning to work, and experiencing challenges in fulfilling their roles as parents or partners. Following the EBCD approach [84], these “trigger films” served to inspire discussions, establish a shared frame of reference, and demonstrate the importance of service improvement. This facilitated the deeper exploration of the issues that were identified during the fieldwork in the subsequent focus group activities at the workshop. This methodological approach has also been outlined in previous publications [87,88].

Data generation

The data for this study were generated during an all-day workshop held at a conference hotel in June 2021. The workshop was introduced with a plenary session reporting findings from the preliminary fieldwork. After the plenary introduction, a total of eight focus group sessions took place in separate meeting rooms. First, the HCPs were divided into three groups, while the participants with ABI and family caregivers formed a separate fourth group. Afterwards, the participants regrouped, with the HCPs being intentionally mixed with the participants with ABI and family caregivers to foster the exchange of diverse perspectives. Table 3 provides an overview of the workshop schedule and details about the composition of each focus group.

During the focus groups, the participants were asked to discuss and reflect on barriers to continuity in the rehabilitation trajectories of adults with ABI in North Norway, drawing on their own experiences and perspectives. Before the workshop, the research team developed topic guides outlining the main themes to be explored. Key points for discussion were the shortcomings and strengths of existing rehabilitation services, challenges in rural

Table 2. Characteristics of the healthcare professional participants.

Participant number	Profession	Healthcare level	Organisational setting
6	Occupational therapist	Municipal	Employed in a small municipality*
7	Occupational therapist	Municipal	Employed in a large municipality**
8	Occupational therapist	Specialist	Multidisciplinary ambulatory rehabilitation team (ART)
9	Occupational therapist	Specialist	Multidisciplinary ambulatory rehabilitation team (ART)
10	Nurse	Specialist	Centre for patient and caregiver education
11	Nurse	Municipal	Quality coordinator at healthcare centre including inpatient rehabilitation in large municipality**
12	Nurse	Municipal	Middle manager in home nursing care in large municipality**
13	Nurse	Cross-sectoral	Intermediate outreach team coordinating transitions between healthcare levels, primarily for elderly patients
14	Physiotherapist	Specialist	Multidisciplinary ambulatory rehabilitation team (ART)
15	Physiotherapist	Cross-sectoral	Intermediate outreach team coordinating transitions between healthcare levels, primarily for elderly patients
16	Physiotherapist	Specialist	Hospital inpatient acute neurological care
17	Physiotherapist	Municipal	Employed in a large municipality**
18	Physiotherapist	Specialist	Adviser for coordination of rehabilitation in a health trust (i.e., hospital)
19	Physiotherapist	Municipal	Private physiotherapy clinic with municipal operating grant in large municipality**

* Small municipality: < 4.000 inhabitants.

** Large municipality: > 75.000 inhabitants.

Table 3. Workshop schedule and overview of the focus groups. Participant numbers can be found in Tables 1 and 2.

Duration (5 h 15 m total)	Activities	Description
30 m	Introduction to the workshop	Welcome to the workshop and presentation of the project. Presentation of fieldwork findings, including trigger films.
10 m	Short break	
1 h 20 m	Focus groups	One focus group with individuals with ABI and family caregivers (participants 1,2,3,4,5). Three focus groups with healthcare professionals (participants 6,10,16,19–9,12,13,15,18–7,8,11,14,17).
1 h	Lunch break	
1 h 30 m	Focus groups	Four groups with healthcare professionals, individuals with ABI, and family caregiver mixed (participants 3,7,10,16,18–1,4,8,11,19–2,6,13,14,15–5,9,12,17).
15 m	Short break	
30 m	Plenary workshop summary	Summary of workshop 1 and preview of workshop 2.

areas, support for community integration, cross-sectoral collaboration, and information access.

Two researchers moderated each focus group, with one serving as the main moderator and the other taking notes and asking supplementary questions. All researchers involved in the workshop were trained in qualitative research, and at least one researcher in each moderator pair had prior experience in conducting focus groups.

Each focus group session was audio recorded and lasted between 60 and 90 min, resulting in approximately 10 h and 45 min of recorded material. The audio recordings were transcribed verbatim, deidentified, and reviewed for accuracy.

