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Experiences of individuals with Acquired Brain Injury and their families interacting with community services: a systematic scoping review

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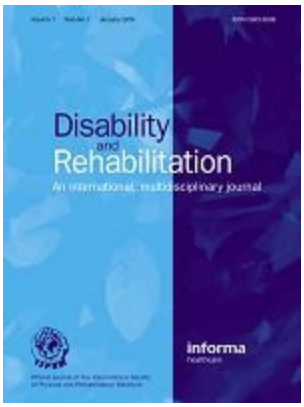

Experiences of ABI survivors and their families interacting with community services: A systematic scoping review

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Implications for Rehabilitation

1. Brain injury is a leading cause of disability worldwide with a range of physical, cognitive, emotional and behavioural difficulties.
2. It is important that service users and families are given appropriate information about the long-term difficulties associated with ABI so they are better informed about the types of support they may need upon discharge from hospital.
3. Rehabilitation professionals need to ensure they have good level of knowledge of the difficulties associated with ABI to ensure appropriate access to services for individuals and their families.
4. Understanding more about unmet needs allows community rehabilitation services to be tailored and person-centred.

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Abstract

Purpose: This scoping review aims to 1) synthesis the research findings on the experiences of individuals with acquired brain injuries, and their families, when interacting with, or accessing, community-based services and 2) identify where gaps in service provision may exist and their cause.

Methods: A systematic search strategy was employed across multiple databases to identify all studies relating to the experiences of individuals with acquired brain injuries and their families when interacting with, or accessing, community-based services. Inclusion was assessed by at least two reviewers at each stage and data extraction was completed by one researcher and validity checked by another. A narrative synthesis was employed.

Results: A total of 101 papers met the inclusion criteria with the narrative synthesis identifying three main themes of (1) Unmet needs, (2) Types of access, and (3) Barriers to access.

Conclusion: The results identify that those with acquired brain injuries, and their families, experience significant difficulties interacting with community-based services and often do not receive appropriate access. Many barriers to access were identified including a lack of knowledge of the long-term effects of acquired brain injury amongst professionals working in health and social care services.

Key Words: Acquired brain injury, unmet needs, scoping review, rehabilitation, community, long term care

Introduction

Acquired Brain Injury (ABI), an alteration to brain function occurring as result of a wide range of illnesses or injuries during or after birth, affects approximately 350,000 people in the UK every year [1]. ABIs have a range of causes including traumatic injury (TBI; road traffic accidents, falls and assaults), as well as strokes, tumours or infections [1]. Symptoms of ABI include; physical symptoms, such as mobility issues, speech difficulties, sensory impairment and fatigue [2),3)]; cognitive problems, such as language loss, and impairments in attention, concentration and memory [4),5]; behavioural problems, such as irritability, aggression, obsessive behaviour and impulsivity [6,7]; and emotional difficulties including mood swings, anxiety and depression, and wider personality changes [6].

For those with moderate to severe injuries the hospital rehabilitation process can be long with individuals with ABI often experiencing months in hospital. While hospital rehabilitation is often highly regarded in the United Kingdom (UK), wider research has indicated that family support and wider signposting to services during this time can be limited [8-10]. Further difficulties present at the point of discharge where service users regularly report feeling “abandoned” and unsupported in their longer-term community rehabilitation and integration [11,12].

Within stroke care, hospitals in the UK have increasingly moved to the model of “Early Supported Discharge” (ESD), where individuals with ABI can be discharged earlier from hospital and receive their rehabilitation at home. This step helps to

bridge the inevitable gap that exists on hospital discharge by providing rehabilitation that incorporates elements of social adjustment within service users' homes [13]. Yet gaps remain; whilst ESD can provide initial rehabilitation support, the long-term needs of individuals with ABI, and their families, are outside the remit of the ESD teams. This is due to the time-limited nature of ESD that is designed to provide short but intensive rehabilitation immediately post-discharge. Longer-term needs may include access to care packages often funded through social care, speech and language therapy, occupational therapy, neurorehabilitation, community mental health, supported housing, vocational rehabilitation, welfare and educational support [8]. These long-term rehabilitation needs often remain unmet [9,12].

The long-term social consequences of ABI have been well documented [8]. For example, a previous systematic review suggested that only 40% of those who have sustained a moderate or severe ABI returned to work after two years [14], suggesting much greater support is needed in employment rehabilitation. The same is also true for those trying to return to education, with children with ABI often struggling to engage effectively with school post-injury [15].

The literature also highlights that individuals with ABI are at an increased risk of developing, or already experiencing, a range of difficulties in areas such as mental health [16] and substance abuse [17]. Moreover, individuals with ABI are far more likely to experience suicidal ideation and to take their own lives [18,19].

Individuals with ABI are highly represented within the homeless [20] and prison populations [21]. This suggests that a significant proportion of those with ABI are experiencing difficulties with community reintegration post-injury. This may be as a direct result of their cognitive, emotional, and behavioural neurological difficulties.

For example, an inability to plan financially may result in homelessness, as might an inability to abide by the rules of a tenancy agreement [22,23]. Alternatively, difficulties with approach behaviour in relation to aggressive acts may lead individuals to end up within prisons or probation for committing violent crimes [24].

While the body of literature identifying both the psychological and social consequences of ABI is growing, there is still limited literature that examines the experiences of individuals with ABI and their families when interacting with, or attempting to access, community rehabilitation and integration services. A recent systematic review of persons with stroke and their families' experiences of community-based and primary healthcare services emphasised the sense of abandonment experienced by individuals [25]. The review highlighted the need for increased information and service provision within the community setting. While this review provides a comprehensive analysis of the stroke literature, it does not contain information about the experiences of other individuals with acquired brain injuries. Stroke and other brain injuries, such as traumatic brain injury (TBI) are often treated within differing care pathways, so it is important to examine the experiences across the range of conditions.

The overall aim of this scoping review was to catalogue and synthesise research findings that investigate the experiences of individuals with ABI and their families whilst interacting with services associated with long-term rehabilitation and support following brain injury. A secondary aim of the review was to identify any possible gaps in services and their possible cause. This systematic scoping review will analyse the literature to present the best available evidence related to the experiences of individuals with ABI and their families when interacting with

community rehabilitation services. This will include gathering evidence from papers that also report service user and family experiences from the perspective of professionals within those fields.

In particular, the objectives are to:

- Document the experiences of individuals with ABI and their families when interacting with community rehabilitation and integration services.
- Document the evidence to suggest that individuals with ABI often do not receive access to community rehabilitation and integration services, and
- Assess the evidence for gaps in service provision and the reasons why these gaps may exist.

Methods

This systematic scoping review followed Arksey and O'Malley's [26] methodological framework. The authors identified a clearly defined research question, identified relevant studies using a search strategy, selected relevant studies using inclusion and exclusion criterion, underwent a process of data extraction from the relevant papers and then collated these in the current paper. The details of each of these five stages are outlined below. A protocol was developed for this review in August 2015 but has not been formally registered.

Search Strategy

The search aimed to identify all studies relating to the experiences of individuals with ABI and their families when interacting with, or accessing, services associated with community rehabilitation or integration for children and adults with ABI. An extensive

search strategy was used to search seven databases; Web of Science, MEDLINE, EMBASE, AMED, PSYCHINFO and SOCIAL CARE ONLINE. Searches were conducted approximately every six months from May 2016. The search was last updated on 18th December 2020. No language restrictions were applied. In addition, reference lists of included papers were searched. Search criteria were adapted to suit the search terms of each individual database, but generic search terms can be found in Appendix A. Each search term was inputted into each database in turn. Section one of the search terms focused on extracting papers addressing issues related to brain injury. Section two of the searches focused on extracting papers on services. Using the 'OR' functions, all searches on 'brain injury' and all searches on 'services' were pooled and then the 'AND' function was used to combine the two searches and then an age filter was applied (Appendix A).

Inclusion criteria

- For papers to be included within the review they had to have been published since 2005. This restriction was set to ensure that all papers reflected current service provision.
- Papers had to be primary research papers rather than reviews. Only peer-reviewed journal articles were included
- Papers that included individuals with ABI, their families, or professionals involved in services to support those with ABI long-term were eligible for inclusion.

- All study designs were included in the review, including both qualitative and quantitative literature and case studies as long as they contained a qualitative or quantitative measure of the experiences of either service users with brain injuries or their families when accessing services or measure the difficulties they experienced when accessing services. Service provision was categorised broadly and included any services within the following categories; physical rehabilitation (including physiotherapy, speech and language therapy (SALT) and occupational therapy (OT)), standard health care (including General Practitioner (GP) services, Emergency care and other hospital care), mental health, substance abuse, housing and homelessness, social care (both adult and child services), decision-making/capacity and advocacy, police, probation, judicial process, legal representation and prisons (including youth offending), welfare services, disability services, learning support, home care services, and education, employment and leisure activities.
- Papers had to be available in English, French or Italian (the languages spoken by the authors) but could be based in any country worldwide.

Exclusion Criteria:

- Any articles that specifically focused on older-adult stroke patients were excluded (those over the age of 65 years). Papers that included some participants under 65 years and some over were still included.

- Interventions or efficacy papers were not included in this review unless they were evaluating current service provision and included information about the experiences of service users and their families as well as efficacy data.
- Any papers not written in English, French or Italian.

Data collection: The initial screening took the form of title and abstract review whereby at least two reviewers from a team of 19 reviewers in total, independently scanned titles and abstracts for possible inclusion. The reviewers were instructed to keep any papers that may meet the inclusion criteria and any papers where there was insufficient information to decide. Search screening took place over six different time points with different reviewers responsible for screening at each stage.

No inter-rater agreement was recorded during this stage. All initial disagreements were referred to the first author, who was responsible for setting the inclusion and exclusion criteria, to decide on inclusion at this stage. Full text papers of any possible inclusions or papers that required further investigation were then obtained. These were then assessed using the inclusion criteria independently by two reviewers from a team of four individuals. Disagreements were resolved through discussion or referral to a third reviewer (the first author). Inter-rater agreement at this stage was 82%.

Data Extraction

The following details were recorded (where possible) from included studies:

- Author, publication year

- Population characteristics: Participant information (numbers, population, length of ABI)
- Complex need studied (type of difficulty, nature of problem etc)
- Main findings: experiences of ABI survivor, their family or professionals working with ABI, nature of difficulties with services.
- Recommendations for practice/authors conclusions

Data synthesis

It was anticipated that the included studies would vary greatly in terms of study design or quality. Therefore, a narrative synthesis approach was implemented [27]. The focus of the narrative synthesis was on understanding the experiences of individuals with ABI and their families when interacting with various services, and the experiences of professionals working within those services. This was performed with a view to producing a list of recommendations for future service provision in this area.

The process of synthesis followed the guidelines developed by Popay et al [28] for narrative synthesis. The process began by extracting the data from each individual paper as outlined above. The reviewers highlighted sections of relevant text that outlined the characteristics of the participants in the reported study, which services they were interacting with, the types of support need they had and what the ultimate outcome of the interaction has been. They also highlighted any recommendations or conclusions pertaining to these variables. These textual descriptions of the data were then summarised in a data extraction table across all papers and verified by a second reviewer. This allowed a preliminary synthesis to be conducted by looking at

lists of the services, types of support needs and the interactions between services and individuals and their families.

Stage three of Popay's [28] approach was then followed by exploring the relationships between those reported elements to identify what the experiences of service users were and how and why problems arose in the interactions. This included looking at the variability in outcomes and study designs as well as study populations to understand where differences in findings may be present. This clustering of the data allowed the development of a narrative structure for the findings. The number of positive and negative interactions were then recorded, along with sample sizes from each paper to provide a measure of robustness.

Due to the large number of papers included in the review and the focus being on understanding the literature rather than drawing firm conclusions, a formal risk of bias assessment was not completed. The final stage of the narrative synthesis was to study the clusters of data to identify key themes across the studies using a process of thematic analysis [29]. This thematic analysis was then verified by the research team. The narrative was then applied in the report by outlining how each theme played out in different ways across a selection of specific studies.

The process outlined above was applied to both qualitative and quantitative papers. While quantitative data was tabulated during analysis, the authors focused on the narrative synthesis across all studies and did not synthesise the quantitative data in this paper. Narrative synthesis is not only used to synthesise qualitative papers but also used to synthesise data from quantitative papers that are heterogenous in nature (e.g., vary in terms of study design, number of participations, populations and across settings) [27].

Results

Of 34,492 studies identified in the initial search of articles (28,873 after the removal of duplicates), reading of the titles and abstracts led to a list of 292 potentially relevant references that were assessed for eligibility. Of these, 191 papers were excluded based on; not reporting appropriate outcomes (154 studies), not being primary research (30 studies), and presenting data prior to 2005 (seven studies). As a result of the screening process 101 articles met the inclusion criteria: 65 included qualitative data, and 47 included quantitative data (some papers contained mixed methodologies). Figure 1 illustrates the flow chart of the review procedure. All included studies are noted in the reference list with an asterisk.

INSERT FIGURE 1 HERE

The 101 included papers revealed the following three main themes: (1) Unmet needs, (2) Types of access, and (3) Barriers to access.

Theme 1: Unmet needs

An overview of the unmet needs of people with brain injuries and their caregivers, identified in this review, is given in Table 1. In summary, papers reported a need for information provision, ABI-specific education and adequate ABI-specific personalised services that involved families and service users. These unmet needs led to difficulties for individuals with ABI and their families in managing symptoms, particularly around fatigue, pain, and behavioural and emotional difficulties. Evidence for these unmet needs was supported by papers focusing on health professionals' perspectives of unmet needs [30-32]. Specific unmet needs were highlighted around return to pre-injury functioning (e.g., return to work (RTW), or education), reengaging

in the community and social environment, and family involvement in decision-making. It should be noted that not all papers reported unmet needs [33].

INSERT TABLE 1 HERE

Information needs were highlighted in the study by Kamalakannan et al. [34] where persons with stroke and carers stated that they received lack of information about the availability of stroke rehabilitation services post-discharge during the discharge process [see also Perry et al, 35]. Similar findings emerged in Martinsen et al's [36] study on the experiences of young and midlife individuals with stroke who reported difficulties in accessing health services and obtaining support. This limited their opportunities to address questions about their own life post-stroke, talk about their individual needs and health-related concerns. All these factors led to experiences of being *"left in the lurch".* Connolly and Mahoney's [37] findings suggest that the need for individuals following stroke to receive detailed and adequate information about stroke symptoms, especially fatigue, is crucial to reduce anxiety and uncertainty. These findings from the stroke papers can be generalised more broadly to all persons after ABI, with a need to provide clear and detailed information about brain injury symptoms and impact on daily activities. For example, Degeneffe and Bursnall [38] reported participants' descriptions of the system-level response to TBI as 'inadequate'. They also stated that many professionals lacked the skills and understanding to provide effective services and did not provide enough information.

It is widely accepted that rehabilitation should be planned on an individual basis, taking account of the patient's specific needs, goals and pre-morbid lifestyle [39].

Individuals with ABI and their families should be offered appropriate information at every stage and be involved as actively as possible in decisions regarding their care [40-43]. Moreover, families should be included in all decision-making processes where they are able and wish to be [9,30,44-46]. Other studies mentioned the need for patient-centred care plans [43-48] and access to adequate community rehabilitation services [36,45-51].

For example, Tverdal et al. [51] found that one-third of the patients in their study were not involved in the discharge process and the quality of information transferred from the trauma hospital about what to expect after discharge was insufficient. In addition, many participants did not experience a patient-centred approach and involvement in healthcare decision-making during care transitions. Similarly, Aadal et al. [48] and others have observed gaps between services and patients' rehabilitation needs at discharge from hospital, the absence of specific highly specialised rehabilitation services (*"Everybody is working on everything"*) and a lack of collaboration between professionals due to missing individual rehabilitation plans or a lack of personal coordinators [9,22,30,45-53]. In Martinsen et al's [36] work, individuals with stroke expressed the need for receiving follow-up programs tailored to their specific needs as young and midlife individuals with stroke. However, just one of the sixteen service users had an individual plan.

After a brain injury an individual can experience several types of psychological issues, such as anxiety, depression, personality change, and anger [52,54]. The physical, cognitive, emotional and behavioural consequences of ABI can be very challenging for caregivers. Thus, both those with brain injury and caregivers may require professional psychological support to deal with emotional and behavioural

challenges [52]. The emotional and mental health needs of patients and caregivers were not addressed in a total of 27 papers. One individual with stroke interviewed by Martinsen et al. [36] mentioned that the *"...health services paid attention to her physical condition but not to her psychological well-being, which resulted in despair. She missed a professional who could listen to her, help her express her problems, and find solutions to persevere."*

Caregivers involved in Kitter and Sharman's study [53] cited that the behavioural disturbances accompanying ABI had a tremendous effect on their day-to-day lives as well as placing psychological stress on them due to the demands of the role. Despite that, they did not receive support to cope with the behavioural disturbances or with the emotional changes. They also pointed out the need to receive education for themselves and their social network, the need to access employment opportunities and social support.

Fatigue management, pain and independent living came up as unmet needs in 16 studies [9,22,30,37,38,45,46,49,53-60], as well as welfare [9,22,34,45,46,57,59,60], support/housing [9,22,55,59,61], social inclusion [9,22,30,38,42,45,46,49,56,57,62-66], community rehabilitation [9,22,30,36,45,46,52,65-69], and family support [9,30,49,67-72] needs. For example, in Krishnan et al's [43] study both persons with stroke and caregivers expressed the need to increase individuals' independence and decrease the burden on caregiving. Patients mentioned the need to be able to walk, to drive, and to use public transportation. However, as the authors reported, rehabilitation professionals rarely taught the skills needed to use public transport. There has also been risks highlighted with the use of public transport in the case of

individuals with severe cognitive impairments, yet the need for other transport alternatives were often not provided by social care services [9,22].

Pickelsimer at al. [57] found many unrecognized needs in people with TBI one-year post-discharge, including; alcohol and drug support, improving mood and managing stress and emotions, support in finding paid employment (RTW), information about services, care support, increasing independence in housekeeping, cooking or shopping, and social inclusion (finding places and opportunities to socialize with others). McIntyre et al's [58] findings showed that people with high care needs experienced difficulties in accessing appropriate housing, essential support services such as rehabilitation and personal assistance, as well as services that promote community and social engagement.