Data analysis

The data analysis followed Braun & Clarke's reflexive thematic analysis approach [89,90], encompassing dataset familiarisation; code generation; theme construction, revision, and definition; and report production. A key question guiding our analysis was how barriers to continuity in ABI rehabilitation were articulated and construed by the workshop participants. While the initial code generation step was predominantly data-driven and inductive, we employed certain theoretical lenses in the subsequent phases of the analysis.

The concept of trajectory served as a lens through which to view ABI rehabilitation as an evolving process across time and settings. While experiences of illness are inherently personal and mapping of individual trajectories relies on retrospective examination, the trajectory concept enables the prospective identification of common phases within the course of ABI rehabilitation, which can be harnessed to locate barriers temporally [91,92]. For instance, the discharge home and subsequent decline in professional involvement are recognised as pivotal points, posing substantial challenges to continuity [91]. Thus, the trajectory concept guided the development of themes, including their gradual evolution into a chronological structure during analysis.

In the discussion of findings, we applied Heaton et al.'s delineation of different perspectives on continuity of care [93] and Egan et al.'s rationale for shifting from impairment-focused to reengagement-oriented rehabilitation as individuals with ABI transition from inpatient to postdischarge settings [94]. These theoretical lenses facilitated a deeper understanding of critical aspects of the identified themes.

The authors of this article have diverse backgrounds, including occupational therapy (AG, CA), physiotherapy (LF, ME, MN), and sociology (HKA). Collectively, the team possesses extensive experience in clinical rehabilitation and healthcare service research. In this study, MN primarily conducted the analysis. Collaborative meetings involving all authors were held to facilitate ongoing discussion related to the analysis and written presentation. This approach was instrumental in enhancing the validity of interpretations, strengthening research credibility, and promoting continuous researcher reflexivity throughout the analysis.

Ethical considerations

Allowing individuals with ABI and family caregivers to meet separately before joining mixed groups during the workshop was a deliberate strategy to empower them. We were also careful to incorporate breaks into the overall workshop and each focus group session out of consideration for the challenges frequently faced by individuals with ABI, such as fatigue [95].

The project was approved by the Norwegian Centre for Research Data (reference number 659996) and by the Regional Committees for Medical and Health Research Ethics in Norway (reference number 237955). Prior to their inclusion, all participants received oral and written project information and provided their signed informed consent.

Results

The data analysis identified four main themes, revealing barriers that hinder continuity throughout the rehabilitation trajectories of home-dwelling adults with ABI in North Norway. These barriers include a lack of awareness in hospitals regarding the detrimental long-term effects of brain injuries, gaps in coordination during home transitions, and a limited capacity for postdischarge rehabilitation in primary healthcare. Overall, our analysis demonstrates how this population “goes under the radar” of the healthcare system throughout the rehabilitation trajectory, leading to limited and sporadic care and leaving individuals with ABI unsure of where to find help when they are left unsupported and struggling to recover. Please refer to Table 4 for an overview of the main themes and subthemes.

“This went fine”: hospitals lack awareness of the rehabilitation needs of individuals with ABI who are discharged home

The HCPs described that short hospital stays lead to brief assessments of individuals who were discharged home, particularly those with less severe ABI. This brevity increased the likelihood of overlooking functional deficits not related to motor control or speech deficits. In the following, an experienced occupational therapist working within the rehabilitation field in specialist healthcare noted that communication of the relative success of acute medical treatment can obscure residual deficits, which can make patients’ everyday lives challenging after discharge:

You know, ‘Here are some recommendations from us’ – stuff like that is rarely provided to patients at discharge. So, they are largely left to the unknown. And perhaps they have problems obtaining insight into their own difficulties? And at *least* family caregivers, they are not properly informed. They might get, ‘This went fine. We’ve coiled that aneurism, and there was some bleeding, but this went fine.’

Table 4. Overview of the main themes and subthemes.

Main themes	Subthemes
“This went fine”: Hospitals lack awareness of the rehabilitation needs of individuals with ABI who are discharged home	(i) Short stay times in the acute hospital setting leads to insufficient functional assessments (ii) Not all individuals with ABI are admitted to the hospital in the acute phase (iii) Individuals with less severe ABI are deprioritised in inpatient rehabilitation
“I send my assessment in the post and hope for the best”: Individuals with ABI who are discharged home slip through the cracks of the system during transitions	(i) Responsibilities for postdischarge care planning within hospitals are fragmented (ii) Referrals are limited by a perceived lack of appropriate postdischarge services (iii) Communication and information sharing between hospitals and municipalities is insufficient
“We’re not used to working in that manner”: The capacity of municipal healthcare services for the rehabilitation of home-dwelling adults with ABI is constrained	(i) There is a mismatch between existing municipal services and needs of adults with ABI (ii) There is a lack of multidisciplinary organisation of municipal healthcare services (iii) Large municipal size is not necessarily advantageous for tailoring care to individual needs
“That’s why I call rehabilitation an act of randomness”: It is unclear where individuals with ABI can turn when they struggle to recover	(i) Gaining access to existing appropriate services is coincidental (ii) There is an overemphasis on motor control and physical fitness (iii) Support in understanding problems and expressing needs and goals is lacking

Some participants raised the point that not all individuals who sustain ABI are admitted to the hospital, particularly those with less severe brain injuries such as concussion related injuries, increasing the likelihood of them being left unsupported. A physiotherapist working in postdischarge ABI rehabilitation said:

If you think about the ones with concussions, right? Those who drive off the road on their bike or get a proper knock in the head at football practice, and then they start to struggle later? I’ve seen a few of those. Some of them *maybe* turn up at the urgent care centre to get checked but are just told: ‘Take it easy for a few days, and you’ll be okay.’ And then they are not detected by anyone after that.

The HCPs highlighted the negative effects of the decreasing extent of inpatient neurorehabilitation at the specialist healthcare level in Norway over the past several years, which has led to priority being given to individuals with severe ABI due to capacity concerns. The combination of short stay times in the acute setting and the lack of inpatient rehabilitation not only has reduced pre-discharge multidisciplinary assessments, limiting the chance of discovering residual functional deficits, but also has decreased the opportunity for individuals with ABI and family caregivers to develop an understanding of the consequences of the impairments while still being supported by skilled clinicians in the hospital environment.

Short hospital stays and limited inpatient rehabilitation also reduce the likelihood of hospital personnel sharing information with postdischarge service providers. A physiotherapist working in a private clinic at the municipal level commented:

Nowadays, they come straight to me. (...) But it wasn’t like that before. They used to be two or three weeks in the rehabilitation department at the hospital after being discharged from the neurology department. And then perhaps at a private rehabilitation institution after that. And *then*. *Then*, I could understand, ‘What is it that this patient requires?’ And perhaps the patient also knew, ‘What do I need?’ And then we could set the course. But now there’s nothing.

“I send my assessment in the post and hope for the best”: individuals with ABI who are discharged home slip through the cracks of the system during transitions

The specialist healthcare HCPs expressed concerns about the unclear distribution of responsibilities within hospitals for planning postdischarge care and referral to appropriate services. The fragmentation of responsibilities was exacerbated by individuals with ABI being treated in different hospital departments based on aetiology and severity, as well as being transferred between departments during their stay.

Several members of regional Ambulatory Rehabilitation Teams (ARTs) participated in the workshop. ARTs are organised at the specialised healthcare level in North Norway, with a mandate to contribute to the support of adults with ABI by assisting with transitions, coordinating care, and guiding municipal service providers. However, ART members expressed concern that their role and expertise are little known outside the hospital rehabilitation departments. Consequently, many individuals who sustain ABI are not referred to them, making ARTs an underutilised resource. An occupational therapist working in an ART described receiving the occasional referral from an acute care hospital department:

We are very pleased with those referrals because there aren’t many of them. So, I think we might need to make an extra effort there, because so many patients are *never* detected. (...) Perhaps they are referred to a physio after discharge but are not considered to require any of the other services that are available in the municipality. But then, later, it

turns out that the person *never* gets back to work, right? And that group of people, I think, goes very much under our radar. We struggle to detect them.

The hospital HCPs reported that they found it hard to navigate the available municipal services due to the significant organisational heterogeneity among municipalities and the large number of municipalities in the catchment area of each hospital. The hospital HCPs also perceived a general lack of municipal-level services that were adapted to the needs of adults with ABI who were discharged home, making it unclear whom to contact to facilitate service continuity.