Harrison et. al, [62] conducted a qualitative interview study to increase the understanding of the experiences of people with TBI and their caregivers. Results highlighted that most caregivers did not develop trusting relationships with local healthcare providers. Communication between previous inpatient rehabilitation facility professionals and local rural professionals appeared to be minimal and linkages with existing community resources were not facilitated for the transition home. Participants encountered challenges related to transportation, housing, and interference with employment. Other unmet needs persisted in terms of medical problems [72], support for caregivers [71, 73-80], community linkages [67,72, 81-87], and participation in meaningful activities [88-92], emotional support, financial support, vocational rehabilitation [93,94] and educational needs [91]. These effects seemed to be exacerbated in cases where individuals and families come from ethnic backgrounds [83,88,89,89,94,95].

Theme 2: Types of access

The papers within this review discussed the types of services people with ABI and their families attempted to access, whether successfully or unsuccessfully. The barriers to access are specifically discussed in the theme below. Types of access included; mental health provision, occupational therapy, neuropsychology, physiotherapy, speech and language therapy, educational support and vocational rehabilitation (VR). These can be seen in Table 2.

INSERT TABLE 2 HERE

During the rehabilitation process, service users may need to access different services to address specific medical, rehabilitation, social, vocational, and educational needs. Unfortunately, these services may not be available, or service users and their families may not be aware of their availability. When services are precluded or insufficient, deeper, and yet unrecognized needs may be unmet. It is important to note that needs are long-term and may change over time. This identifies the need for ongoing service provision and regular assessment of need

[9,22,30,45,46].

Individuals with ABI reported improved physical and psychological functioning immediately after completing community rehabilitation. Immediate care was found to improve long-term functioning and be more beneficial in recovery then later introduced care [89].

Social and community integration services were highlighted as important in several studies [9,45,46,54]. For example, participants in Adams and Dahdah's study [54] expressed the need for both caregivers and individuals with TBI to be involved in a

local support group as sharing their experience with others that were going through the same issues could offer suggestions and resources. This was also seen as a form of emotional and mental health support.

Return to work services are particularly important in ensuring return to pre-injury functioning. Grigorovich et al., [90] conducted a case study of one community-based agency that provided specialized employment services (ES) to people with brain injuries. Results showed that individuals with brain injuries accessed support on average for sixteen years post-injury. Despite 64% of them securing at least one competitive employment outcome (employment success), their job tenure was short (average of 368 days) and job intensity was mostly low (average 3.8 hours/day). Other studies have also identified that many individuals who 'return to work' do not necessarily go back to their pre-injury job with many returning to jobs with lower pay, less hours and involving unskilled work [96,97].

Job development, job coaching, case management and job retention services were identified as the most efficacious services to guarantee employment success [90]. Interviews revealed that people with brain injuries were provided a tailored combination of employment services including job goal identification, assessment of work-related abilities/skills, job development, on the job support and job retention assistance.

A study by Davis et al's. [98], highlighted the efficacy of resource facilitation services in identifying referral needs for people with brain injury who wish to return to work, as well as facilitating access to available state vocational rehabilitation (VR) services. Case coordinators' (CCs) contribution was crucial to increase the awareness of the availability of these kinds of services among participants, to assist them during the

application process, and to facilitate communication between clients and their VR counsellors. Furthermore, once accepted for services, CCs made sure that participants' needs were met and that they followed up with recommendations made by the counsellors.

Theme 3: Barriers to access

In this review, 77 of the included papers recognized several barriers that could prevent gaining access to services. The major barriers identified in this review are reported in Table 3 in two distinct groups (factors associated with service users and families, and factors associated with professionals).

INSERT TABLE 3 HERE

The lack of specialist knowledge and poor training among professionals, were reported as barriers to accessing adequate rehabilitation and care services in 21 studies [9,22,30,45-46,59,60,63,65-69,95,98-104]. For example, O'Rourke et al. [99] explored the knowledge about TBI and the prevalence of misconceptions among members of the probation services. The authors identified clear gaps in knowledge among members of the probation service regarding brain injury. Additionally, Glang et al. [105,106] found that the lack of knowledge, training and awareness among educators, parents, and community about TBI, are responsible for the gap between incidence of childhood TBI and identification of students with TBI receiving special

education services. Furthermore, educators often lack awareness that a student with a TBI, even a mild TBI (or concussion) might have needs, especially if no physical signs of injury were apparent. All these barriers can lead to a misidentification of students whose needs may not be recognized and met.

A lack of awareness of ABI, alongside a lack of advocacy and case management emerged as service barriers in many other studies [107,108], including in Pickelsimer et al's [57] study as well as transportation problems, lack of financial resources, health and medical problems and, service inflexibility. Participants were unaware of the availability of services or where to go for receiving assistance. The transportation problems, the limited financial resources and lack of advocacy and case management precluded seeking and/or accessing services that were needed.

Clearly, the barriers to services described above can negatively impact the interactions between individuals with brain injury, their carers/family members, and healthcare providers. For example, in Degeneffe and Bursnall's study [38] the lack of empathy, the lack of respect and continuity of care led to poor interactions with social workers, healthcare and social care professionals. These findings were also demonstrated in other studies [9,22,30,45,46,59,60,70,71,96,97,99,105,106,109-112].

Other barriers included; inability to get appointments due to a lack of service provision or poor staffing [112], difficulties attending appointments due to caring responsibilities [113], a lack of communication around care plans, transitions and discharge planning [114] and a lack of financial management services [75,115].

It is important to note that positive feedback on interactions between patients and healthcare providers were highlighted within some of the papers included in this review [e.g., 34,36,48,54,64,72,116]. In most of these studies, the factors that contributed to the development of positive relationships with healthcare professionals included good/proactive communication, the sharing of information across service providers, empathy and readiness showed by the medical staff in accommodating patients and caregivers' needs, and a good understanding of ABI amongst staff.

Barriers to services varied depending on the type of service individuals and their families were attempting to access. For example, while generally physical rehabilitation services were highly thought of by both families and service users, issues with access were present in the community setting [116]. This was often associated with poor transportation to allow access to community services [117,118] or a lack of specialist community service provision [117,118].

More significant issues were identified when accessing mental health services where lack of services and poor understanding of brain injury exacerbated barriers associated with poor transportation [9,22,119]. Limited access was available to mental health services for caregivers due to a lack of service provision [120] A similar picture was found for social and community integration services with support for returning to functional leisure activities, support with relationships and access to support groups lacking due to poor staffing, poor referral, a lack of knowledge of existing services and a lack of professional awareness of the needs of those with ABI and their families [22,30,45,46,60,120-125].

A final area with multiple barriers to access was return to work (RTW) services. In a study by Mansfield et al. [117], the major reported obstacle to RTW following work-

related mild TBI was poor understanding and knowledge of TBI (especially of the persistent physical, cognitive and psychosocial impairments) among employers and colleagues. For instance, four participants stated that their employers did not consider a brain injury as a serious incident, underestimating the impact of TBI's sequelae. In addition, in most of the cases no adaptations or changes were made in the workplace environment which was described by some participants as unsupportive and unsafe. Indeed, three participants were re-injured on the job upon RTW. Bush et al. [63] reached the conclusion that individualized job modifications and strategies are necessary for adults with TBI to succeed vocationally.

Other barriers identified include a lack of suitable jobs and hiring incentives, and difficulties in establishing support in the workplace [109,119,120]. Davis et al., [98] identified a range of barriers to RTW including; unawareness of the availability of the services, difficulties in completing the multi-step process to receive access to services experienced by individuals with ABI and caregivers (e.g. contacting the appropriate services, obtaining information about the application requirements, completing the application process, etc.), and difficulties in communication between clients and VR counsellors to ensure that their needs were met. Additional issues were associated with the cognitive and emotional difficulties of persons with TBI, lack of understanding of VR service procedures and requirements, budgetary and staff restrictions within organisations, financial limitations, transportation difficulties, and lack of family support [107,126,127].

Discussion

The overall purpose of this review was to examine the literature on the experiences of individuals with ABI and their families during the interaction with services

associated with long-term rehabilitation following brain injury. We particularly focused on the interactions among people with brain injury, their caregivers and community rehabilitation services to document the existence of difficulties in interacting with these kinds of services, as well as difficulties in accessing community rehabilitation services. The secondary aim was to highlight any gaps in service provision and their possible causes. The analysis of the literature revealed three major themes: unmet needs, types of access and barriers to access. These themes identified that while there was evidence of good interactions, individuals with ABI and their families had significant difficulties interacting with community services and often did not receive appropriate access. The findings also identified that, in part, a lack of knowledge of the long-term consequences of ABI among professionals served as a barrier to accessing services.

It is evident from the review that there is a high prevalence of unmet needs amongst individuals with ABI, carers, and family members. These unmet needs were related to support services, health, return to community and pre-injury functioning [9,22,30,48,49,57,37,54,65-67,96,97,128]. These were further exacerbated for those from ethnic minority backgrounds and with marginalized vulnerable status who have more unmet needs due to less access to services. The need for information provision was one of the most reported from the included papers [9,22,30,48,49,57,34,37,41,65,66,68] as well as the need for receiving specific education about ABI and ABI-related services [9,22,30,48,49,57,37,69,70,87,88,96,39].

The review highlighted the need for emotional support for both persons with ABI and their families, and the need for help to manage the long-term consequences of ABI

such as fatigue, pain, emotional and behavioural changes [9,30,49,36,41,47,51-53,64,99]. Moreover, from our analysis, specific needs related to pre-injury functioning, like, return-to-work or education and returning to the community and previous social/leisure activities came out as frequently unmet [9,22,49,37,46,53,54,55,60,63,83].

Certainly, the extent to which service users' and caregivers' needs are met is reliant upon availability and accessibility of relevant services. Unfortunately, in all papers it emerged that the unmet needs are largely caused by a lack of service provision [9,30,47,49,57,34,51,65-68,87,88,89,98,99]. This may be a lack of services, a lack of ABI-specific services, or a lack of referral to services. The last of these was associated with a lack of knowledge among professionals [9,22,30,48,49,57,37,59,60,63,87,88,89,90]. Overall, support and community rehabilitation services appeared limited, fragmented and often difficult to access.

The papers paint a clear picture of a lack of specific services for individuals with ABI and their families across all countries represented in the review. Where services did exist, these were often inappropriate and/or not ABI-specific so were unable to meet the specific needs of individuals and their families. Furthermore, many studies identified that individuals were often denied access to services due to eligibility criteria that often prevented those with ABI from seeking support [9]. This was exacerbated by individuals with ABI and their carers often being unaware of the type of services they needed, what was available, and how to access these services. Poor service referral is associated with poor understanding of ABI amongst professionals, individuals with ABI and carers/families and was associated with issues such as lack of insight and poor information sharing amongst professionals

[22,48,49,57,35,51,65,66,96,97]. It was also associated with a poor understanding of need for ABI-specific services among service planners which resulted in no services being available [1,8,9,23,30,45].

This review identified many different barriers and issues that might preclude individuals with ABI and their families from accessing and using post-acute services. It is evident from the review that multiple long-term services are needed in the community across a wealth of areas including mental health, psychoeducation, physiotherapy, occupational therapy, neuropsychology and community and social integration. Without improved service provision and an appropriate knowledge base amongst professionals to ensure adequate referral, service users and their families will continue to have these unmet needs [9,22,30,48,49,34,37,59,60,86]. The evidence from this review highlights the importance of resource and service coordination for people with ABI. To ensure that needs are met it is important for individuals to receive appropriate information about their conditions, and information should also be provided to family members to circumvent issues associated with lack of insight. Needs must be assessed appropriately and signposting to services provided. This must also happen alongside advocacy to ensure that individuals with ABI can interact with services in an effective manner that enables access where possible. Outside of statutory care, this process of care coordination and assessment is provided by professional expert case management [129]. This approach provides this integrative service much needed by individuals and their families [107]. Further research is required to identify how this approach could be integrated within a statutory care model.

Strengths and limitations of the review

One of the strengths of this review is that it included a broad search strategy to capture studies from across a wide range of different community services, both rehabilitation-focused and those focused on social integration and welfare support. However, this has led to a large review with many different papers with a wide range of methodologies and varying methodological quality. The review did not assess methodological quality of the papers as the focus was understanding the literature. However, this is a shortcoming as was an inability to perform a more comprehensive meta-synthesis due to the heterogeneous study sample in the review.

A further shortcoming is the number of iterations of the review process that had to be undertaken with different reviewers at each stage. To provide consistency, each new set of reviewers were asked to look at a sub-section of the searches from the previous time-point and these were cross-referenced with those that had been accepted for inclusion to provide training for the reviewers. It is possible, however, that this led to errors in the process.

It is interesting to note that during the various iterations of the searches for this review, the authors identified an increasing number of relevant papers for inclusion. This suggests that the issue of better support within the community for individuals with ABI and their families is becoming a more popular focus for research. It is important now that the information from these papers is used to improve service provision and practice.

Recommendations for practice

This review has highlighted many recommendations for future practice:

1) It is important to increase the accessibility and quality of community-based services to ensure that they can meet the needs of individuals with ABI and their families. There needs to be improved access to services through an increase in funding for such services and better knowledge among service planners of this long-term need. This increased funding could be used to increase the number of services available for individuals following ABI and their families to address the need for more provision outlined in this review.

2) It is also important that individuals with ABI and their families receive clear and accessible information about their conditions at every stage of their patient journey to maximise their experience of care. As this is a heterogeneous group of individuals with a wide range of different cognitive, physical, emotional and behavioural difficulties, it is important that services offer tailored and individualised care approaches that include both the individual and family members in the decision-making process, where appropriate. These approaches would help to improve transitions in care and help to improve discharge into the community.

Individualised care is particularly important within this group because they are also widely heterogenous in terms of their wider characteristics, such as ethnicity, sex, gender, sexual orientation, and socioeconomic status. While there were limited papers that specifically focused on such characteristic (e.g., 83,88,89,94), these do suggest that those from diverse and marginalised groups may be less well-served and less likely to gain access to the limited services that do exist. It is important that clinicians and service providers are

mindful of protected characteristics and possible intersectionality of their service users when considering their needs and those of their families.

3) Extensive training for professionals working within specialised and generic services is needed so that they can better understand the impact of ABI long-term and know where to signpost individuals. There are many examples of such training tools and clinical guidance worldwide. Within the UK, organisations such as the Brain Injury Social Work Group (BISWG) have developed training materials for social care professionals [130] and the Brain Injury Rehabilitation Trust has developed a screening tool and a needs analysis to support healthcare professionals in their work with service users and their families [131]. In addition, there are clinical education and training resources have been developed outside of the UK involving thorough ongoing reviews of peer-reviewed published evidence: the Evidence-Based Review of moderate to severe Acquired Brain Injury (ERABI) [132-134] and the Ontario Neurotrauma Foundation supported brain injury clinical practice guidelines [135].

4) An integrated case management approach is required that provides not just short-term coordination of care, but a process that continues long-term to ensure ongoing signposting and linkages to community services, both in the context of rehabilitation, but also social integration.

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Declarations of interest statement

The authors report no conflict of interests.

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Appendix A: Search terms

Brain Injury search terms:

1. Acquired brain injury
2. Traumatic brain injury
3. Head injury
4. Brain injury
5. Brain tumour
6. Stroke
7. Brain haemorrhage
8. Aneurysm
9. Hydrocephalus
10. Encephalitis
11. Hypoxia
12. Anoxic brain injury
13. road traffic accidents

Service search terms:

14. Service needs
15. speech and language therapy
16. occupational therapy
17. physiotherapy
18. primary health care
19. emergency health care
20. acute medical admission
21. mental health
22. depression
23. anxiety
24. psychosis
25. recreational drug use
26. financial services
27. benefits
28. welfare
29. substance abuse
30. suicide
31. homelessness
32. complex needs
33. social services
34. adult social care
35. child social care
36. vulnerable adults
37. housing
38. decision-making
39. social work
40. advocacy
41. Probation
42. prison service

43. offending
44. offenders
45. arrests
46. legal representation
47. solicitors
48. lawyers
49. barristers
50. disability
51. disability services
52. learning support
53. home care
54. police
55. education
56. employment

Combing Search terms:

57. combined searches 1 to 13 using OR function
58. combined searches 14-56 using OR function
59. Combine searches 57 AND 58
60. Search 59 with age filter >18 years

Figure 1. Flowchart of the systematic review

Table 1. Major unmet needs identified in included studies

UNMET NEEDS		
Support unmet needs (by professionals/healthcare services)[*1]	Health unmet needs	Living & Leisure/work unmet needs
Need of information (16[*2]) Need of education about ABI (11) Need of involvement in care (11) (transition/discharge planning) Need of service provision (14) Need of support services (26) Need of person-centre care plans (13) Need of adequate rehab services (8) (community rehabilitation)	Fatigue management (7) Pain (3) Emotional/Mental health (27) (depression, anxiety, personality change, coping, grief) Behavioural management (3) Marriage guidance (2) Memory (3) Mobility (6) Acute ABI care/inpatient rehabilitation (3)	Independent living (8) Return to school (3) Return to work (10) OT (3) Returning to social/leisure activities (15) Welfare support (8) Housing/ home adaptations (5)

*[1]Some studies contained more than one unmet need.

*[2] Numbers represent the frequency of studies reporting each issue

Table 2. Types of access identified in included studies

TYPES OF ACCESS	
General types of services*3	Specific types of services
Trauma-specific acute care (3)*2 Access to ABI-specific inpatient rehabilitation (3) Access to community-based resources (10)	Mental health provision (7), Occupational therapy (8), Neuropsychology, physiotherapy, speech and language therapy (6), Educational support (5), Vocational rehabilitation (VR) (2)

*2 Numbers represent the frequency of studies reporting each issue

*3 Some studies, participants accessed more than one service

Table 3. Synthesis of the major barriers to access services identified in the review

BARRIERS TO SERVICES	
Brain injury service users & caregivers*4	Healthcare professionals/services
Transportation (8)*2 Finance (7) lack of insight (6) cognitive impairment and emotional difficulties (6) lack of awareness (6) poor referral/signposting (5)	**Lack of specialist knowledge (18);** health professionals (13), non-health professionals*5 (14) poor training (6) lack of awareness (8) poor communication (9) poor referral/signposting (9) poor organisational structures and processes (19) lack of services (18) lack of person-centred care (10)

***2 Numbers represent the frequency of studies reporting each issue**

***4 Studies often reported more than one barrier to services**

***5 non-medical professionals included police, care workers, educators and employers**

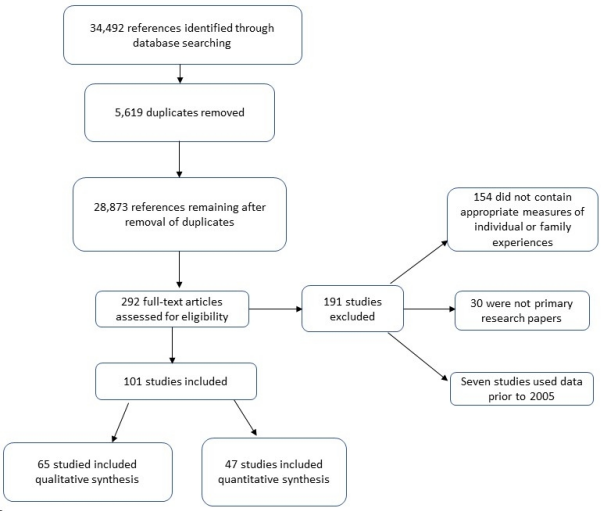

Figure 1. Flowchart of systematic review

Figure 1: Flowchart of review process

338x190mm (96 x 96 DPI)

Supplementary Material: Study characteristics of included papers

Author & Publication Details	Country	Participant information	Study Aims and focus	Key findings	Recommendations for practice
Aadal et al, 2018	Denmark & Norway	11 patients (6 Danish, 5 Norwegian), aged 25-65 years, and suffering from a confirmed diagnosis of stroke with moderate disability, were followed from the time of discharge from hospital until about 1 year after onset. Professionals included were members of the municipal health services who were involved in service provision to any of the included patients.	Explore and compare the content of rehabilitation practices in, respectively, a Danish and a Norwegian region, focusing on how the citizens' rehabilitation needs present at discharge after stroke, are met during rehabilitation in the municipalities.	The majority of participants from municipalities of both countries experienced a time gap between 1 and 4 weeks between discharge from hospital and initiation of municipal rehabilitation. Gaps were mainly due to long waiting lists, patient wanting a "vocation", communication gaps in visitation procedures, discontinuity in therapies. The professionals mentioned a lack of collaboration due to missing individual rehabilitation plans or personal coordinators. Patients' complexity needs taking into consideration, the lack of a rehabilitation plan and a coordinator is surprising, given that it is required by Norwegian law. National diversity was found in present health profiles, time resources and integration of rehabilitation services in the patients' everyday lives and home environment. In the Danish municipalities, the integration of rehabilitation provision in valued daily life activities was dominant, while work life movements, counting, and writing in authentic environments were more obvious in the Norwegian cases. A key emphasis on body function appears in the included cases in both settings. Large differences were found in complying the ICF (participations of patients in their own care pathway) recommendations, especially in relation to approaches to participation, including family roles, relationships, employment, and social life. In the Danish communities, the family members were routinely offered professional support and included in planning processes. The patient's interaction with peers was facilitated in group training	More consideration should be given to the aspects of activity and participation in community setting contexts. This will help determine how patients with stroke and those in their closest networks can be supported in becoming less dependent on public services and, as far as possible, be able to understand and manage their own everyday lives. This requires an accordance between the ideology of the ICF and clinical rehabilitation practice in the political and the managerial arenas of the health care system.

				sessions or sharing of experiences. In the Norwegian cases, the professionals assumed that there were unmet needs related to participation. They addressed loneliness and issues arising from changes to personality in their conversations, but found no specific interventions, for either the patients or their families.	
Ablewhite et al, 2019	United Kingdom	Twenty one occupational therapists working in stroke services, with a knowledge of community services were recruited to participate in telephone or face to face interviews.	The aim of the study was to explore the key issues relating to occupational therapists in undertaking cognitive assessments with patients following stroke in the community. The Authors wanted to understand (a) which cognitive screening measures were used and the reasons for their use; (b) issues relating to the interpretation of assessments; (c) perceived barriers and facilitators to undertaking cognitive screening with patients following stroke and (d) how cognitive assessments were used to inform clinical decision-making, particularly in community settings.	Seven main themes emerged from the analysis: post-stroke screening for cognitive problems; screening assessments used; reasons for using cognitive assessment measures; interpretation of cognitive assessments; impact on rehabilitation; barriers to cognitive screening and facilitators for cognitive screening assessments. Findings indicated a lack of consistency in routine cognitive screening for people with stroke in the community (There is no protocol or national guidelines on how to conduct cognitive screenings in the community). This variation seemed to depend on the occupational therapists' judgement of the patients' cognitive problems and of their circumstances. Also, tests chosen for the assessment were not always appropriate to detect post-stroke cognitive impairment and this raises the concern that some cognitive problems may be missed during evaluation. Therapist knowledge and experience determined test choice and interpretation.	In conclusion, findings highlighted the need for occupational therapists to receive greater training in conducting cognitive assessments and in their choice of measures.
Abrahamson and Wilson, 2018	United Kingdom	46 patients (30 with caregivers) and 28 professionals were interviewed between December 2015 and	Exploring the effectiveness and contribution of the 6-month review (6MR) to the overall recovery for	Patients and caregivers were unclear about the purpose of the 6MR. Only 2 patients found it a useful space to ask questions about their condition, prognosis, etc., and discuss concerns. Patients and carers reported mixed experiences, particularly of	Authors believed the 6MR should be embedded into the care pathway and strategies for secondary prevention reviewed and

		October 2016. Patients were between 28-91 years old and 18 (39%) were under 65 years old of whom 8 were working pre-stroke but only 4 resumed work during the study period. Professionals were interviewed within and across three sites located in South East England.	patients and carers. Particularly, the aim was to understand how is the 6MR conceptualized by patients (its purpose), to explore factors that shaped patient responses to it (mechanism), and describe the outcomes.	inpatient stroke care. Patients identified gaps where they felt unsupported which appeared related to systemic problems, particularly care co-ordination within and between services. These gaps occurred during transitions between units, discharge home, waiting for community rehabilitation to commence and when services withdrew. Data highlighted 3 different approaches in the way patients negotiated the care pathway and 6MR: (a) proactive and engaged: patients had an active orientation to recovery and were determined to improve their abilities. They trusted the staff and followed advice. They were focused on self-managing their condition and were well informed. They considered the 6MR a source of reassurance, information and advice); (b) proactive and self-managing on their own terms: a smaller group of patients were determined to continue their rehabilitation independently, albeit in a way that conflicted with their therapists'' approach. Lack of motivation, compliance and insight with therapists. (c) passive orientation: the smallest group of patients adopted a passive orientation to rehabilitation and did not appear interested in self-management or secondary prevention. They had mostly negative relationships with staff and ignored, forgot, or rejected advice. Patients felt that therapists did not understand, while therapists were frustrated by their passive approach. They considered 6MR irrelevant or unhelpful. There was little evidence that the 6MR played a key role in recovery.	consolidated at each stage. Moreover, patients should be allowed the freedom to individualise the process on a needs-led basis rather than adhering to a rigid framework. Findings suggest that 6MR should review therapy goals and facilitate patient-led goals to encourage participation in valued activities, including return to work.
Adams and Dahdah, 2016	United States	11 individuals W-TBI and 6 primary caregivers. TBI individuals were at least 18 years old, one year post injury, diagnosed with mild/moderate/severe TBI and able to participate in purposeful	To establish expressed needs of TBI survivors in the community and their primary caregivers, as well as to investigate methods of coping and adaptation by TBI survivors in response to those needs. Significant	The needs primarily identified by both populations were patience, understanding, and support. Understanding was the most reported need by survivors and caregivers. Participants specified the importance of family and community understanding personal, family, and social dynamics specific to brain injury. Self-reported deficits included short-term memory loss, fatigue, anger, and personality changes. Problem focused, emotion focused, and avoidant	Participants offered suggestions for mental health professionals addressing how to more effectively work with brain injury survivors and their primary caregivers. Further research addressing medical and mental health

		social interaction. Primary caregivers knew the TBI survivor before the injury and spent at least 40hrs/week with the survivor overseeing their daily living post TBI.	to this study was the development of coping and adaptive strategies by the participants after their discharge from inpatient and rehabilitation treatment.	coping were utilised in their adjustment to home life and activities of daily living.	education, linkage with community resources and increasing social support is necessary to increasing the functioning of TBI survivors and improve quality of life for all those affected by brain injury.
Adshead et al, 2019	United Kingdom	The study interviewed eight individuals self-identified as having an ABI who were homeless or had a recent history of homelessness an had current or historic substance misuse issues.	The study aimed to understand the relationship between homelessness, ABI and substance misuse	The study identified that a complex history of adverse childhood experiences and trauma led to high levels of vulnerability for experiencing ABI and developing substance misuse. Participants expressed a love of mental health issues and difficulties with cognition, particularly executive impairment, that led to adverse experiences and poor experiences with services and other significant others in their lives.	Healthcare professionals need to engage with children, their families, and adults, who have been exposed to ACEs and should employ routine screening tools for brain injury to ensure their presence is factored into developing appropriate models of intervention.
Alenljung et al, 2019	Sweden	Nine women were selected to participate in the study. Inclusion criteria were the following: mild or minor stroke during the last two years, with at least three months having passed since onset, be of female sex and a maximum of 65 years old, be experiencing cognitive problems/ impairment, and be able to communicate and understand the purpose of the interview.	The aim of the study was to explore how women of working age affected by cognitive impairment after mild stroke experience and manage their everyday lives.	Three main themes and seven sub-themes emerged from the analysis. The main themes included: (1) The everyday is affected by the symptoms, (2) Living strategies, (3) The social environment effects and changes. Participants described feelings of uncertainty and lack of control on their lives as well as fear of losing their job and to affect other people, due to the cognitive limitations. They also reported to be unable to cope with everyday life as effectively as before influencing their self-esteem. Fatigue was also reported as challenging to master and negatively impacting their everyday lives. Participants also said that planning, adjusting, prioritising and finding new solutions were key strategies to make various activities of daily life work. The participants described changes in the family especially with regards to their role as mothers. The reduced energy caused participants to feel that they could no longer have the role of taking responsibility for everything at home and that the distribution of tasks at home had changed.	Results highlighted the importance of professional support in getting to know participants limitations and supporting them to deal with these; the need for support before returning to work is especially evident. Rehabilitation professionals should be aware that the whole family of the patient are affected, that the distribution of tasks in the home can be changed, and that the demands on people with mild stroke must be managed. The future focus in research on people with milder symptoms and

				Finally, participants reported that lack of understanding from the environment of what the cognitive impairment meant really affected their daily lives. It was an important component in getting help and support with different activities at home, at work and in society. Participants described having disabilities that were not visible, and how this caused concern about how they would be treated. The feeling that others did not understand their situation created frustration.	decreasing age requires changed occupational therapy measures and interventions to give people living with stroke an opportunity to participate in work, family and social life. Furthermore, in the encounter with the client, there is a need for professionals to be aware of how their own values, thoughts and previous experiences can influence the outcomes with the clients if gendered perceptions are not identified, as has been shown in studies on occupational therapists as well as occupational therapy students. The constant impact of fatigue influencing cognitive tasks affects everyday life, especially working life, and needs to be addressed continuously by rehabilitation personnel over the long term. Further search could investigate whether men and women have different experiences of how they prioritise activities in everyday life after mild stroke. It is also important to investigate how men and women look at the distribution of home

					chores and changing roles and responsibilities both in general and after mild stroke.
Andrew et al, 2016	Switzerland	765 participants. Inclusion criteria: (1) be aged 18 years or over; (2) be living in the community; (3) have a clinical diagnosis of stroke; (4) have had their first stroke at least 1 year prior to survey completion; and (5) be able to complete a survey with or without assistance.	There is a lack of research on how quality of life in the early period following stroke relates to the development of unmet needs in the long term. This is needed to find solutions through understanding the personal, social, environmental, and organisational factors that may lead to needs not being met. It may also help identify those most at risk of developing unmet needs. The aim was to investigate attributes of health-related quality of life using the EQ-5D dimensions and visual analogue scale between 90 and 180 days after stroke, and the association with long term unmet needs (12+ months)	From 602 surveys, 173 were completed and returned. A strong association was found between health-related quality of life in the early period after a stroke and the number of long-term unmet needs reported at 2 years post stroke (on average). Evidence suggests those who have long-term unmet needs are more likely to have experienced reduced HRQoL in the early period following stroke.	Routinely collected HRQoL data can identify survivors at risk of experiencing long-term unmet needs. This information is important in helping predict long-term unmet needs in stroke survivors and identifying those who could benefit most from a tailored intervention early on after discharge from the hospital.
Anke et al, 2019	Norway	Family members of 110 patients with sTBI completed the questionnaire one year post-injury, and family members of 70 patients were followed up at two	The research study goals were to assess changes of family needs from one to two years after sTBI using the six subscales of the FNQ-Revised, and to identify	Mean ratings of met family needs changed with a small decline between one year and two years post-injury on the FNQ-R subscales of Health Information and of Community Support Network. Proportions of needs met at one and two years ranged between 28% and 55%. Needs rated most frequently as unmet belonged to the Emotional Support and Professional Support	Health professionals should be aware, from the early acute phase, that spouses of patients and the family members of older and more disabled patients more often experience their

		years after trauma. Family members were mostly female, the majority (85%) were married, and 63% were living together with the TBI survivor. Relatives were often working/studying at both the 1-year follow-up (75%) and at the 2-year follow-up (65%). The majority of patients were male (87%), with a mean GCS score at admittance of 5.4. The main differences between the groups of relatives were the following: 2-year participants lived with a patient who more often had a severe disability ; the patients had a higher mean age (43 vs. 34 years, $p < .05$); the family members were older (mean 53 years vs. 48 years, $p < .05$); they spent more time with the patient (24 h/day 34% vs. 18%, $p < .05$); and they were less often working outside the home.	family members at high risk of unmet needs in relation to the patient`s demographics, injury characteristics, and functioning at 1-year post-injury, and in relation to family member's gender, age, education, and relationship to the individual with TBI.	subscales at both time points after the injury. Caring for older patients, patients with more functional disabilities, female patients and being a spouse of a patient were associated with statistically significantly greater unmet family needs.	family needs not being met as time progresses. The proportions of unmet needs are high at both time points, and health care services need to address long-term service needs. The need for understanding and guidance prevails for families living in the community. In addition to reassessments and caregiver support group programs, a system with supervising outpatient teams might be valuable. The high and persistent unmet needs for emotional support might be solved by peer-support meetings, repeated professional guidance, and information for the social network. Not least, practical assistance and relief from care responsibilities for family members is important. To improve the situation for the whole family, perceived needs must be determined individually and should guide service provision.
Armstrong et al, 2019	Australia	n=5 male Aboriginal TBI survivors with identified	This study highlights issues faced by	Themes identified included: significant long-term life changes; short-term and long-term dislocation from	The authors identify the different context of

		acquired communication disorders took part in a case study approach, utilising qualitative interview and file review. Length of time post TBI between 2 and 20 years, age at time of injury between 19 and 48 years	Australian Aboriginal traumatic brain injury (TBI) survivors in terms of real-life consequences of the high incidence of TBI in this population, current treatment and long-term challenges. The authors note the overarching cultural context of the brain injury survivor, particularly that related to minority peoples with a history of colonisation and discrimination, has rarely been referred to in the research literature, despite profoundly influencing a person's recovery journey in significant ways, including access to services.	family and country as medical intervention and rehabilitation were undertaken away from the person's rural/remote home; family adjustments to the TBI including permanent re-location to a metropolitan area to be with their family member in residential care; challenges related to lack of formal rehabilitation services in rural areas; poor communication channels; poor cultural security of services; and lack of consistent follow-up.	Aboriginal people following TBI and the need to incorporate this understanding within rehabilitation planning. Particular attention is drawn to the issues affecting those with complex cognitive communication difficulties in a culture that is centred on oral communication.
Ballard and Dymond, 2016	United States	6 participants. 1 16-year-old high school pupil w/ acquired SD and CHCN, and 5 members of the student educational team.	Studied high schoolers access to inclusive education. Also experiences in English class after an acquired brain injury, including severe disabilities and complex health care needs.	Minimal access to inclusive education resulted in delayed re-entry into schooling, limited professional knowledge around dealing w/ TBUI at school. The students English class experiences showed a lack of proper communication, causing an over reliance on adult staff, minimal peer interaction, and unclear goals to achieve.	Additional research needed related to students w/ brain entry re-entering schools, and the support needs of the child, parents. Along w/ more professional training for schools.
Baptiste et al, 2015	Canada	2013 users of case management services, 273 non-users - 476/1960 questionnaires met the criteria. TBI individuals were 15+ years, CM	To determine factors associated w/ case management service use in people with TBI and to identify the differences between	Significant differences between users and non-users of CM were found. Users were far younger than non-users, had less education, severer activity limitations, and lower community integration. Non-users were also more likely to live alone.	Information from this study may help clinicians identify needs of patients W-TBI, and help better understand issues of service access.

		users had more severe injuries than the non-users	groups of individuals W-TBI who had and hadn't used case management services		
Beaulieu, 2019	United Kingdom	Sixteen (10 males - 6 females) brain injury survivors were recruited to participate in the study. The inclusion criteria were the following: being over the age of 18 and able to consent; having sufficient communication skills to participate in an interview, to have sustained either a traumatic or acquired brain injury of moderate to severe severity. Participants needed to have returned to full or part time paid work within England for a minimum of 6 months post injury. Participants' median age at the time of their injury was 37 years of age and their median age at interview was 47 years	The aim of the study was to identify the barriers and the success factors relating to return to paid work following brain injury.	Six key themes emerged from the analysis: Coping with ongoing difficulties, Expectation and timing of return to work; Workplace colleague reactions, Things that help, Change and return to work options, Feelings of success. The main obstacle to successful return to work was the lack of a clear path or route to return to paid work. The majority of participants had to find themselves jobs on the open market. Immediate return to work after the injury resulted in failure. The most prevalent ongoing difficulties experienced by the majority of the participants were fatigue and having a poor memory, and for half of the participants, transportation and welfare benefit difficulties.	There is the need to create a more consistent return to paid work approach to inform future occupational therapist and rehabilitation. Occupational therapists need to support and guide individuals better to return to paid work at the best time. Occupational therapists need to assess and help individuals to manage fatigue and memory difficulties from the earliest opportunity, and to continue supporting them to manage these during return to work. In addition, different forms of transportation need to be arranged that do not increase fatigue levels, and further assistance provided to access ongoing welfare benefit support. It is also important to help workplace colleagues increase their awareness of invisible problems, such as fatigue and memory difficulties, and to better understand them.
Braaf et al, 2019a	Australia	6 adults with severe TBI 48 month post-injury and	To explore the experiences of care	A lack of case managers were identified. Participant reported difficulties accessing services, poor timing of	There is a need for enhanced care

		family members of a further 12 individuals with severe TBI	coordination in the 4 years after severe TBI	support, inefficient and inappropriate service provisions with no long-term planning because of a lack of care coordination. Where effective coordination was present, service provision and quality was good.	coordination to ensure the individuals with TBI and their families receive appropriate access to support services.
Braaf, et al, 2019b	Australia	Fifty four people with severe brain injury were included in the study. Most participants were male, with a mean (SD) age of 43.2 (16.1) years, and transport-related crashes were the predominant cause of injury. Nearly 40% of the participants were compensable. Most lived in a major city (57%) and two thirds of participants had returned to work within 6-months of injury, 32 participants consented to an interview but were not working at 3-years post-injury.	To explore how people with serious injuries returned to paid employment in the first 3-years after injury.	Participants frequently reported supportive employers and co-workers as enablers for successful RTW. Social networks were also an important part of RTW. Family and friends were sources of support that facilitated RTW processes and enabled sustained work engagement. Responsive employers, insurers and health professionals strengthened employment opportunities. Health professionals such as general practitioners (GPs), rehabilitation specialists and OTs, enabled and supported RTW for workers with injuries by providing advice and advocacy, and by dealing directly with employers.	Findings indicated the need for a multidimensional approach to the occupational rehabilitation of people with serious injuries and development of personalised plans, as well as the need the need for interventions that preserve worker-manager relationships during recovery and time off work, or that connect workers with injuries to managers who are open to negotiating tailored working conditions. Employers, health professionals, and insurers that partnered with the injured person to collaboratively tailor and personalise RTW processes were part of a supportive system that facilitated work outcomes. Interventions that build and reinforce resilient thinking about, and plans for, work during injury recovery could therefore support sustained work in meaningful and appropriate employment.
Brunsden et al, 2017	United Kingdom	6 male participants aged 49-67 years, white	Exploring the male partner experiences of	Main themes – entering the unknown world of ABI, imprisoned by the ABI, compassion without self-	Male partners should be offered support services