A wide range of participants agreed that individuals with ABI who are able to live independently at home are usually given low priority in municipal healthcare services due to capacity concerns, resulting in delayed or nonexistent follow-up. Some participants raised concerns that this recurring lack of priority could discourage referrals to municipal services and further obscure the support needs of individuals with ABI. Furthermore, the hospital HCPs reported that they found the limited feedback from municipalities about their care plans to be challenging. For instance, a hospital physiotherapist working in acute care expressed frustration about the barriers to direct communication between HCPs across healthcare levels during patient discharge, which was created by municipal administrative application processes:

I can't be sure *what* the patient gets and *when* they get the service that I've applied for. I check those boxes in the application form: 'The patient needs physiotherapy.' I write a summary of my assessments, send it in the post, and hope for the best.

The HCP participants across organisational contexts lamented the obstacles to information exchange across care environments. These obstacles stemmed from separate documentation systems and a lack of shared communication platforms. In particular, many participants reported that the deficiency of information transfer from hospitals to municipalities constitutes a major barrier to service continuity. Delayed or insufficient information transfer often results in municipal HCPs spending considerable time interpreting fragmented information and acquiring additional details. A recurring issue is that information from hospitals becomes stranded at the general practitioner's office, leaving other municipal service providers without vital information. This predicament is particularly problematic in cases where discharged individuals with ABI are independent in basic everyday activities but have cognitive deficits that create everyday problems and are difficult for the individuals to convey themselves.

Several participants emphasised that the lack of structured information transfer between hospitals and municipalities constitutes a waste of resources, as it leads to the underutilisation of existing knowledge. For example, a physiotherapist working in acute care noted that although routines for cognitive screening after ABI have improved at the hospital, the assessment outcomes are not consistently shared with HCPs responsible for post-discharge care:

Hospital physiotherapist: So, I think that information should be passed along one way or another. I believe it would be very useful that you knew what assessments had been made of the patients.

Municipal occupational therapist: Yes, we spoke a lot about that earlier today. That's one of the challenges created by us not working on the same system, right? We have no access to the [hospital journal system].

Participant with ABI: So, those assessments that the speech therapist and the occupational therapists did of me in [the hospital], you can't just access them?

Municipal occupational therapist: No. Because we have two... The municipality and [the hospital], they have two separate systems.

Participant with ABI: Oh, but that's so sad! Just think about all the examinations that had been done already.

"We're not used to working in that manner": the capacity of municipal healthcare services to provide rehabilitation for home-dwelling adults with ABI is constrained

Overall, the participants described a mismatch between existing municipal healthcare services and the support needs of home-dwelling adults with ABI. This discrepancy not only leads to inadequate service provision but, more fundamentally, leads to an inability of the services to identify and address issues such as cognitive dysfunction, fatigue, psychosocial problems, and caregivers' support needs.

The participants also expressed that municipal service provision tends to be based on existing services rather than being tailored to individual needs, resulting in insufficient professional support. For example, one municipality routinely referred discharged adults with ABI to a rehabilitation facility meant for more severe cases or older patients awaiting institutional care, resulting in them being put on a waiting list. Another example was assigning home care nurses as coordinators for adults with ABI based on their availability rather than expertise. A home nursing care middle manager who participated in the workshop stated that nurses lack the time, flexibility, and competence for effective coordination for individuals with ABI:

What we're financed for is that direct face-to-face contact. That is, the things we're actually going to *help* that person with, that's what we get paid to do. (...) So, we still haven't got enough money to work in a preventive manner or do the kind of work that these patients need. It's not enough money. We don't have enough ... *data* to tell how much time it will take. And we're not used to working in that manner.

The lack of multidisciplinary organisation in municipalities was a recurring issue in several focus groups. A participant with ABI who had been discharged directly home after suffering a stroke provided an illustrative example of the consequences of mono-professional service delivery:

I guess it took between two or three months before the occupational therapist could find the time [to visit me]. And at that time, you are... I didn't really *get* what was missing or was gone. Or perhaps I was just hoping for things to sort themselves out over time? Anyway, we figured out that I didn't really *need* much occupational therapy. So, that visit was a bit pointless. Because, at the time, I didn't really understand what I was struggling with.