		British. Relationship with partners ranged from 19 to 40 years (5 were married, one was cohabitating). Length of time since brain injury ranged from 2-15 years, 5 females sustained subarachnoid haemorrhage, one had sustained a head injury – all moderate to severe. Age range from 49-67	living with a female with ABI – impact of ABI on role change in and out of the home, on the relationship and male partners' hopes and expectations for the future.	compassion, holding onto hope. Male partners expressed feeling trapped and imprisoned by the ABI, unable to express their feelings to their partner and others around them. It felt as though their wife had been lost and they were left living a monotonous life with no joy. Men were able to overcome these feelings with hope, commitment and personal growth. The men gave accounts of coping and "just getting on with it". Their resilient and pragmatic personality traits kept them strong.	and information regarding their partners ABI. It should be recognised that the male partner is jointly limited so the couple should be encouraged to work together to cope with and accept their new future. Further research should be considered for the male partner role to be recognised and incorporated into the recovery process.
Bush et al, 2016	United States	12 people, from the Midwest US, constituting 3 participant groups, served as research participants: (a) 5 adults with severe TBI, (b) 6 family members of the participants W- TBI, and (c) 1 current job supervisor of one of the participants W-TBI.	Return to work experience with severe TBIs	4 of the 5 participants returned to their pre-injury jobs. 2 were subsequently fired and, at the time of research participation, unemployed. 1 participant never returned to paid employment; however, held 2 volunteer positions for several years post-injury. Interview transcripts allowed for the identification of five to eight themes pertinent to each case which were developed into 3 major conjectures. • Job satisfaction • Cognitively demanding careers • Modifications of job duties and strategies	Interpretation of themes led to three theories on return-to-work experiences following TBI: (a) job satisfaction may relate more to involvement in productive activities than monetary compensation; (b) adults with TBI can be successful in holding and maintaining positions w/ high cognitive demands; and (c) individualised job modifications and strategies are likely necessary for adults with TBI to succeed vocationally.
Carlozzi et al, 2018	United States	Participants were 45 caregivers of service members and veterans (SMV) who sustained a medically documented mild, moderate, severe, or penetrating TBI. Age	Barriers and support that caregivers, of individuals w/ military-related traumatic brain injury, encounter when navigating the military healthcare system.	Barriers identified and discussed: 1) obtaining services (most discussed 66%), 2) healthcare for SMV (50%), 3) healthcare for themselves (34%), 4) family care (5%) and 5) community organizations (5%). (1) Barriers to obtain services for SMV include the difficulty to access the services because depending upon injury documentation, diagnosis, and TBI	To best support caregivers and their SMV while pursuing military healthcare services, it is essential to increase accessibility and quality of services and

		mean 37.3 years (9.6 SD), Female 42 (93%), Relationship to service user: Spouse 33, Child – 7, Parent – 2, other 3, Time in role as caregiver = 4.4 years (2.5 SD)		disability severity rating; the inability to get a timely appointment, time commitment of the appointment due to the distance to care facilities; difficulty for caregivers who are not beneficiaries in getting onto a base to bring an SMV to an appointment; burden of paperwork. (2) Caregivers expressed a poor quality of treatments received. In particular, SMV's felt a lot of their medical issues were overlooked and were often told their problems were simply "in their head". Lack of communication among care providers and slow response times in scheduling appointments and fixing malfunctioning at home medical equipment, also concerned. Financial barriers were also discussed. (3) Caregivers expressed concern with access for services for themselves. Infrequently, (4) they discussed barriers to family care of children of SMV's including unmet healthcare needs, and child care coverage enabling SMV and caregivers to attend medical appointment. (5) barriers to community organizations. Support to obtain services comprised 34% of the caregivers'' discussion. Regarding SMV support, caregivers discussed financial support, support scheduling appointments, proximity to services, and easy access to services such as therapy, lawyers, and treatments. About their own healthcare (24%), they referenced caregiver stipends, care coordination, support groups, healthcare insurance, and access to counseling. Community organisations were a helpful resource in obtaining services (25%) and for last support for family care (5%)	reduce the financial burden.
Cogne et al, 2017	France	57 participants w/ brain injury. 42% were male, 65% were single and the average age was 34.7 years, ranging from 20 to 54. They were recruited from those who completed the 2008	Focusing on the social and vocational integration of an individual w/ serve brain injury. To evaluate the 5-year outcome of individuals w/ severe brain injury, including	Approximately half were satisfied w/ their quality of life. At the 5-year follow up, 23% lived w/ a partner, 21% lived in their own home, and 47% were working (only 11% were working upon entering the programme). Associations between: -Life satisfaction and high educational level, being in a relationship, having a health condition, having a good spirit and having a job. -Having a job in 2013 and high educational level,	The UEROS programme was effective in helping individuals w/ returning to work and improvement in general autonomy - this was regardless of length of time from brain injury. Therefore, this programme

		UEROS programme, (typically a person 6 years post injury participated). 5 years later an interview study was conducted assessing: family and vocational status, autonomy and life satisfaction. This was then compared to results from the 1997-1999 programme. The study initially began in 2008.	changes in working life, living situation, psychosocial and community integration and general life satisfaction.	cognitive difficulties upon admission, having a job upon admission, having a health condition in 2013 and life satisfaction in 2013.	could be more widely used in order to aid recovery. It also demonstrates the usefulness of a retraining programme long after the outcome of the brain injury.
Colantonio et al, 2016	Canada	Participants were all between 18-65 years old, all fluent in English, and had sustained a work-related mild-to-moderate TBI. They all provided informed consent, and valid self-report and performance testing. Out of 116 available participants, only 50 participated in the study.	To compare demographic, clinical and occupation-related factors following mild-to-moderate TBI between those who returned to work and those that didn't, and identify factors that help and hinder returning to work	Age and education were significantly different between those that returned to work and those that didn't – higher education and lower age were both associated with higher likelihood to return to work. Most common factors seen to help return to work were support from family, friends and treatments providers and employers who provide accommodations. Hindering RTW (returning to work) was difficulty thinking and concentrating and fatigue	Educating employers and injured workers may help facilitate the development of work modification programmes for workers to rebuild confidence and competence to successfully return to work. Future research could focus on the relationship between self-confidence/motivation and RTW after TBI.
Connolly and Mahoney, 2018	United States	31 ischaemic stroke survivors (21 years + mean age 56 years/ 14 (45%) female) discharged directly from the hospital to home. 22 were prescribed either outpatient therapy or in-home therapy (occupational therapy, speech therapy, etc.) The majority lived with	Challenges (life experiences) that patients who suffer an ischaemic stroke must face in the first 4 weeks of discharge home - transition from discharge to home.	5 main themes emerged: The shock caused by the stroke interrupting a normal day Transition to an unfamiliar home: being directly discharge home from the hospital was a relief for the majority of the participants. However, within the first few days they perceived that home was not the same place as it was before the stroke. ISSs discussed home positively and the hospital negatively. Uncertainty: mainly related to the interpretations of stroke symptoms and its implication and consequences to the everyday life, which were difficult to recognize for many ISSs. The understanding of fatigue: in particular seemed to be crucial. Difficulty to differentiate strokes' symptoms	Healthcare professionals must focus on the transition from hospital to home creating a patient-centred plan of care beyond physical or psychological testing to assess the ISS's needs and concerns and be designed to address the identified concerns specifically. Crucially, giving detailed information about the many aspects of

		someone (family or friends) after discharge.		from other symptoms. Emotional reactions. Understanding a new sense of self: Receiving information and having questions answered by health care providers, perceiving a helpful support system through family, friend, and healthcare providers gave participants the confidence that they could cope with their new life situation. Adjusting a new sense of self: complex and individual process, that involved coping with uncertainty, balancing facilitators and barriers, and in the context of a new sense of self.	symptoms to relieve anxiety and uncertainty. Healthcare professionals, nurses in particular, can mitigate sources uncertainty by working w/ patients to determine personal goals, listening to ISS's questions/concerns and jointly creating solutions, as suggested by the Naylor's Transitional Care Model (TMC). It encourages nurses to interact frequently with patients by either telephone or face to face and work w/ all areas of the healthcare discipline as ISSs transition from hospital to home. Focusing on patient's individual needs and concerns = creating a tailored plan of care
Crowe et al, 2016	Ireland	10 participants, 18 years or older and living at home, recruited through a stroke service of an adult hospital. Participants were in the clinical range for psychological distress, according to the Hospital Anxiety and Depression Scale, (they all had to score above 11 on the scale). They were used to explore their experiences of	At the time of the study there is very little qualitative data on the emotional impact of having a stroke on the individual and their life. This and further understanding could act as forming future guides and interventions for stroke survivors, along w/ tailoring rehabilitation. The study aims to explore, by means of qualitative	3 superordinate themes emerged from the interview data, reflecting on the subjective nature of the participant's stroke experiences, w/ a focus on their psychological distress. Results suggested that lack of acceptance and self-compassion underlined these themes. The three themes were: The fear of stroke: the suddenness of having a stroke and having to live w/ the sudden awareness of one's own morality afterwards. The word "frightening" was used by participants. The loss of self: mourning one's previous self and a rejection of one's new post-stroke self. Participants often struggled with psychological effects such as depression and had difficulty dealing w/ and accepting physical impairments. Sense of alones and isolation: the external alones associated w/ a	Provides insight into the association between psychological distress and having a stroke. The themes that emerged may indicate the direction in which future psychological distress interventions should follow. Along w/ helping to target the isolation and alones stroke patients might feel whilst still in initial recovery and after discharge. Psychological distress

		psychological distress, post-stroke.	analysis, the lived experience of stroke survivors w/ clinically recognised psychological distress and look at the processes underling the experience, to try to inform future theoretical approaches and clinical interventions.	withdrawal from other people and previously enjoyed activities. And internal alones associated w/ psychological isolation. Internal isolation was found to be a huge issue in participants.	experienced by stroke victims is complex and multifaceted. The distress is associated w/ an understandable fear of a recurring stroke but also a sense of internal and external isolation following the event combined w/ a loss of self and lack of self-compassion. All these elements may be susceptible to therapeutic intervention to reduce the distress suffered by stroke survivors.
Curran et al, 2014	Australia	Adults aged over 18 years, family members, such as parents, and close friends (identified by th family or individual) were used for the study. 111 participants were used, 47 with AB, 32 staff, and 32 significant others. Both genders were studied.	Focused on how community-based rehabilitation can help to maximise rehabilitation and recovery post injury. Due to limited research into community based treatment, and unmet needs this study focuses on providing more information.	Patients reported improved physical and psychological functioning immediately after completing community rehabilitation. Immediate care was found to improve long term functioning and be more beneficial in recovery then later introduced care.	More in-depth research in needed due to the lack of current research. Active accounts from patients is crucial. Findings are promising and could lead to better and improved care of stroke patients and future rehabilitation.
Danzl et al, 2015	United States	13 stroke survivors (9 female, 3.6 mean years post-stroke, 63.4 mean age) 12 caregivers (7 female, 55.9 mean age)	To examine rural Appalachian Kentucky stroke survivors and caregivers' experiences of receiving education from health care providers to optimise educational interactions and interventions. To identify barriers, support needs to improve	Patient and caregiver education is recognised as important in facilitating optimal outcomes of post stroke. There is a low level of satisfaction with education and perception of inadequate communication from providers.	A need for improved access to educational sources in the community based chronic phase of stroke, proactive identification of informational needs by providers, greater inclusion of caregivers in education, enhanced communication when providing information

			service provision, facilitate community reintegration, and maximise quality of life.		and a multi-model approach involving multiple sources, delivery methods and time points.
Davis et al, 2016	United States	45 patients with complicated mild to severe TBI aged seeking return to work (RTW), who were aged between 18-64 years old, and recruited from acute trauma care (Level I Trauma Centre). Average of 62.43 days post-TBI (15-180 days range)	Identifying difficulties in accessing state vocational rehabilitation (VR) services (e.g., difficulties in locating local VR offices, submitting an application for services completely and correctly, getting assigned to a VR counsellor, understanding the need to comply with various requirements of the VR programme in order to receive needed services, etc.), and highlight the role of the Resource Facilitation (RF) in overcoming these difficulties.	RF fills a gap in the continuum of care for people with TBI seeking RTW. It provides systematic assessment and referral for a variety of services and can help facilitate the access to available state VR services. However, many participants were unaware of the availability of the VR services. Even though, CCs played an important role in increasing awareness of the availability of these services, the awareness alone was not enough to ensure utilisation. Many people with TBI and their caregivers experienced difficulties completing the multi-step process to receive the services, such as contacting the specific local state VR office serving the participant's area, obtaining information about the application requirements, completing the application for services, and following of the status of the submitted application. Sometimes, participants called the agency without finishing the application. Once accepted, further issues were facilitating the communication between clients and VR counsellors, ensuring their needs were met and that they followed up with the recommendations made by counsellors. Further barriers to successful utilisation of state VR included cognitive and emotional difficulties of those with TBI resulting in difficulty communicating, lack of understanding of services procedures and requirements, frustration with budgetary and staff restrictions at the agency, financial limitations, transportation difficulties, and lack of family support. Some participants would not have received VR services without the assistance provided by CCs using an RF model.	Recommendation for the establishment of statewide networks of CCs, who automatically contact all hospitalized people with TBI on the basis of hospital discharge records as a standard and pervasive feature of state-sponsored programmes throughout the US.
DeGeneffe & Bursnall, 2015	United States	267 participants between the ages of 18 and 72 years (M= 37.9 years). 65.5 percent of the	Quality and availability of professional supports provided to individuals with traumatic brain	Siblings' comments suggested that the system-level response to TBI serving injured people and their families was inadequate, that many professionals lacked the skills and understanding to provide	Social workers need to prioritise advocating enhanced long-term community-based

		participants were female. Most participants were white (97.8 percent), married (62.5 percent), employed full time (66.3 percent), and had an undergraduate (36.3 percent) or graduate or professional (21.7 percent) degree. Average participant income was $51,613. Participants lived in 23 states and 1 resided outside the United States.	injury (TBI) and their families.	effective services, and that professionals did not provide sufficient information. However, most siblings endorsed a positive view of at least one of the professional services provided.	professional supports following inpatient and acute-care rehabilitation.
DeGeneffe et al, 2016	United States	21 primary care givers for individuals with acquired brain injury (ABI), who have recently been discharged from an ABI acute-care facility. The average participant age was 48.6 years. 78% were female. 71% were spouses/partners. 57% white. 62% were Catholic or protestant. The mean participant income was $79,916. (Four participants did not provide income information). 43% worked full-time. 24% worked part-time. 48% held undergraduate or graduate degrees. The average time since ABI was 10.1 months, with the time ranging from 7 to 20	Raising awareness of the barriers and issues associated with the access and use of post-acute care services for those with ABI. To use the results gained to improve the delivery of support for ABI suffers and their families, and to help navigate the different services available to them and find which ones will best meet their individual needs.	The average number of used post-acute care services used was 4.9, with a range of 0 to 11 services. Three families did not receive post-care services from the ABI facility. The most used services (66.7%) were, in-person consultations with psychologists/physicians and social workers, Occupational therapy, and physical therapy. The least used were ABI facility group recreational programmes and home health care (4.8%). In five service areas patients were not aware of the availability of that service.	Raises importance of face-to-face visits with care professionals. It also highlights the importance of acute rehabilitation units with assisting families and patients in finding support facilities after acute-unit discharge. Professionals involved with ABI rehabilitation units should be aware of the range of available possible support services, and educate those injured, with family members, on what they can access post-discharge. Whether the service is provided through the ABI facility or by an outsider source.

		months. The average time since discharge from acute care was 8.1 months, and the average time spent in acute care was 1.4 months.			
DeGeneffe, 2015	United States	60 participants in total, 30 parent and adult sibling dyads. 66.7% of parents were female. Age range of 38-83 years old. 53.3% of siblings were female. Age range of 18-70 years old. 70% of injured family members of participants were male. Age range of 17- 61 years old. Average time since brain injury was 120.5 months.	How parents and siblings prepare for the future care and support of family members with acquired brain injury.	Disconnection between what parents and siblings wanted to do verses what they think they should do in regard to future care planning. Despite reluctance for siblings to assume future caregiving, 50% of parents agreed that siblings should assume the caregiver role after they were unable to. 56.7% of siblings also agreed that they should take over care when their parents are unable. Large amounts of families ignore future planning due to uncertainty of how to proceed.	Professional need to focus more attention on the needs of families to engage in future care planning and start preparing siblings to assume a greater caregiving role, if that is the agreed upon plan. More support and guidance in sorting out future care, such as information of facilities, support groups, and living with someone with ABI.
Denham et al, 2019	Australia	n=24 interviews with carers of stroke survivors, 79.2% female, 83.3% spouses, length of post stroke between 3 weeks and 17 years, average 5.7 years, 54.2% of stroke survivors were male	The study aimed to qualitatively explore the unmet needs of carers of stroke survivors, and their preferences for interventions and support services.	Key unmet needs identified by carers of stroke survivors in this study centred on four main themes: (1) social relationships and support; (2) adequacy of information; (3) taking care of oneself; and (4) accessing appropriate services.	Carers in this study desired the development of services which provide connectivity to information, training, education and community support; and inclusion in a community with social relationships and other carers of stroke survivors. Ongoing unmet needs often result in adverse health and quality of life outcomes for carers of stroke survivors. Co-designed programs and resources for carers, particularly relating to unmet needs in social, information, self-care and

					service access domains are needed.
Douglas, 2020	Australia	n=23 adults with a severe TBI, 86.9% male, ranging in age between 19 and 55 years, with between 2 and 20 years post TBI experience	The aim of this study was to understand the post-injury experience of friendship from the perspective of adults with severe TBI.	Exploratory correlations between number of friends and quality of life, depression and strong-tie support revealed significant associations of moderate to large effects. The post-injury experience of friendship was broadly conceptualized as “going downhill” with four overlapping phases: losing contact, being misunderstood, wanting to share and hanging on.	The authors identify the importance of supporting friendships and how rehabilitation can focus on friendship by supporting established relationships and facilitating access to activities that afford interpersonal encounters and opportunities to share experiences.
Driscoll et al, 2019; Brickell et al, 2018	United States	n=264 caregivers of US military veterans with TBI. 95.8% female, 85.2% spouse were recruited to a prospective observational study which utilised 3 outcome measures (Caregiver Appraisal Scale, SF-36v2 TM Health Survey, and Caregiver Questionnaire.)	The objective was to examine the prevalence of unmet caregiver health care and social service needs, and determine the impact of unmet needs on health outcomes in a sample of caregivers providing help to service members or veterans (SMV) following traumatic brain injury (TBI).	The majority of caregivers reported the need for help on six of eight health care and social service needs (42.4%-70.1%). For each service need, 29.5%-52.7% reported that their needs were unmet. There was a significant linear relation between the number of needs and worse physical and mental health outcomes on all measures (i.e., 4-8 Needs>1-3 Needs >0 Needs; all p’s<.05). The cumulative number of unmet needs was significantly related to worse outcomes in most areas, while most individual needs were not significantly related to outcomes; with the exception of the caregiver’s unmet need for medical health, which was significantly related to increase bodily pain.	A large proportion of caregivers reported unmet health care and social service needs. The number of unmet needs was associated with worse health outcomes. Expansion in the breadth and scope of health care and social services offered to caregivers is required to overcome the barriers preventing them from meeting their health care and social service needs.
Dulhanty et al, 2019	United Kingdom	A survey of 400 individuals with subarachnoid haemorrhage discharged from a neurosurgical unit between 1-5 years post haemorrhage	The study aimed to report the met and unmet needs of individuals with subarachnoid haemorrhage	Of 203 participants, 86% reported one or more need and 78% reported at least one unmet need. The most commonly reported need related to fatigue	There is a need for post-discharge services to address long-term needs of those with brain injury.

Dwyer et al, 2019	Ireland	Six young adults with brain injuries residing in care home settings	To explore the experiences of young adults living in care home settings	Participant identified feeling that they were living in an environment tailored to 'terminal' care that was confining to their freedom and disempowering with a distinct lack of rehabilitation provision	There is a need for more appropriate residential placements for individuals with brain injuries who are younger and the need for more long-term rehabilitation services for those individuals
Ernst et al, 2016	United States	Educational professionals, 21 years and older working in public schools w/ at least one year of professional experience in their current positions. 94 participants, 38 had training in TBI, 56 reported teaching/knowing someone W-TBI	Determine knowledge of TBI amongst educators - important for TBI children returning to school to have appropriate support for short and long term. The Common Misconceptions of TBI (CM-TBI) was assessed for internal reliability. Factors relating to experience and exposure were analysed to determine predictors of total TBI knowledge	There was a relatively low rate of misconceptions (only 4 items w/ a misconception rate of 20/.+) Only 'training in TBI' was a significant predictor of CM-TBI total score. Educators demonstrated accurate knowledge in aspects relating to identifying TBI individuals and understanding of common socio-emotional effects of TBI as well as recovery of TBI. There was uncertainty in areas relevant to school settings. The CM-TBI questionnaire had a good internal consistency suggesting it is a useful in measuring knowledge of TBI in educators.	Education for TBI should be incorporated into training programs for educators. Accurate knowledge will assist educators w/ accurately identifying students W-TBI and in developing appropriate interventions and educations programming.
Fitts et al, 2019	Australia	n=11 Aboriginal and Torres Strait Islander individuals who had experienced TBI were interviewed, 18.18% female, ranging in age from 24 to 54, mean age 40	The study aimed to understand the lived experiences of Indigenous Australians during the 6 months post-discharge, identify the help and supports accessed during transition and understand the gaps in service provision or difficulties experienced.	Some transition experiences for indigenous Australians are similar to those of other populations but a lack of meaningful interaction with treating clinicians in hospital, challenges managing direct contact with multiple service providers and the injury-related psychological impacts are some of the factors that could prevent Indigenous Australians from receiving the supports they require to achieve their best possible health outcomes in the long term. Five major themes were identified within the data. These were labelled ‘hospital experiences’, ‘engaging with medical and community-based supports’, ‘health and wellbeing impacts from the injury’, ‘everyday living’ and ‘family adjustments post-injury’.	A holistic approach to care, with an individualised, coordinated transition support, may reduce the risks for re-admission with further head injuries.

Glang at al, 2014	United States	Schools were recruited through Oregon school activities association. Criteria: 1; registered athletic trainer on state or contracted by school for services, 2; school access to internet, 3; agreement to expose students participating to training. 25 schools (13 intervention, 12 control). 4804 fall student athletes (2264 intervention, 2180 control). 1004 of their parents (445 intervention, 559 control)	Many sports concussions happen during school-sponsored sports events - most state concussion laws hold schools accountable for coach training and effective concussion management practices. Brain 101: the concussion playbook - training for school communities, guidelines on creating concussion management team, strategies for supporting students in classrooms	Brain 101 schools implemented best practice guidelines at school level than control schools. 77% of Brain 101 schools created CMT that met regularly - 54% had assigned coordinator. 20% of control schools established CMT and 0 had assigned coordinator	Develop evidence based cost effective approaches for concussion management. Demonstrated that when school implemented w/ Brain 101 intervention rates of knowledge and behavioural intention to implement effective concussion management practice among parents and students increased - concussion management practices improved
Glang et al, 2015	United States	46 State Directors of Special Education, 43 of which responded to the survey. 49 states participated overall. A follow-up interview was conducted with each respondent as well as with 45 representatives of state brain injury consumer organizations (BICOs), who provided advocates' perspectives of how children with TBI fare in the educational system.	To find significant changes in patterns of identification of TBI in children and service delivery for their needs had occurred since 1999, when a survey was sent to state directors of special education asking about emerging initiatives for children with TBI and their capacity to serve this population.	Some improvement was seen in the delivery of services for students with TBI since the original 1999 survey. However, only half the states reported having personnel dedicated to BI in their State Education Agencies (SEA). Most state education administrators provided validation that the gap between incidence of childhood TBI and identification of students with TBI receiving special education services remains. Factors that contributed to this gap were identified as lack of knowledge, training and awareness about TBI and its implications for educating children.	Since the original survey, improvements have been seen in TBI service delivery, but gaps remain – SEA directors reported that students W-TBI are not appropriately identified for special education and there were fewer TBI specialists within the SEA than in 1999. Recommendations were made to identify policies and practices that improve outcomes for students W-TBI, improve pre-service TBI training of school personnel, develop assessment procedures to help school personnel identify cog. Deficits related to TBI, expand in-service

					TBI training of school personnel and expand parent information centres to give parents and caregivers access to info and support on being advocates for their children.
Greenwood et al, 2015	United Kingdom	41 carers were recruited from voluntary organisations focusing on carers, BME (black and minority ethnic) groups or stroke survivors. Participants had to be currently or have recently been caring for stroke survivors and be 45 years or older. Ethnic groups included Black African, Black Caribbean, Asian Indian, Asian Pakistani or White British.	Carers from all ethnic groups, particularly from BME groups, fail to access support services. Experiences of carers of stroke survivors aged 45+ from 5 ethnic groups were explored, focusing on accessing and receiving social care services after hospital discharge. BME carers are less likely to use formal services	1) Gap between discharge and home carers struggled to adjust and felt abandoned and unprepared. 2) Carers as persistent advocates knowing the system and fighting for support. They felt ignored and had to make a scene to gain support. 3) Balancing the effort in accessing services w/ their needs and unsuitable services - difficulties in getting adequate support was exacerbated by unresponsive services and led to carer frustration. 4) carers as best person to care due to poor services carers saw themselves providing the best and most genuine care as they had a history and relationship w/ the patient. 5) Cultured aspects of caring ethnicity, culture, religion and language - carers faced difficulties communicating in a second language and discussing personal topics. When care workers shared a culture with the carers, support was better and more genuine as well as better respecting of religious needs.	Carers want to be seen and treated as individuals. The process of accessing services needs improvements and extra challenges for BME carers needs recognition. Services need to work alongside carers and families in a better and more supportive manner.
Grigorovich et al, 2017	Canada	A mixed methods case study of one community-based agency who provides specialised services to people with brain injuries. Relationships (PWBIs), between demographic, service-related variable and employment outcomes (2009-2014) were analysed. (Therefore no specific participants as it was a	Understand how employment services are provided to individuals with brain injuries, and the impact service delivery has on competitive-employment outcomes (Ontario, Canada). To explore relationships between demographic, injury-related variables and competitive-employment outcomes,	Individuals with brain injuries accessed services, on average, of 16 years post injury. 64% secured at least one competitive-employment job, (which was how employment success was defined in this study). Average job tenure was 368 days, and average job intensity was 3.8 hours/day. Employment success was significantly associated ($p < 0.05$) with use of job development, job coaching, case management and job retention services. Interviews revealed that those with brain injuries were provided five services: job goal(s) identification, assessment of work-related abilities/skills, job development, on the job support and job retention	PWBIs employment outcomes and success may be supported by using employment services to assist with the development of realistic goals, and job finding skills. These can all aid rehabilitation and lessen social isolation post-injury, which is commonly seen in those with injures. Furthermore, this could ease the psychological impact that isolation would

		review of the agency rather than clients).	examine the impact ES delivery may have on competitive-employment outcomes and to describe how ES are implemented within a Canadian context (e.g. process and types of services provided).	assistance. Challenges to employment service delivery included lack of suitable jobs and hiring incentives, and difficulties in establishing natural supports at the workplace.	have on rehabilitation and recovery. It is also suggested that time should be dedicated to assisting the PWBI with developing clear and realistic goals based on achieving an understanding of their current work abilities and the requirements of the jobs they are interested in. They further recommend that long and short-term support, be provided on the job, due to the challenges that cognitive strategies may present for those with more severe BI. Although use of these services was found to be associated with employment success, findings revealed several challenges to delivery of services and to long-term job retention.
Guldager et al, 2018	Denmark	11 relatives of 9 patients with severe TBI with impaired consciousness at admission to subacute rehabilitation in the states of unresponsive wakefulness syndrome (UWS), minimally conscious state (MSC) or post-traumatic confused state. Relatives of low, medium, and high	Investigating the experiences of relatives of patients with TBI in the rehabilitation process, focusing on relatives' strategies and practices. The research question was: "What kind of strategies do relatives of patients with a TBI apply and use in	3 main strategies emerged: (a) The warrior: fully proactive and engaged in the decisions about care and directing the process to maximize benefits for their relatives. The relationship with the providers is based on dialogue and receiving information. They care more about the cognitive and mental aspects of the illness rather than physical disabilities and participate actively in training. (b) The observant: collaborative with, and helpful to providers in which they trust. Their relationship is based on loyalty and solidarity. The observant are concerned with whatever providers direct as being in the best interest of their relative.	Healthcare professionals need awareness of the 3 different relative positions in the rehabilitation process and should meet and support relatives differently to meet their (and patients') diverse needs. Particularly, they need to differentiate relatives' requirements of information, support, and involvement.

		working class were included. Participants (relatives) had varying age and relationship with the patients (>18). Patient data: 8 males 1 female, 1 sibling, 4 partners, 4 child, 1 parent age range 18-72 of patients	the rehabilitation process?"	Therefore, they are less engaged in the process of care than the warriors are: "I observe a lot but I know he is in good hands". They highlight the mental and cognitive capacities and have a little concern about the physical disability. The participation in the training is not an active option. (c) The hesitant: uncertain about their role in the rehabilitation process and relates and respond passively to the health professionals. They are much concerned about the physical disability rather than the mental and cognitive one. They don't, or rarely participate in training sessions. The strategies are not fixed positions but relatives fluctuate between them depending on both patients' conditions ad progression. They are also influenced by the interactions with the healthcare professionals, and cultural and socioeconomic variables.	
Hahn et al, 2020	United States	131 caregivers of service members/veterans with TBI who were over the age of 18. service members/veterans has mild, moderate or severe TBIs	To examine the health literacy of caregivers of service members or veterans	21% of caregivers demonstrated low health literacy. Individuals who were male, from ethnic minorities and had lower levels of education were more likely to have low health literacy.	There is a need to understand the link between low health-related quality of life and health literacy to better support the needs of caregivers to improve quality of life outcomes
Harrison et al, 2017	United States	Participants, 21 years and over, living in Kentucky, sustained a traumatic brain injury at least 6 months prior and/or their caregiver W-TBI. Participants were required to participate in a 60-90-minute interview.13 individuals and 6 caregivers participated.	Increase the understanding of the lived experience of people W-TBI and caregivers in rural regions of Kentucky across the continuum of their case and to provide their perspectives on barriers and facilitators of optimal function and well-being.	4 main themes were found. TBI onset and emergency care: 11 participants' TBI was caused by a motor vehicle accident, one by a self-inflicted gunshot wound, and one due to complications of surgical removal of a brain tumour. Most felt the duration emergency services took to arrive at the scene was positive. Barriers w/ emergency care were, lack of neurologists, inadequate knowledge base among practitioners, and participants' distrust in local healthcare systems. Participants felt inconsistency and confusion on if the TBI patient would survive the trip from the local hospital emergency department (ED) to the next care stage. Acute care: Participants in local rural hospitals or EDs were transferred to large hospitals, with reported mixed interactions w/ health	Case managers who understand the needs of individuals W-TBI and their caregivers could provide service coordination early and across the continuum. Furthermore, trained community health workers living within the local community could extend the case management support when the individuals W-TBI return home. This could create trusted relationships

				care providers. Some felt they received adequate information and understood what the doctors communicated to them. Family members did not have accommodation during the acute care phase due to hospital distance from their rural homes. Inpatient rehabilitation: Most patients transferred to an inpatient rehabilitation facility during the sub-acute phase. 3 patients transitioned from acute care to a skilled nursing facility or long-term acute care hospital. Many felt facilities had expert support, resulting in positive change. Most began regaining their memory and realised the seriousness of their limitations. Most returned home and independently achieved their basic needs, impressed and moved by the support and passion of the rehabilitation team. Transitioning home and reintegration into the rural community: All patients but one returned to their rural community. 3 participants took part in career rehabilitation support. A barrier to community integration was the lack of knowledge about TBI in local communities. Most thought the services their rural communities were inadequate, so travelled far to receive outpatient rehabilitation services in urban areas. Many participants reported a lack of knowledge and support to help address financial burdens due to the TBI. Some believed living in an urban environment would aid the process of returning home. Most felt community support.	throughout the continuum of care and improve linkages to services that facilitate continued development of functional competence upon returning home.
Hewitt et al, 2014	United Kingdom	50 patients and 33 carers in acute inpatient rehabilitation and community phases of care.	Patient and carer perception of good and poor teamwork and its impact on experiences of care were explored.	Participants struggled to identify incidents of teamwork and their descriptions rarely included any perceived impact on their experiences suggesting teamwork was not seen as important.	Patients and carers were unaware of, or interested, in how inter-professional stroke teams operate. Therefore, if healthcare professionals want them to engage in team-working more than the benefits should be made more visible. However, including patients and carers in inter-

					professional teams is challenging.
Hobbie et al, 2016	United States	41 adolescent and young adult survivors of childhood brain tumours successfully completed interviews. 186 caregivers and 135 survivors took part in a telephone interview. Survivors were between 14 and 40 years, 5 years from the last evidence of disease and off treatment for 2 years.	Adolescents and young adult survivors of TBI describe their quality of life (physical, emotional and social functioning)	Differences in neurocognitive functioning influenced functioning and were embedded into survivor's accounts of their daily life. Emotional health issue involved survivors recognising the need to rely on others for day-to-day functioning. Loneliness was a prevailing theme for all and they acknowledged that their family members were their best friends	New systems to accommodate the changes following an individual's treatment and to provide a better foundation for growth and development with the challenges they face. Programs are needed to help survivors develop and refine social skills and combat their sense of loneliness
Hodson et al, 2019	Australia	a male participant (64) with a mild stroke and his wife (62)	To explore the transition from hospital to home following mild stroke and the impact on the spousal dyad.	The study found that the couple experienced confusion at first and then went through a period of adjustment and adaption to their 'new normal'. The transition back to their old life was difficult and changes remained at 9-months post-discharge	The findings indicate a need for information for those with mild strokes post-discharge.
Holloway & Tasker, 2019	United Kingdom	n=110 relatives of individuals with an ABI completed an inline survey, 85% female, age range 18 to 75, 74.5% parents of person with an ABI	Survey sought the views of family members of people with ABI to ascertain their experience of the condition and their views and experience of related health and social care services. Respondents ranked the difficulties met by their relative living with an ABI and rated the services they had encountered. A series of open questions enabled respondents to provide greater detail regarding	Relationships between the injured and non-injured parties change, alterations to roles and responsibilities are difficult and mediated via unending and complex grief. Relatives reported poor levels of involvement in decisions regarding the provision of social and health care services, a failure to be given good, accurate information in a timely fashion and the need to 'fight' for virtually any service provided. Service provision was very regularly criticized for being either entirely absent, unaware of the impact of brain injury, failing to take account of actual functioning and/or structured in ways that are not concomitant with the needs of the injured person or the relative. Lack of knowledge of the impact of ABI by non-specialist staff and services is particularly highlighted as a barrier to progress and an added burden for relatives to contend with. Social work in particular was commented upon most negatively, most often for a failure to understand the condition and needs. Valued services and	Commissioners and providers of social and health care services need to work more closely with family members of people living with ABI. Services and individual practitioners need to be more knowledgeable about the likely functional outcomes of ABI, in particular the impact of invisible impairments to cognition and executive functioning. Relatives identify the benefit of good quality, accurate information and of a knowledgeable single point of contact across time

			their experience and knowledge.	professionals are noted to be humane, knowledgeable about ABI, aware of the impact ABI has on the non-injured relative and able to act as a single 'one-stop' focal point for service provision.	and setting. Knowledge of ABI, of neurorehabilitation and of the impact of ABI upon family members by social workers is noted to be poor and attention to this may help with people's rehabilitation and to prevent unnecessary additional carer burden.
Holloway et al, 2019	United Kingdom	n=16 relatives of people with severe ABI interviewed, 93.75% female, years since injury 2-28	Study explores how families are affected and integrates their views on the formal/informal support received as a consequence of ABI	Family members' experiences are complex, enduring and are affected by the context in which the ABI occurs as well as by formal/informal support. The grief experienced by family members is ambiguous, develops over time and they perceive little option but to remain involved. Experience of formal and informal support is noted to vary significantly in availability and quality, poor support exacerbates difficulties and isolates family members.	Services require a greater understanding of the lived experience of family members of people affected by ABI to support more effective responses to both them and the individual with ABI, integrating services and families to improve quality-of-life.
Irgens et al, 2019	Norway	19 physiotherapists working with 10 individuals with ABI	To investigate the experiences of physiotherapists of the communicating of patient information across a range of health care levels through ABI rehabilitation	The participants identified shortcomings in discharge information in terms of written information for patients. There was also a need for improved verbal communication with patients and between professionals in different clinical settings	there is a need to improve routine information communication across health care settings and services
Jourdan et al, 2019	Finland and France	10 Medical practitioners specialising in neuro-care	The study aimed to compare the TBI care pathways in Finland and France	Differences were identified in the structure of care (availability of services from a cute to re-entry support). Financial issues were identified as a cause for preventing patients accessing services and coordination between acute and post-acute services was an obstacle to care. Poor follow-up of mTBI was identified in both areas and for those with more severe injuries, rehabilitation did not start early enough.	Key categories of determinants of care pathways included; the need for less delays in starting rehabilitation. Improvements to outpatients services were also needed to improve long-term rehabilitation outcomes.