Several participants emphasised that municipal healthcare services in North Norway rely on generalists who cannot be expected to specialise in neurorehabilitation. The ART members, who had experience from operating in the interface between specialist and primary healthcare, acknowledged that although it is "easy" to find service shortcomings to criticise municipalities for, it should also be considered that these services face the challenging task of providing long-term care within the complex context of patients' everyday lives with resources that are limited. Furthermore, several participants underscored the *opportunities* of municipal HCPs supporting the reintegration of individuals with ABI into valued roles and activities by leveraging their proximity to the everyday context as well as knowledge about the unique characteristics of each local community.

While small municipal size (i.e., a low number of inhabitants) was frequently cited as a potential barrier to service quality due

to the perceived lack of advanced neurorehabilitation expertise, several participants highlighted distinct advantages associated with smaller rural municipalities. In contrast to municipalities with larger healthcare organisations, smaller municipalities were praised for having less bureaucracy, which enables direct communication among HCPs across healthcare levels. Smaller municipalities were also perceived as more flexible and easier to navigate, making it less complicated to tailor services to individual circumstances and needs. An experienced occupational therapist working in an ART said:

[Y]ou have some very small municipalities that just ... take care of it. They have some amazing arrangements, and just ... see people, in a way. And they just know, ‘Wow. Something’s happened to him. We just have to staff up, here.’ And then there’s some of the larger municipalities, where you perhaps just disappear in the crowd. It’s just not always the case that a lot of *services* means good *care*.

Although these benefits were described more as the result of smaller municipal size than deliberate service design, the participants emphasised that features such as compact organisational units, few care providers, and colocated services facilitated the tracking of individual needs, information sharing, and inter-professional cooperation. In these municipalities, HCPs also tend to take on several roles, simplifying care coordination and service utilisation.

“That’s why I call rehabilitation an act of randomness”: it is unclear where individuals with ABI can turn when they struggle to recover

The participants with ABI shared the view that being discharged home was not only a relief but also the beginning of realising how the residual deficits impacted their daily life. Over time, the initial consolation tended to be replaced by a sense of loneliness and uncertainty about where to find support. A participant who suffered a “minor” stroke had faced significant challenges for years, including severe fatigue when attempting to return to work, although he appeared to have recovered fully at hospital discharge:

Participant with ABI: And I believe that’s why I was sent home with just some medicine prescriptions, and a message that, ‘You’ll brush this one off. You’re only 45 years old. You’ll brush it off.’ And I thought, ‘Yes, of course I will.’ Right?

Researcher: So, that was your perception?

Participant with ABI: Yeah. And you keep expecting that for a long time. And in my opinion, that has contributed to all the disappointments that I’ve experienced. When you finally start to realise that things are going of the cliff, to put it that way, I got ... I got very depressed.

Furthermore, the participants highlighted the tendency of both HCPs and individuals with ABI to emphasise motor control and physical fitness while overlooking “less apparent” problems such as cognitive dysfunction, psychosocial issues, and fatigue. Such problems are often challenging for individuals with ABI to express, complicating their opportunity to seek support. Several participants raised the point that it is not uncommon for individuals with ABI who live independently at home to “collapse” before eventually being detected by services. A municipally employed occupational therapist stated:

And then you have the ones with impairments that are less visible. Our experience is that those people are not connected to any services. And then, in the end, it all *falls apart*. When they finally turn to us, they

have already been struggling for a long time. (...) They need someone who [is in touch with them] earlier.

During the workshop, several HCPs said they were struck by how existing services applied a crisis-driven and reactive approach, which requires individuals with ABI to initiate contact and formulate their challenges instead of services actively monitoring needs and offering timely support. A municipally employed physiotherapist summarised this as follows:

What has left an impression on me today is to realise that *we demand* too much of the patients. That they’re supposed to state, ‘This is the support that I need.’ I think we start out wrong. (...) As service providers, we may ask, ‘What’s important to you?’ And then the patients are unable to formulate exactly what that is. And because of that, we conclude that the needs aren’t there.

The participants also stressed that accessing appropriate services was often a matter of coincidence, leading to participants with ABI coining the phrase “rehabilitation as an act of randomness.” One of the participants recounted incidentally meeting a doctor acquaintance several months after discharge and being asked if he had received any rehabilitation:

So, that conversation ultimately led to me being referred to [the local hospital] for an initial rehabilitation stay. And at a later point, another doctor who I know privately told me about Sunnaas¹, right? But when I mentioned that to my general practitioner, it was like, ‘Sunnaas!?’ It sounded as if it was located on the other side of *planet earth*.

The previous quote illustrates two recurring issues among participants. First, existing services that facilitate self-management after ABI are located far away and are perceived as less accessible for people in North Norway than those in other regions in the country. Second, the participants lamented the lack of a clear point of contact for ABI support. While several participants with ABI praised the services they eventually had received, they also voiced concerns about the potential inequity resulting from the random nature of service access:

Participant with ABI 1: I’ve received more support than I considered possible. But what I miss is some kind of overview. Easier access. Because it isn’t... It’s really hard. At least when you’re having cognitive issues.

Participant with ABI 2: Yeah, the system is great in many ways, but also... It’s too person-dependent and coincidental, right? (...) But, of course, I agree with you; I’ll never complain about the tax rates again.

Participant with ABI 1: But it must become easier to navigate. For everyone.

Participant with ABI 2: Yes. A system that detects you early, and then follows you for a long time. In summary, that’s what’s important. Because, like I said earlier: The way it currently works, you are likely to go through six to twelve months of merry-go-round and chaos on your own first.

Discussion

The aim of this study was to identify and explore barriers to continuity in the rehabilitation trajectories of home-dwelling adults with ABI in North Norway. Our findings highlight key challenges that hinder the provision of adequate services, precluding the return to valued roles and activities for individuals with ABI. An overarching finding is the significant misalignment between the support needs of adults with ABI who are discharged home and the existing healthcare service system in North Norway. This

discrepancy leads to this population “going under the radar,” as their needs go unnoticed by healthcare services and remain challenging for individuals themselves to express. This results in a situation characterised by limited and sporadic professional support, leaving home-dwelling adults with ABI unsure where to find support when they struggle to recover.

A population in need of navigation assistance

One important contributor to the current situation is the tendency of both individuals with ABI and the healthcare system to underestimate the seriousness and long-term impact of ABI during the initial phases after injury. This finding aligns with previous research reporting similar observations [15,19,25,26,34,60,96,97]. A key challenge often faced by individuals with ABI is to comprehend their issues and express their needs without professional assistance [98]. Consequently, they often encounter difficulty in locating support, asking relevant questions to care providers, and providing the information necessary to demonstrate service eligibility [99]. These challenges are compounded by contemporary healthcare systems that, rather than facilitating these processes, often shift the burden onto individuals with ABI and their family caregivers to obtain, remember, synthesise, and convey information from various HCPs once they transition back to the community [32].

As identified in this study, the risk of inadequate support for this population is further exacerbated by a lack of referrals to appropriate postdischarge care and deficiencies in information transfer and communication among HCPs. These findings echo recent literature reviews concluding that individuals with less severe ABI are often left to manoeuvre the healthcare system alone [100] and feel marginalised and unable to re-engage with services [32].

Given these challenges, it has been proposed that individuals with ABI should be recognised as a population requiring assistance in navigating complex healthcare systems [99]. A recent review [52] identified the use of navigators to coordinate and deliver care as a prevalent rehabilitation model for the promotion of community integration among adults with ABI in rural contexts, supporting the notion that navigation assistance can enhance rehabilitation continuity in regions such as North Norway.

It is also interesting that although smaller municipalities were reported to lack ABI expertise, several participants suggested benefits associated with their organisational features. Some rural communities were seen as more navigable, adaptable, and attentive to individual needs, which may be linked to community transparency and the presence of fewer HCPs, fostering greater personal responsibility. Further research is needed to confirm these findings and explore the mechanisms behind successful support in smaller municipalities, potentially informing strategies to achieve similar responsiveness regardless of municipality size.