Kable et al, 2018	Australia	25 health professionals involved in discharge planning and transition, from acute and rehabilitation hospitals to primary and community health-care services. Participants included 8 nurses and allied health staff from an acute care stroke unit, two junior medical officers from acute stroke unit, seven rehabilitation health professionals (nurses, physicians, and allied health) from a rehabilitation hospital, four health professionals (GPs and practice nurses) from general practice settings and four participants (nurses and allied health) from the community stroke team (CST group).	The aim of this study was to understand health professionals' perspectives on the discharge process and continuity of care, and to identify factors that contribute to the discontinuity of care during the transition between hospital and home for stroke survivors.	According to participants perspectives, for achieving an ideal discharge process and continuity of care, it is fundamental that at the time of discharge the patient receives clear information from the multidisciplinary team and a tailored post-discharge management plan, which provide the survivor and carer with a copy of a completed discharge summary and information about planned services, appointments, and medication changes; provide the survivor and carer with a week's supply of medications and a pharmacist's medication plan, and educated about them; they would be advised to see their GP within 1 week; to assess carer' needs and provide information about long-term follow up and health professional contacts in the community. At the time of discharge, provide the GP with the completed discharge summary and information about planned services, appointments, medication changes, and requested to arrange for medication reconciliation in the home. Barriers to a successful discharge and continuity of care process identified in the study were the following: Pressure to discharge patients quickly and at short notice, Discharge medications and associated risks, Inadequate or late provision of discharge summaries, Challenges involving carers, Availability of post-discharge services and eligibility restrictions for services, Number of services arranged at the time of discharge, GP follow up after discharge, Delays and waiting lists, Carer problems, Long-term follow up.	Findings highlighted the barriers that leads to discontinuity of care following discharge. It is important to address the deficits in this process so that stroke survivors and their carers can make the transition to home with minimal risk and adequate support. It would be helpful reduce the pressure of discharge too quickly as allow the team more time to complete the discharge process more comprehensively. They could provide patients and carers with education about the patient's diagnosis, medications, and associated risks, and routinely provide a list of medications and appointments and planned follow-up services to patients and GPs. It would be also helpful to increase education prior to discharge and having discharge summaries completed and sent the day of discharge. A better involvement of the carer would also help reduce the burden of care and cope better with injury related difficulties. Increasing referrals to the long-term

					stroke program would be beneficial for patients by reducing social isolation and depression and improving support. Future studies should develop and implement targeted interventions to improve processes during and after discharge to ensure patient safety and continuity of care during transition to the community. These interventions should target organizational barriers and support staff to address communication via discharge summaries, medication safety and reconciliation, and carer stress.
Kamalakannan et al, 2016	India	Adults diagnosed with a minor or moderate stroke within the previous 6 weeks that had been discharged from hospital and were residing at home with a primary caregiver. 50 stroke survivors and their 50 caregivers did quantitative surveys. 12 stroke survivors and their 10 primary caregivers and 8 healthcare professionals did qualitative in-depth interviews	Rehabilitation needs after hospital discharge for stroke survivors in Chennai, India.	Quantitative results showed that 1. The most important need for stroke survivors and caregivers was information about "stroke and stroke rehabilitation service" 2. The second most important need was financial needs and support. From the qualitative interviews, the following was found: 1. big gap between demand and supply of stroke rehabilitation services. 2. Acute insufficient of rehabilitation services for disabilities in general. 3. Participants found a hospital to receive treatment and rehabilitation after a minimum of 2 days. 4. Reported quality of the available rehabilitation services was not adequate. 5. Reported they were dissatisfied with services from the hospital where they were being treated. 6. One government managed general rehabilitation centre for patients with disabilities in Chennai for the whole state - this centre is free, but patients paid to travel long distances to access the free services. 7. Many access nearby	Research demonstrates the unmet need for post-stroke rehabilitation services in Chennai, India. The lack of stroke awareness and ways to manage stroke-related disabilities was the main reason for this. Providing therapeutic care and support for stroke survivors is a financial implication that becomes another burden to stoke survivors and their families. With the lack of resources for rehabilitation in India, developing an innovative,

				physiotherapy clinic but many cannot afford this. 8. Participants were not prepared for the stroke, and most were unable to organise resources for managing the problems of individuals affected by stroke within their family. 9. Availability and affordability of stroke rehabilitation services were the main service level barriers. 10. Lack of information and knowledge about stroke and stroke rehabilitation services was the major barrier to accessibility. 11. Lack of awareness about stroke, stroke-related disability and rehabilitation hide the demand for rehabilitation services. 12. None of the participants could identify the warning signs of stroke and seek immediate treatment. 13. a main concern for caregivers and stroke survivors were the support needs of caregivers	multidisciplinary, patient-centred, culturally sensitive rehabilitation intervention is of high public health importance and could bridge the gap in accessibility and meet the rehabilitation needs of stroke survivors in India. These findings contributed towards the development of a smartphone-enabled caregiver-supported educational intervention for management of disabilities after a stroke in India.
Kingery et al, 2017	United States	58 children W-TBI (16 severe, 14 moderate, 28 complicated mild) 72 children w/ orthopaedic injury (OI) recruited as a comparison group to control for child and family characteristics predisposing children to traumatic injuries All completed the long-term follow-up 6.8 years after injury. Injury occurred in early childhood (3-7 years of age). Additional inclusion criteria included overnight hospitalisation, accidental cause of injury, no history of preinjury neurological issues or developmental	Understand the possible need, within the school setting, and identify predictors for receiving academic services to elucidate possible avenues for decreasing long-term unmet academic needs after early TBI. Objective: Examine the prevalence of academic need, academic service utilisation, and unmet need, as well as factors associated with academic service utilisation 6.8 years after TBI in early childhood.	At the long-term follow-up, children w/ moderate to severe TBI continued having higher rates of academic need compared to the orthopaedic injury group. There were no major differences in academic need between the TBI groups. The severe TBI group had higher rates of need than the OI group in all domains of need. Compared to the OI group, both moderate and severe TBI groups had higher rates of parent and teacher reported need and the severe TBI group also had higher rates of IQ/achievement need than the complicated mild TBI and OI groups. While the complicated mild TBI group had a greater rate of parent reported need than the OI group, they had a lower rate of teacher reported need than the moderate TBI group. 46-63% of children w/ TBI experienced an unmet academic need	The need for academic services among patients who sustained a TBI during early childhood remains high 6.8 years post injury. Findings show the importance of continued monitoring of behaviours and academic performance in students w/ a history of early childhood TBI. This may be especially true among children with less severe injuries who are at risk of being underserved

		delays and English as the primary spoken language.			
Kitter and Sharman, 2015	Australia	20 caregivers, mean age-54.9 years, 16 female, 4 male	The challenges, support needs, and coping strategies, of caregivers and people w/ an ABI are explored	Caregivers attributed their stress partly to the uncertainty and lack of direction of their loved ones present and future circumstances. Additionally, behavioural circumstances accompanying ABI had a tremendous effort on their day to day lives and placed psychological stress on them. Caregivers complained about the financial issues they face being unable to commit to a 9-5 job and thus relying on funding. Furthermore, they were unhappy with the lack of services across Queensland.	Short and long term changes should be implemented to increase carer quality of life, which will affect the rehabilitation outcomes of persons with ABI.
Krishnan et al 2017	United States	24 stroke survivors and 15 informal caregivers were included in the study. The average age for the stroke survivors was 68 years, w/ most being male (67%). The average age of caregivers was 58 years; the majority were female (80%) and mostly spouses (73%) of stroke survivors. Many patient participants received inpatient rehabilitation or cared for a survivor receiving inpatient rehabilitation. 2 of them had aphasia. The stroke survivors were roughly between 1 and 30 years post their stroke event.	Explore the mobility-related post-stroke consequences, rehabilitation activities, and outcome preferences of stroke survivors who receives post-acute rehabilitation in inpatient rehabilitation or skilled nursing facilities, and their informal caregivers.	3 themes emerged: 1) post-stroke consequences, (2) rehabilitation activities and gains, 3) outcome preferences advice to other stroke survivors. (1) The inability to walk was the most common limitation mentioned by both stroke survivor (58%) and caregiver (33%), followed by an increased incidence of falls. To maximise survivor independence and decrease the burden on caregiving, 63% of survivors and 73% of the caregivers reported survivor utilisation of some form of assistive device like wheelchair, walker, cane, and orthoses. 33% of caregivers accommodated their home with modifications including tilt bed, shower bench, toilet seat. Other included inability to drive, transfer, or balance, and increasing financial burden. (2) The most mentioned rehabilitation activities included walking, standing and mobility, strength and balance, and stair climbing. Participants who went through inpatient rehabilitation mentioned training for transfers and getting up after a fall. 18 participants (10 stroke survivors and 8 caregivers) said the survivor was able to re-gain the mobility related outcomes following rehabilitation (walking, was the most common, then ability to drive, transfer, stand and climb stairs). 3 stoke survivors were frustrated and disappointed by the rehabilitation process, as they were unable to walk or accomplish	Stroke survivors and their caregivers tend to differ in outcome preferences. It is important to understand the person-centred needs of stroke survivors and caregivers to when prescribing interventions. The most preferred outcome preferences for the participants were to walk, move, balance, and acquire specific assistive devices to move independently. It is also important to note that outcome preferences of stroke survivors and their families may change as their clinical and financial situation change. Health professionals should involve themselves in all stages of care and provide patient-centred measures post-stroke. There is

				their mobility-related outcomes. Furthermore, their rehabilitation process was not patient-centred. (3) The main outcomes mentioned by stroke survivors were the ability to walk independently, ability to move, drive, balance, and stand. Many expressed a need to acquire assistive device to move independently to transport in the community. This shows how stroke survivors have difficulty in using public transportation, increasing their dependency. Caregivers mentioned the need for the survivors to drive, concerns about the survivors' safety and the need to prevent falls, have appropriate home accommodations, and aid survivors transfer independently. Stroke survivor and caregiver expressed need to be actively involved in the rehabilitation process, gaining realistic information on post-stroke mobility outcomes and importance of rehabilitation in improving outcomes.	importance to educate stroke survivors to continue the rehabilitation interventions at home during the temporary cut in therapy. Increasing community based rehabilitation services, for example, can help manage long-term stroke patients. Caregivers should be trained and educated during the rehabilitation, so they can provide therapy once the patient is discharge from rehabilitation. Use of technology including tele rehabilitation, brain gaming, activity monitors may serve as a solutions to improve recovery among individuals.
Langbecker et al, 2017	Australia	27 did the qualitative interview but data was taken from 19 patients, of whom, 8 were diagnosed with a malignant brain tumour, 9 a benign brain tumour, and 2 reported being unaware of the malignancy of their brain tumour.	The reasons why some adults w/ primary brain tumours do not use support services.	Participants reported many and mostly complex supportive care needs. From the discussion of the needs, 3 themes were identified; support services were not needed, a desire to not use support services to address needs, and difficulties in accessing support services to meet the needs experienced. Frequently occurring reasons for not needing support services were they were doing well compared to other brain tumour survivors, their needs were already met by their healthcare team and they had not been aware of their needs. The theme of desire not to used support services had a few participants stating they did not want to use a support service, despite the possible benefits. Participants reported they did not see the value of using support services. Some participants stated they wanted to self-manage the issues. Other	Research extends current knowledge on patients reasoning about support services. The authors state the recommendation to assess patients, physical and psychosocial needs and refer to appropriate support services represents a modifiable pathway to improve patient well-being. A practise implication of this research is the recommendation for health professionals to assess patient's needs for

				participants reported they had prioritised other issues over their unmet support care needs. For the theme of being unable to get help, participants reported the barriers to access were cost, geographical isolation from support services, and the administrative processes required to access a support service. Other barriers were a lack of information from health services, their tumour or treatment-related incapacities/limitations, participants' personal knowledge and beliefs, and identifying a service that could help with the problems participants were experiencing.	help and their desire for assistance. Another implication is the promotion of support services and their impact to help reduce the low levels of service utilisations and consequently reduce patients' unmet needs.
Langbecker, & Yates, 2016	Australia	40 adults diagnosed with primary brain tumours. Representing 18.9% of the eligible population of 203 patients. Took place approximately 3 months after diagnosis.	Assess patients supportive care needs early on after diagnosis, and quantify service awareness, referral and utilization.	Findings suggest that early onset needs that are unmet have a correlation with later decline of physical and psychological needs. This is consistent with the findings of previous cancer patient studies. However participants did report awareness of and referral to, and use of 32 informational, support and health services.	Limiting referrals to support programs may limit patient's recovery and their individual use of available support after brain tumour/cancer diagnosis. Early intervention and referral is important to prevent support needs going up met, which will therefore show a decline in later development of negative psychological and physical changes when that are resulted from early unmet needs of support, information and assistance.
Libeson et al, 2020	Australia	15 people (8 males - 7 females) with brain injury (mean age = 47.33 years) approximately 4.5 years post-injury, of whom 14 had moderate to severe TBI. Twelve individuals had successfully returned to work.	The aim of the study was to understand the RTW experience of individuals with TBI, who had received comprehensive VR, and to identify facilitating and limiting factors in the RTW process.	Client, work and rehabilitation related factors impacted the RTW process. Client factors that facilitated RTW included family and social support, personal motivation and readiness to return to work. The client factors that hindered RTW included motivation to RTW quickly and resume preinjury role (returned too soon, poor performance, unable to cope), lack of family and social support, injury related cognitive and mood difficulties. With regards to work related factors, results indicated that support of the	Persistent cognitive deficits and fatigue were frequently reported to have impacted working ability over the long term, and that motivation to RTW too early was reported to be associated with unfavourable outcomes. This study also highlighted the significance

				employer support (flexibility, willingness to make modifications), work modifications (reduced hours and responsibilities enabled initial RTW), Financial incentives (TAC-funded work trials) facilitate RTW. Whereas the lack of support from the employer, the nature of the job (complexity), termination of financial incentives and work modifications still in place after years (limiting to resume the previous job role) represented barriers to RTW. Finally, rehabilitation related factors that assist with RTW process were RTW programme (imperative to RTW), the role of the OT (vital in implementing the RTW programme, interaction and advice to employer most helpful), work preparation (support with getting ready for work, public transport and technology), client involvement (associated with feeling supported). RTW was limited by longer RTW programmes, lack of knowledge of the OT, lack of cognitive preparation, client involved too much, client increasing hours and conforming to unrealistic employer demands and expectations, taking on work beyond capabilities).	of many non-injury related factors in facilitating RTW, such as family and employer support, potential for work modifications and the importance of support received from the RTW rehabilitation programme. Findings provided important insights into the development of more effective RTW programmes and into the complexities of RTW from the perspective of the brain injury survivors. In order to avoid the negative consequences of returning to work too soon after injury, VR professionals should try to ensure clients with high levels of motivation to RTW quickly, have as much opportunity as possible to develop some awareness of their difficulties before returning to the workplace. Secondly, significant focus should be given to cognitive support and preparation prior to returning to work. Future studies should further examine the RTW experience of individuals with TBI, with a lower level of education than the current sample and include more perspectives from

					those who have been unsuccessful in returning to work. It may also be valuable to investigate the views of employers, clinicians and close others of those with TBI, to increase the triangulation of RTW findings.
Long et al, 2011	United States	Participants included 10 surrogates, half of whom chose to withdraw life support and half chose to continue life-sustaining treatment following the patient's severe TBI. All surrogates were patients' parents, children, or spouses (7 females - 3 males). In 2 cases, there were co-surrogates for a patient. Surrogates average age was 44,4 years old and they had known the patient for a broad range of years (M 15,3).	The purpose of this study was to describe how surrogates made the decision to withdraw or continue life support and whether they believed that the health care team could have been of greater assistance during the decision-making process.	Three themes emerged from the interviews with regard to surrogate decision making, including surrogates' (1) reliance on internal and external resources to inform decision making, (2) frustration with physicians' limited availability and communication skills, and role of an alternate health care professional, and (3) appreciation for intensive care unit (ICU) nurses' help in understanding the nature of patient care. The surrogates who chose to withdraw support did so on the basis of prior conversations with the patients regarding their preferences, the patients' prognosis, intuition, faith, their perceptions of the patients' likely quality of life, and the burden of recovery from severe TBI on patient and family. Surrogates were frequently frustrated with physicians for not discussing patients' prognoses. Surrogates expressed gratitude and praise for ICU nurses' skill at answering questions, providing explanations of interventions, and helping translate what the physician told the surrogate and family.	Findings demonstrated the need for a trauma or critical care advanced nurse with the technical knowledge to answer questions and help the surrogates understand the patient's condition and the time to spend with them while they were in the process of making decisions. Another resource would be the early involvement of a palliative care team, where the team's interdisciplinary members could provide technical information, offer psychosocial and spiritual support, and enable greater communication between the surrogate and the medical team. These resources would offer surrogates a stable presence, support, and information about the patient's potential outcomes, which can help make their decision making less challenging.