Shifting the emphasis from eliminating impairments to supporting reengagement

Two interrelated findings warrant further discussion. First, from a medical and acute care perspective, the treatment of ABI patients, especially those with less severe brain injuries, is often concluded early in the overall rehabilitation trajectory. Second, the existing healthcare services in North Norway exhibit limitations in detecting and addressing the needs of adults with residual impairments after ABI. These two characteristics of the healthcare system converge to leave this population poorly connected to services.

These findings are consistent with the tendency to base healthcare service delivery on acute, episodic care models rather than the longitudinal processes associated with rehabilitation and chronic care, which remains a well-known global challenge [101]. However, as residual ABI impairments gradually stabilise during the first 3–6 months postinjury, conceptual models that highlight community participation and everyday life activities are suggested to be better indicators of change compared to those centred around pathophysiology and impairment [102].

To enhance continuity in rehabilitation processes, it is necessary to recognise that the needs and goals of individuals with ABI evolve across time and contexts [9,32,96,103,104]. This recognition is also a central feature of the trajectory concept and highlights the necessity of maintaining a prospective vision when designing and implementing services to foster long-term recovery [91]. These perspectives stand in contrast to conventional conceptions of needs and goals, which assume universality across contexts, stability over time, and shared characteristics among all individuals with the same condition [94]. Instead, they underscore the vital importance of continuously adapting assessments and interventions to address evolving needs and goals. Overlooking these dynamic aspects of rehabilitation processes can constrain the utilisation of HCPs' expertise and restrict innovation in both research and practice [94].

Drawing on these conceptualisations, Egan et al. [94] propose the need for a fundamental shift in the overall approach to rehabilitation as individuals with ABI transition from inpatient to post-discharge settings. By emphasising the importance of moving beyond a narrow focus on impairments and bodily functions, the authors suggest that postdischarge rehabilitation should prioritise self-management and reengagement in activities and roles that contribute to a satisfying life. This perspective does not diminish the significance of functional improvement but acknowledges the reality that the complete normalisation of bodily functions after ABI is not always achievable. Such a shift is also supported by extensive research demonstrating that individuals with ABI can lead fulfilling lives and experience overall satisfaction despite persisting impairments [94,105–107]. Furthermore, the reengagement of adults with ABI may enhance their contribution to society, for instance, through the resumption of productive activity and continued roles within the family [25,37,40].

Interestingly, service models aligning with this perspective have been successfully implemented in jurisdictions outside of Norway. For example, professional “community navigators” have been used to coordinate care and facilitate community integration in home-dwelling adults with stroke [108]. Another example is the use of multidisciplinary teams in community-based ABI rehabilitation [109], although a recent review highlighted the need to develop team-based approaches for long-term ABI rehabilitation that are adapted to rural settings [52]. Further promising service models for enhancing community integration and participation after ABI include the use of telerehabilitation for addressing executive dysfunction [110], leisure participation support [111], and comprehensive community-based programs aimed at enhancing independence and societal participation [112–114].

If the suggested shift from impairment-focused to reengagement-oriented ABI rehabilitation is given serious consideration, it could have profound implications for the organisation and allocation of ABI rehabilitation services [94]. However, this study's findings indicate that this transition has not been implemented in healthcare services in North Norway. Earlier research in this region has similarly highlighted that a biomedical perspective continues to dominate rehabilitation efforts, even after hospital discharge, resulting in inadequate support for

self-management, psychosocial function, cognitive issues, and family life [60–64]. Nevertheless, adopting existing models such as those outlined above can help inform and inspire service development in North Norway, thereby contributing to improved rehabilitation trajectories and long-term outcomes for individuals with ABI in this region.

Achieving continuity through collaboration

The findings of this study highlight the barriers faced by adults with ABI who are discharged home in accessing and maintaining contact with rehabilitation services. Given the potential detrimental effects on their care and health outcomes, it is crucial to take measures to ensure that their needs are identified and addressed. Our findings suggest the need for a “proactive” approach to rehabilitation to prevent marginalisation and maintain continuity. However, the tendency of needs and goals after ABI to fluctuate unpredictably over an extended period underscores the limitations of relying on the prediction of needs as the basis for service delivery. This suggests the need for an alternative approach to the concept of proactive rehabilitation services.