Lou et al, 2017	Denmark	Inclusion criteria: mild stroke patients discharged from the specialised stroke unit to their home and early supported discharge services. Patients living in their own home with a partner willing to be interviewed. Patients with sufficient cognitive abilities to complete a qualitative interview of approx 30 mins. Patient and partner would be available for an interview 3-6 weeks after stroke onset. 22 patients and their partners participated.	How mild stroke patients and their partners experience and manage everyday life in a context of early support discharge.	Home as a healing place: Timely discharge - Independent of whether participants had a positive or negative hospital experience, all reported the timing of discharge was appropriate. Participants and their partners felt secure about leaving the hospital and recognised it was right to do. For most participants, the recognition was related to the confidence in hospital staff's evaluation of their stroke. None of the participants felt the discharge was rushed or too early. Home as my space - Patients described returning home as 'nice' and a 'relief'. Compared to the hospital, participants described home as calm, well known and personal, and a place where time and space was structured by the couples' needs and preferences. Participants saw home as a suitable arena for continued recovery in accordance with the couples' routines and preferences. Not alone - Participants' acceptance of and sense of security about early discharge and home rehabilitation were closely linked to sharing their home with a partner. Discharge and transition to home were eased by the awareness that the early discharge team would contact the patient within a few days. The flow of everyday life: Physical and cognitive impairment - participants suffered mild stroke, and the severity of their impairments varied from no difference to considerable change compared with life before stroke. Adjusting through collaboration - Most participants did not experience major changes in their everyday lives but it had to be slowed down and adjusted to fit new conditions. Participants tested and challenged their abilities at home within their everyday routines. Couples adjusted their routines accordingly. Future scenarios - participants were focused on the future and hoped full recovery would be achieved. Professional safety net: Home as arena for rehabilitation - participants valued visits from the ESD team. Quality of service - most participants reported satisfaction with the ESD team	ESD is a viable and acceptable solution for mild stroke patients living in their own home with a partner. Hope and optimism may wane in cases with continued residual impairments, ESD teams should consider the possibility of later contact with patients when necessary.

Lu et al, 2019	China	n=26 family care givers of individuals post stroke, semi structured interviews, 76.9% female, 80.7% spousal carers, length of caring role ranging from 2 months to 35 years	The aim of this study was to explore the experience of family caregivers taking care of stroke survivors in China.	Family caregivers' experience was described as living on the edge, which pulled their lives in multiple directions, created an unstable situation, and reduced their well-being and health. The participants believed they had total responsibility and felt that this was expected from both themselves and society. Little external understanding and insufficient support was emphasised, resulting in the caregivers feeling all alone, drained by caring, and like prisoners in their own lives. The family caregivers had to face all of the family events and make all of the decisions by themselves. They expressed love for their family members with stroke, but this was often overshadowed by feelings of sadness, depression, sensitivity, and anger. This resulted in an inability to see how things could improve and in the family caregivers being uncertain about the future.	Healthcare authorities and professionals need to recognise and understand the lives and situations of family caregivers of individuals post-stroke to further identify their difficulties and needs. Appropriate and effective support, both from government and society, should be planned and implemented for family caregivers to relieve them from caring for their relatives with stroke and maintaining the quality of their own lives.
Mansfield et al, 2015	Canada	12 workers diagnosed w/ a work-related mild TBI reported on their return-to-work experiences. Their TBI had occurred 3–5 years prior to the time of the interview.	To explore how individuals w/ work-related mild traumatic brain injury experience return-to-work processes when returning to the workplace where the injury occurred. Analysis is guided by the question 'How do individuals with persistent work-related mild TBI impairments experience returning to work?".	Participants faced difficulties related to workplace and insurer dynamic following workers' compensation insurance claims, coping w/ the stigma of having a brain injury and reconstructing work roles. A frequently reported obstacle was adverse relationships w/ workers' compensation representatives who had little understanding of mild TBI. Employers had inadequate knowledge of mild TBI, 4 participants reported their employers considered their brain injury as a non-serious incident. 4 participants reported no changes in the workplace following the event of injury.	Workers typically returned to the pre-injury workplace following a work-related mild TBI. Injured workers sometimes return to workplaces where unsafe hazards and practices have not been addressed. The injury is often a public event and eliminates the individual's choice whether to disclose a brain injury, stigmatising their condition that can have negative effects on their career. It is critical that employers, co-workers and workers' compensation representatives are aware of the impairments resulting from mild TBI so injured

					workers can receive support and stigmatisation can be mitigated. Attention to the structural and social elements of workplace and compensation environments could inform strategies to break down barriers to successful return-to-work following a work-related mild TBI.
Martinsen et al, 2015	Norway	16 stroke survivors were included between the ages of 18 and 67, had lived with stroke from 2-10 years after the stroke. 11 men, 5 women	Young and mid-life stroke survivor's experiences w/ the health services was explored and their long-term follow-up needs were identified	Stroke survivors struggled to understand their life and situation. Difficulties accessing health services and lack of tailored follow-up services increased stroke survivor's difficulties by limiting the opportunities to address questions about their life after the stroke, and discuss individual needs and discuss health concerns	Follow up programs must fit with long-term needs of the stroke survivors, consider their particular challenges as stroke survivors and be planned in collaboration with the stroke survivor. Healers must consider stroke survivors experiences and perspectives and support their motivations to continue w/ life through individual and knowledge-based support and encouragement
Matérne et al, 2017	Sweden	10 patients, 18-65 year old, were recruited from a county in Sweden, from an outpatient unit for mild and moderate brain injury. Participants returned to their pre-injury work or to a new job, working at least 20 hours per week, for 1 year, after ABI. Participants also had the	To increase ABI patients' knowledge of opportunities and barriers for a successful return to work (RTW).	Opportunities and barriers for successful RTW, three themes were identified, individually adapted rehabilitation, motivation for RTW, and cognitive and social abilities. Individually adapted rehabilitation. Participants reported a successful vocational rehabilitation process with a lot of transparency and communication between the authorities, colleagues and themselves. They reported various situations and reactions from employers and colleagues. One participant felt her boss eased the transition between job training and being integrated at work.	An individually adapted vocational rehabilitation process is important for a successful RTW, according to these findings, meaning patients with brain injuries must be involved in their own vocational rehabilitation. The authors note importance of support from society, employers, colleagues, and relatives. A

		ability to communicate in spoken Swedish and were able to work full-time prior to ABI. 7 participants had a mild brain injury and 3 had a moderate brain injury.		One participant received wage subsidies, consequently he did not feel pressured to perform at his new job. One participant reported support and empathy from a work colleague. 9 participants reported that informing their workplace about their disability increased the likelihood of a positive attitude from management and colleagues, and of changes of tasks in line with their ability. Motivations for RTW. All participants thought of returning to work as a meaningful goal in life. 5 participants reported setbacks during their RTW. At least 8 of the participants thought creating goals in the vocational rehabilitation process was important. One participant liked the challenges she was given at work, and another wanted to continue her professional development but felt unable to. All participants felt understood and accepted by their employer. Participants found their values changed from pre-injury to ABI. Cognitive and social abilities. Participants reported how their cognitive impairments affected their communication and RTW. They also reported they found strategies for their job despite cognitive fatigue-related problems and lower self-esteem post-ABI.	balance in motivation for RTW to make sure it is not a hindrance. Goal setting can increase motivation. Awareness of cognitive and social abilities is essential for finding strategies to handle different situations that occur in vocational rehabilitation. RTW support may be organised as a long-term contribution.
McIntyre et al, 2017	Australia	Age: 18-65 years Had high care needs (e.g. severe/profound core activity limitations). Had an acquired disability due to injury or illness. Were residents of South East Queensland (Australia). Were able to give informed consent. Possessed adequate communication skills to participate.	Often adults under 65 years of age, with high care needs, are unable to easily access age-appropriate housing and support, therefore, rely on residential care or family members who may be unable to support their care needs. This qualitative study was designed to focus on the individual experiences of high	5 main themes were found to categorise the experiences: 1. Travelling in different directions: this highlighted the diverse needs of adults with high care needs and the challenges often encountered when trying to negotiate and access responsive housing and support. Most participants felt that they or their family member had different needs, expectations, and preferences, or were ‘‘traveling in a different direction’’ to other disabled individuals. 2. The “fight, the battle and the war”: experienced by family members and showing their determinations to obtain appropriate housing and support. 3. Willing but wanting: family members expressed a desire to be actively involved in providing care. They	Current disability policies in place are not satisfying the needs of adults with high needs or their families. Results show a need for urgent change within the system to better satisfy the requirements. Along with offering a wider variety of services to better target needs alongside information.

			care needs adults and the struggles they face in care and recovery. By doing so, future rehabilitation and professional services may be tailored and shaped in more productive and interactive ways to aid high care needs adults in more beneficial way.	wanted acknowledgement of their role in filling the gaps; some wanted acknowledgement through payment, while some wanted acknowledgement of their capacity to provide quality care. However, it was evident that family members saw their care as ''work'' which was undervalued in the system. 4. Uncertainty and vulnerability: often characterised the experiences of the individuals and families in this study, regardless of health condition, or housing setting. For some families this was related to their concern about the environment in which their family member was to reside. However, most participant's uncertainty and vulnerability related to the longevity or reliability of funding for housing and support in the future. 5. Redefining social roles and relationships: related to the need to redefine social roles and relationships throughout the participants' pathways. For some individuals, this meant discovering a new social group or social opportunities, but others reported experiences such as marriage breakdown or changes in relationships with parents as they took on new carer roles.	
Mealings et al, 2020	Australia	n=12 students with an ABI severe enough to require inpatient rehabilitation were recruited to the study, 75% male, age range 17 to 37 years	The study sought to identify themes related to adjustment and identity that emerged from students' reflections about their study journey. The data for the project are drawn from a longitudinal, predominantly qualitative investigation. Twelve students completed up to three in-depth interviews over a period of 4–15	The theme of "Is it Me or is it the Injury?" emerged from the context of students' descriptions of self, "Me" and thoughts about their injury, "The Injury." This emergent theme was indicative of the complex processes involved in adjusting and reshaping identity that arose from students' participation in education.	Clinicians and educators must adopt a comprehensive, holistic and flexible approach to supporting students that can be adapted to reflect the individual and dynamic processes involved.

			months. Data were analysed using grounded theory methods.		
Moore et al, 2016	United States	82 children w/ moderate to severe TBI and rehabilitation providers in Washington state	The associations between English proficiency, insurance status, outpatient rehabilitation service availability and travel time for children w/ TBI was explored	Less than 20% of providers accepted children with medi-card and provided language interpretation. Only 46% of providers reported accepting children with medi-card. Children with medi-card had less access to rehabilitation services	Barriers, in inequalities, availability, and proximity of rehab services, were highest for poor children with medi-card. There are barriers to outpatient rehabilitation services including providers refusing to provide care for children with medi-card insurance or language services
Moore et al, 2019	United Kingdom	A survey of 93 Brain Injury Case Managers with a follow-up interview of 12 case managers in the UK	This research aimed to explore issues of safeguarding clients with brain injuries and hoe mental capacity is assessed and shared decision-making achieved.	The study revealed a series of themes identifying the difficulties associated with the hidden nature of brain injury when addressing and assessing potential issues with mental capacity. Case managers highlight conflicts with The data revealed four main themes: disagreements with other professionals, particularly within statutory services, a lack of understanding of the vulnerability of clients with brain injuries and difficulties with implementing the mental capacity act and assessments.	The findings highlight the need for changes to the way mental capacity assessments are conducted and the need for training for professionals in the hidden effects of ABI so that they can better understand the long-term needs of individuals and their families.
Morrow et al, 2020	United States	A survey of 1800 speech and language therapists about their knowledge of TBI	To understand the knowledge base among speech and language therapists about the communication and cognitive deficits experiences by those with TBI	While some participants demonstrated a high level of training in TBI and the speech and language needs of patients short and long-term, others showed little to no specialist knowledge.	The findings highlight the need for more consistent training, specifically around cognitive-communication difficulties to better meet the long-term needs of patients
Nemeth et al, 2016	United States	8 focus groups with 39 community members and 13 healthcare providers. In 2 of these groups, participants were patients	The barriers and facilitators of early stroke care were investigated as well as	4 identified barriers: lack of trust with the healthcare system and providers, weak relationships fuelled by poor communication, low health literacy, and financial limitations related to health care. 2 community potentials were found, community-based	Building a trusting relationship is important to understand the community to effectively intervene. Convening groups to

		who had strokes within the past 3-5 years. 2 focus groups had participants who were family members of stroke patients. 1 focus group had participants that were community leaders. 1 focus group had emergency department professionals. 1 had emergency medical service (EMS) providers. 1 focus group had local primary care and community health care providers.	implications for improvement.	education and faith as a message of hope. Fewer community potentials than barriers were found. A hierarchy of needs related to improving early stroke treatment, was created and showed that health care needs be affordable, patient centred and prioritised. Family and patients need to improve their understanding of the nature of the symptoms, treatment and recommendations for self-management. Places where people work, play and congregate were put forward as somewhere to reach citizens to overcome their fear and mistrust of the medical and healthcare systems. The strength of the church and faith can bring hope and awareness to the community toward improved healthcare behaviours. The hospital and primary care environments need to reduce wait times, financial barriers and make prevention as a priority to facilitate good relationships between patients, the community, and the healthcare system. The EMS system can be used to ensure protocols and resources are implemented in a learning and quality improvement paradigm.	prepare and disseminate appropriately tailored health education in line with the local context is critical. Considering the needs and preferences of communities into care delivery builds trust. Findings have given new insights and contribute to ongoing community action in Georgetown County to improve hospital nursing, medical, EMS, and primary care responsiveness to the needs of the community. This provides support for context-sensitive comprehensive multi-level interventions in places where the needs of a population require significant collaboration and trust-building.
Norman et al, 2020	United Kingdom	The study surveyed 117 participants; 30 individuals with ABI, 26 family members, 31 specialists in ABI and 30 professionals working in health and social care settings. Time since injury of those with ABI ranged from <1 year to over 41 years. Follow up interviews were conducted with 31 participants; 12 individuals with ABI, 5	This study aimed to understand the knowledge base of professionals across a range of organisations within the UK with regard to ABI. This was with a view to understanding how lack of knowledge among professionals may lead to poor access to services.	The study identified a lack of knowledge and understanding of ABI among health and social care professionals, from those in acute care through to long-term community services. Poor knowledge was associated with a lack of understanding of hidden disabilities associated with ABI, a lack of empathy and a lack of knowledge regarding specific safeguarding.	Health and social care professionals across a range of services could benefit in ABI-specific training to improve their knowledge and improve the service currently being provided to individuals with ABI and their families.

		family members, 4 experts in ABI and 10 health and social care professionals.			
O'Rourke et al, 2018	United Kingdom	65 participants among probation officer, probation service officer, manager, and other were included. Sample averaged age was 42 years. Most of the participants were female. (55) 43% of staff had daily contact with offenders, 66% knew someone w/ a brain injury and despite 77% having experience working with someone w/ a brain injury, only 7.7% reported ever having received training on the condition. Almost half on the sample reported to have worked w/ the PBNI for over 10 years and a large proportion of the sample were highly educated. Experience in the probation service (years) <5 15 (23.1%), 5–10 19 (29.2%), 11–15 17 (26.2%) , 16–20 3 (4.6%), >20 11 (16.9%); Job title: Probation Officer 46 (70.8%), Probation Service Officer 7 (10.8%), Psychologist 5 (7.7%), Manager 6 (9.2%), Other 1 (1.5%)	Considering the high prevalence of TBI among offender populations, this study aimed to explore the knowledge of members of the probation and the prevalence of misconceptions surrounding TBI among members of the PBNI.	Mean percentage of misconceptions was 22.37%, representing greater level of knowledge about TBI among the PBNI compared to general public. The subdomain w/ the highest rate of misconceptions was "insight" (38,21%). This included beliefs about self-awareness of deficits following TBI. Despite this, it is common for individuals W-TBI to show a lack of understanding of the extent and severity of their impairments, the 73,8% of the sample incorrectly endorsed the statement: "People who have survived a brain injury usually show a good understanding of their problems because they experiences them every day". This belief highlights the potential for many behaviours and symptoms of TBI to be misidentified. Offender may also lack the ability to associate their current difficulties w/ past injuries. This may further extend the belief that traits such as increased aggression, lack of empathy, or difficulty in adhering programs are simply fault of the offender. A possible reason for the prevalence of misconceptions in the domain of insight may relate to the high number of participant who reported knowing someone W-TBI (tendency to over-rely on anecdotal knowledge of TBI, belief based upon personal experiences). Another important finding was that 92,3% of participant reported having no formal training in brain injury.	The high rate of misconceptions in the domain of insight suggest an overreliance on offenders' self-awareness of their injuries. This may pose major barriers in rehabilitation for offenders. Most offenders are unaware of the severity of past injuries, or do not understand the extent such injuries are affecting their cognition and behaviour, so it is likely that many TBIs are not identified. There is need for clear and tailored information on identifying TBI, understanding its outcomes and challenges. Moreover, when considering programs of support and re-integration into the community, probations officers should be fully informed of the possible impact past TBIs may have on offers ability to access and engage. Failing to link problems w/ memory, concentration and behaviour to past injuries. It is important probations officers receive adequate training and access to