Heaton et al. [93] suggest that care continuity can be improved by organising services to facilitate ongoing collaboration among patients, family caregivers, and HCPs. From this perspective, care continuity is viewed as coconstructed by the involved parties maintaining connections and relationships over time. Integrating this approach into clinical practice may enable rehabilitation services to adapt to individual needs and goals as they evolve and move away from an approach that is predominantly based on prediction. Key strategies to achieve this may include continual assessment, open communication, collaborative goal setting, and the deliberate use of rehabilitation plans.

Embracing a more collaborative approach may also challenge conventional views on stakeholders’ roles within rehabilitation. For HCPs, this shift involves moving from simply “delivering services” to fostering working relationships [93]. Individuals with ABI, in turn, may need to take a more active role and assume greater responsibility for their own rehabilitation journey. Nevertheless, organising healthcare services to foster reciprocal interactions holds the potential to enhance the self-reliance of individuals with ABI and support them in developing skills to manage the consequences of their condition, ultimately reducing their dependence on professional support [32].

Study limitations

Several potential limitations to this study should be considered. First, the investigation concentrated on the experiences and perspectives of adults with ABI, family caregivers, and HCPs in North Norway. Therefore, the findings may not be fully generalisable to other geographical locations or cultural contexts. Furthermore, variations in healthcare service organisation across countries, including variations in the organisation of primary care and the delineation of responsibilities between specialist and primary care, should be considered when interpreting and applying the results from this study.

Second, a purposeful sampling strategy was employed in the recruitment process, with the aim of including participants with diverse knowledge and experiences related to rehabilitation after ABI. Although the perspectives and experiences of individuals with ABI were pivotal in the methodology of this study, the lower number of individuals with ABI compared to HCPs in the focus groups may have led to an underrepresentation of their

perspectives. Furthermore, the limited attendance of family caregivers at the workshop is a notable limitation. As a result, their perspectives may not be fully represented in the current analysis. Future studies should make efforts to improve the level of family caregiver participation and ensure that their voices are adequately captured.

Another limitation concerns the use of focus groups as the primary method for data generation. While focus groups offer rich insights, they are susceptible to group dynamics that may lead to certain participants dominating the discussion or others feeling hesitant to fully express their views [115]. To address this limitation, skilled moderators were employed, and a supportive environment was created to encourage open dialogue and foster equitable participation [116,117].

Conclusion

This study elucidates the current mismatch between the needs of home-dwelling adults with ABI and the healthcare system in North Norway. The findings underscore the importance of acknowledging these individuals’ need for assistance in navigating complex healthcare systems, gaining insight into their functional problems, and expressing their needs and goals.

We propose that recognising the nonlinear and dynamic nature of needs and goals following ABI, combined with the establishment of ongoing working partnerships between individuals with ABI, family caregivers, and HCPs, can contribute to a more proactive and comprehensive approach to rehabilitation. This, in turn, can enhance the management of its consequences and foster greater self-reliance among individuals with ABI.

Our findings align with existing calls for a paradigm shift in ABI rehabilitation, advocating for a transition from impairment-focused to reengagement-oriented strategies, particularly as adults with ABI transition from inpatient to home settings with increasingly stable residual impairments. From the HCP perspective, the lack of structured systems for communication and information sharing stands out as a pressing challenge. For individuals with ABI, there is a clear imperative to develop services that are not only accessible but also tailored to their specific needs. Additionally, we recommend investigating the potential benefits of service organisation characteristics in smaller, rural municipalities, as understanding and implementing these mechanisms could enhance service responsiveness regardless of municipal size.

We hope that the identified barriers and proposed pathways for improvement will inspire concerted efforts to enhance rehabilitation services, ensuring equitable and accessible care for individuals with ABI not only in North Norway but also in other regions worldwide.

Note

1. Sunnaas Rehabilitation Hospital is located in southeastern Norway and offers multidisciplinary rehabilitation to patients with complex functional impairments, including education of individuals with ABI and family members and rehabilitation approaches focusing on community re-entry.

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Data availability statement

Exemplary excerpts of the data utilised to support the conclusions of this study are integrated into this article. However, the entire dataset is not available in an unrestricted manner due to reasons of sensitivity. Interested parties can request access to data from the lead researcher and co-author, CA. At the time of publication, data are stored in a controlled access data repository at UiT The Arctic University of Norway.

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