					effective screening tools to identify and refer offenders to the appropriate services, ensuring their needs are met early in the criminal justice process.
O'Callaghan et al, 2012	Australia	16 participants ranging from TBI victims to relatives	The ease and difficulty of the availability of healthcare for those with TBIs. Opinion and suggestions from victims and relatives for health service to increase care for those w/ TBIs	Most with TBI are in the 36-45 year gap and seek financial support from the government rather than private sources.	Awareness of impairments in adults W-TBI and their readiness to engage in therapy. The concept of readiness relating to the experiences of engaging w/ care by adults W-TBI
O'Callaghan et al, 2013	Australia	23 people w/ brain injury and their partners were interviewed - 3 narratives in the paper. Bettina= born overseas, TBI in 2008 during neck surgery and has accessed healthcare. Malinda= 37years at time of interview and stopped working after TBI. Oscar= sustained injury following assault and was 28 in the interview	How the needs and experiences of adults with brain injury change throughout time its effect on their ability to access care	Bettina = could only effectively access services in the acute phase of her care and rehab services twice in her rehab, accepting TBI and willingness to accept services increased over time. Melinda = shows the dynamic and complex relationship between person-related factors appearing to influence how people access services regardless of service availability after brain injury. Oscar = began accepting injury over time but initially expectations for service did not match his expectations for those who would serve him, consequently desire to engage slowly increased.	Service providers and guideline formulators should be mindful of service provision adaptations, regardless of time pressures imposed by service policy - the same approach to treatment does not work for all patients
Oddy et al, 2012	United Kingdom	100 homeless individuals recruited through homeless hostels.	The study aimed to map the prevalence of TBI among a population of homeless people	The study identified 48% of individuals had experienced a head injury, of which 90% has sustained their injury prior to homelessness indicating that their injury led to difficulties maintaining suitable housing.	Local authorities are not providing suitable accommodation for those of priority need and there is a need for training of staff in homelessness services in understanding the needs of individuals with TBI
Odumuyiwa et al, 2019	United Kingdom	Study surveyed 76 individuals; 31 specialists	Study explored the experiences of those	Participants highlighted that the consequences of ABI were long-term and often were not appreciated by	Long-term specialist care for ABI survivors is required

		in acquired brain injury, 26 family members and 19 survivors. A further 21 took part in interviews; 12 survivors, 5 family members and 4 ABI experts. Time post-injury ranged from <1 year to over 41 years.	with ABI and their families interacting with community services and their experiences of community rehabilitation services	professionals in community services with cognitive difficulties particularly being overlooked. Participants identified the need for tailored, specialised and interdisciplinary care and highlighted poor access to services caused by a lack of understanding of ABI among professionals, the hidden nature of ABI, organisational structures and a lack of available services	that is tailored to their specific needs and involves effective interdisciplinary team working. This should involve effective information sharing and the inclusion of carers and family members where appropriate. Professionals working in community health and social care settings should receive appropriate training on the difficulties associated with ABI and the needs of patients and families.
Olaiya, et al, 2017	Australia	485 participants used. 67% male, median age of 73. Stroke or TIA saviours.	Look into the complex unmet needs of stroke/ TIA patients and the prevalence of these unmet needs.	Considerable unmet needs were found in patients, this included health care, intimate care, community services, therapy, etc. Professional health care was rated the most important and valued. The community care received was highly associated with unmet needs.	Due to the considerable amount of unmet needs found in stroke/TIA patients after discharge there is a need for more research and the use of such finding to be put forward to change and structure the care and services which need to be provided for patients.
Paniccia et al, 2019	Canada	Young people and young adults with ABI; 8 females, 6 males asged 15-25 years	To explore the transition to work following ABI in childhood	The themes identified; 1) a need for the participants to understand the 'new me' in order to understand their capabilities and their need for accommodations in their work, 2) a need for support from a wide range of places including parents, peers, school and work and colleagues and 3) taking control of the experience of ABI	There is a need for awareness of brain injuries and their associated impairments among employers to allow adequate accommodations to be made.
Pedersen et al, 2019	Norway and Denmark	n=11 stroke survivors interviewed 12 months post onset. 36.36% female, age range 35 to 66 years	Study aimed to explore quality of life (QOL) during the first year of recovery after stroke in North Norway and Central Denmark.	Findings focussed on the reconstruction of self which was identified by three intertwined themes: a familiar self, an unfamiliar self, and a recovery of self. Reconstruction of the embodied self and QOL were framed as an ongoing and interrelated process of “being, doing, belonging and becoming”. Enriching	Supporting an individualized and tailored rehabilitation practice better enables the reconstruction of the embodied self.

				social relations, successful return to work, and continuity and presence in professional support during recovery enhanced the experience of QOL. Fatigue and sustained reduced function hindered participation in meaningful activities and influenced the perceived QOL negatively.	
Perry et al, 2018	United Kingdom	36 stroke patients (17 F, 19 M) 38-90 years old, with adequate cognitive functions, along with 17 partners or carers were included in the sample. Patients were recruited from 3 case study sites in Greater Manchester (the sole 24/7 HASU, 1 of 2 in-hours HASU, 1 of 10 local stroke units) and 4 sites in London (two of eight 24/7 HASU, two of 24 local stroke units). Thus, a range of experiences of the centralized pathway was represented (people admitted to HASU or a local stroke unit, people transferred internally or repatriated to a local stroke unit).	Analysis of the impact of the Greater Manchester (GM) and London centralized acute stroke care pathways on the experience of patients. 1. Initial contact with the emergency care services and transfer to hospital; 2. Reception at hospital, whether stroke was treated as a medical emergency; 3. In-hospital care, particularly in relation to admission to a more distant HASU; 4. Repatriation to local stroke unit; 5. Discharge home, particularly if from a more distant HASU; 6. provision of information across the care pathway	Findings are presented in relation to the 5 chronological phases of the centralised stroke care pathway. Patients reported similar experiences in both locations. In relation to the "Initial transfer to the hospital", patients felt ambulances arrived quickly w/ staff giving clear information about likely diagnosis, reducing anxiety. However, being told of by-passing a local hospital to attend a more distant HASU caused concern and confusion (in particular for family members). Also, the repatriation did not always occur promptly. Patients' experience w/ the initial reception at the hospital was good. Stroke was treated as a priority and medical emergency. Once admitted to hospital, patients described awareness of who was treating them, received clear explanations about their care, and were involved in decisions. Carers recounted difficulties in visiting, in terms of time and financial costs, but most prioritised quality of care and outcomes over the issues presented by being cared for at a more distant site. Repatriation had most participants perceive the transfer as having no adverse effect on the trajectory of their recovery. However, one described being moved from a HASU to another ward for 1 night, before repatriation to a local stroke unit, due to pressure on HASU beds. Capacity issues need to be carefully considered in centralised services. The most difficult transition for patients was discharge to the community. No clear information about the follow-up care were provided. One possible explanations is the staffs' lack of knowledge about local discharge procedures.	The centralisation of care pathways, generally, can offer patients a good care experience. However, to improve patients and family experiences is necessary for all staff on a centralised care pathway to understand the patient journey and provide clear and accessible information to patients at all stages. For example, giving clear information about the care pathway by the paramedic team, and being kept informed about when and where repatriation would happen by HASU staff, led to patients reporting a more satisfactory experience. To best support patients and their families in visiting hospital distant from their home, staff could have more flexibility over visiting times, officially extending the visiting hours for those on centralized care pathways, or ensuring that visiting times coincide with the timing of public transport, as well providing

					information about financial help available towards travel costs and assistance with making these claims. It's vital for care to be carried on seamlessly in the community.
Pickelsimer et al, 2007	United States	Participants in South Carolina, TBI follow-up registry, 33% mild, 67% moderate/severe, 15-75+, interview 1 year after discharge from acute care facilities, 1830 participants	Unrecognised needs: controlling alcohol/drug use, improving mood, finding paid employment, getting services/managing them, improving job skills, finding places/opportunities to socialise with others, increasing independence, general health, social support, employment, satisfaction with life, paid care attendant, information about services, injury severity, cognitive issues, limitations in ADL	Perceived need= far less than unrecognised need in 5 categories, widest gap= controlling alcohol and drug use -> 340% underestimation rate, finding paid employment= underestimated by 68%, increasing independence= underestimated by 47%, getting/managing services= underestimated by 33%, comparable levels for obtaining help from care attendant, improving job skills, receiving information about services, finding places/opportunities to socialise, unmet needs reflected gap between perceived need and unrecognised need.	(35.2%) of patients had at least one perceived unmet service need seen as critical to maintaining activities of daily living. If judged on an unrecognised need, 51.5% of respondents had at least one unmet service need. Due to the high rate of secondary cases and functional limitations after TBI, it is vital to identify previously unrecognised needs and refer patients W-TBI to the service necessary to increase chances of a full recovery.
Porcello and Gaskins, 2017	United States	Article on using occupational therapy to help brain injury patients to deal with financial dysfunctions post brain-injury. Case study of 26 year old male.	Financial dysfunction post-brain injury. Difficulty handling money, paying bills, money management problems- such as impulsivity, memory, and organization. Along with debt prevention.	Participants had difficulties with money management but occupational therapy could be used to aid patients to become more aware of the difficulties with handing and sorting out money, along with helping to keep them on track.	More research needed on larger participant samples
Powell et al, 2020	United States	Paraprofessionals (28), professionals (45), people with brain injuries	The study surveyed the training experiences of paraprofessionals	The results suggested that paraprofessionals require comprehensive training to be able to meet the complex needs of those with moderate-severe brain	There is a need for more comprehensive training of

		(41) and family member (22)	working with adults with moderate to severe TBI	injuries. The study found that an array of training options and modalities were preferred and that there are significant challenges to providing appropriate training including time, funding, limited numbers of staff and a lack of supervision	paraprofessionals in working with those with TBI
Ramos et al, 2017	United Kingdom	3 case studies of individuals with brain injury who either are still in prison or have been in prison due to violence (one case study was still in prison but for a non-violent crime)	Research has suggested that those with a history of head injuries who were never treated are prone to violent behaviour so an early treatment of the cognitive, behavioural and emotional consequences was proposed as a crime prevention measure. The brain injury Linkworker is a service approach to identify and support prisoners who have a history of brain injury	The case studies suggest that the individuals have significant difficulties that reduce their ability to benefit from standard offender rehabilitation which may results from the severe brain injury but also a cumulative effect from minor TBI's. The examples also demonstrate how interventions provided by the Linkworker such as addressing functional difficulties associated with memory problems, executive functions or emotional regulation can make a significant difference to the ability of the person to cope in prison and after release	There are clear early benefits to the Linkworker approach. A service and training package has been developed so Linkworkers can be quickly trained in their role.
Riley et al, 2020	United Kingdom	Partners of those with ABI (26)	To explore their experience of care needs and continuity/discontinuity of the injured person post-injury	Continuity post-injury was associated with a more person-centred response to challenging care needs associated with general relationship characteristics	The study suggests that the fostering of person-centred care among partners by healthcare professionals may improve relationships and outcomes for those with brain injury
Roscigno, 2016	United States	29 parents of children w/ severe TBI from 25 families.	Parents expectations of caring encounters, specifically w/ nurses, after childrens severe TBI	Parents spent the most time interacting with nurses so believed they were best positioned to help navigate the system and get their needs met. However, they felt that some nurses only witnessed the family in the early weeks when the family is emotional, inhibiting nurses to see how the family can adjust and adapt. Parents wanted empathetic understanding from nurses, and to be available and mindfully present, with nurses showing consideration for not further burdening the	Partnerships between parents and nurses cacn assist families in meeting informational, emotional and cultural needs. A need for a palliative care approach with families after severe TBI is emphasised

				family. Parents reported nurses being adept at anticipating parent needs and coaching them in how to continue parenting in this context	
Sansonetti et al, 2018	Australia	30-bed inpatient acquired brain injury rehabilitation unit in Victoria, aged 18-73 years, w/ 9 women, their family members or significant others, and 5 occupational therapists (mean age 28 years, range 23-34 years, all female) were included in the sample. Diagnosis TBI 6 Stroke 17 Hypoxic brain injury 4 Encephalitis 3 Time post-onset of ABI (days) Mean (SD); range 173.3 (111.7); 4–453, Employment status at time of ABI onset Employed 17 Unemployed 11 Retired 2, FIM score on admission: Mean (SD) 46.93 (30.57), FIM communication/cognition, sub-scores 19.37 (8.48)	Exploring the link between goal setting in clinical practice and life roles for people w/ ABI in impatient rehabilitation. Identify the barriers and enablers to life role discussions within a patient-directed goal-setting framework.	Shows the alignment between goals and life roles adopted since admission by participants in the area of family members and home maintainers. While people experienced role losses in the area of worker, hobbyist, friend, religious participant, student, and volunteer (only 3.5% of the overall rehab goals). They were the least prioritised by both patient and clinician. Self-care task comprised over half of the 67% of documented goals indirectly aligned with life roles. This should lead clinicians to pursue goals relating to self-care, despite unclear alignment roles. 1 key barrier to alignment of life roles to therapy goals, identified by patients and clinician regarded readiness to engage in life role discussions due to cognitive impairment and lack of knowledge on what constitutes achievable goals in the early phase of rehabilitation. Some clinicians considered the lack of availability of a caregiver was a barrier to identify patients' life roles in cases where the patients were unable to participate in this process. Other barriers identified by clinicians were: clinician's perceptions of expectations, role change, and environment. The rehabilitation environment was considered both a barrier and an enabler to alignment of life roles and goals. According to clinicians, the transitional living service settings is a facilitator of the alignment due to the environmental structure and model of care. Clinicians considered the use of structured tools like the Activity Card Sort, an enabler in facilitating life role discussions and aligning goals for people with TBI. Patients and clinicians expressed the need for opportunity to regularly review rehabilitation goals to allow for goal modification as priorities shifted or as a goal were achieved. This shows the need to build a goal review process into rehabilitation programs.	Goal discussions should commence early in rehabilitation and involve consideration of previously valued life roles. It is vital for clinicians to regularly review goals with patients and significant others. Use of a structured tool can facilitate goal setting in alignment with life roles.

Satink et al, 2014	Netherlands	27 healthcare professionals.	Challenges for allied healthcare professionals with stroke rehabilitation. Professional's beliefs about self-management in stroke patient rehabilitation, the negative and positive impacts. Factors surrounding self-managements, issues surrounding it.	Professional perceptions are important to consider when dealing with rehabilitation care, and stroke self-management care. Professionals focused more on disabilities and doubting the self-management ability of the stroke patients. They made it clear that client-centred goals were important for self-management, but had difficulty implementing them.	Professionals could benefit from behavioural change models. Self-management stroke interventions would be most beneficial when delivered post-discharge at patients home.
Satink et al, 2015	Netherlands	16 community living stroke survivors. 53-84 years old. All had been living at home for at least 3 months post-stroke.	Studied the reflections of persons post-stroke, as they way in which stroke survivors reflect on self –management after ABI has not been studied yet. Important to pave the way for future research	Found that many discharged stroke survivors did not feel ready for self-management, and they viewed it as a complex long term learning process. They also were found to miss the professional guidance of health care workers. Stroke self-management may be optimised if more focus it put on emotional coping management strategy and community integration post-stroke alongside medical self-management.	Stroke self-management programs should focus on co-management with relatives alongside self-managements. Support of self-management should start as soon as possible and continue post-discharge in the patient's personal environments.
Shannon et al, 2016	United Kingdom	10 stroke survivors with residual impairment, who reported zero or to one unmet need post-stroke, were used as participants. The study was conducted 11 months after the participant's strokes (on average).	Stroke survivors often report longer-term problems post stroke such as physical difficulties and mental challenges; suggesting that their needs are not being fully met. By studying those who have reported zero to one unmet need post stroke, more accurate knowledge about the necessary services and assistant needed to help can be acquired.	Despite participants self-reporting zero- few unmet needs, the study made it clear that this did not necessarily mean they had no problems or issues in their rehabilitation process.	Despite having residual physical or cognitive impairments, reporting no/low unmet needs is explained through: acceptance of changed circumstances, making comparisons with other people and circumstances, valuing pride, determination or independence, and also viewing issues in the context of their expectations and experiences of services.

			Two questionnaires identified the main stroke survivor unmet needs and the most important/useful services to them. This allows for a better understanding of specific issues and needs that need to be addressed, rather than using broad/vague knowledge of unmet needs.		Additionally, all participants were receiving some support.
Simpson et al, 2018	Australia	n=588 individuals with a severe TBI accessing community rehabilitation services, 78.1% male, 79.3% less than 5 years post injury	The study sought to compare the clinical and employment characteristics of people with a TBI accessing new employment with those resuming previous employment.	Individuals with a TBI who accessed new employment were significantly more likely to be younger, single, less educated, with more severe injuries and more likely to be displaying challenging behaviours than those resuming their pre-injury work. Time to return to work was significantly longer for new employment. Stability of new employment was significantly poorer with jobs twice as likely to break down compared to previous employment. New employment positions were also more likely to be part-time and unskilled compared to previous employment.	Supporting placement into new employment made a substantial contribution to employment outcomes after TBI but requires more intensive and tailored programmes to meet the multiple clinical and workplace challenges.
Tang et al, 2019	Canada	51 individuals with stroke living in the community within 6 months post-stroke	To understand the environmental barriers to leisure participation among individuals with stroke	Physical and structural environmental barriers were reported as the most frequent ($n = 26$, 51%), attitude and support and policy barriers were less common ($n = 6$, 12%). Depressive symptoms were most common attitudinal barrier.	There is a need to support individuals with stroke with their mental health as depressive symptoms serves as a common barrier to engagement in leisure activities.
Theadom et al, 2018	New Zealand	n=55 individuals who had experienced a stroke, 52.7% female, median age of stroke onset 71, interviewed 4 times over a 36 month period	This study aimed to explore people's experiences over the first three years post-stroke and identify what helped or hindered recovery.	Participants described an ongoing process of shock, disruption, and fear, making sense of what happened, needing to fit in with what's offered, finding what works for them and evolving a new normal, whilst managing the ups and downs of life. This process needed to be renegotiated over time, as people experienced changes in their recovery, comorbidities and/or wider	Services need to support patients to make sense of their stroke, navigate the health system, address individual concerns and priorities and to know what, when and

				circumstances. The adjustment process continued over the three years post-stroke, even for those who perceived that they were recovering well.	how much to challenge themselves. Rehabilitation plans need to be revised as circumstances change to facilitate adjustment following a stroke.
Toor et al, 2016	Canada	With TBI (n=105) 5 to 12 years post-injury and women without TBI (n=105) matched on age, education, and geographic location.	Utilisation and satisfaction of: Family physician and community-based Health services, Maternity/conception health services, Barriers to receiving care when needed, Perceived access to social support	Compared with women without TBI, W-TBI reported using more family physician and community health services. W-TBI reported that they did not receive care when needed (40%), particularly for emotional/mental health problems. W-TBI reported financial and structural barriers. There were no significant differences in reported satisfaction with services between women with and without TBI.	Health service providers and policymakers should recognise the long-term health and social needs of W-TBI and address societal factors resulting in financial and structural barriers, to ensure access to needed services.
Torbica et al, 2014	Italy	Primary caregivers of stroke patients were interviewed at 3, 6 and 12 months after the acute event. Forty-seven per cent of caregivers were spouses of the patients while approximately one third were their children. Majority of caregivers were women (86%), with mean age ranging from 55.19 (SD 13.4) to 55.93 (SD 13.3) years.	The aims of the study was to investigate whether the presence of a potential caregiver and the amount of informal care provided influences the use and the costs of healthcare services, and in particular rehabilitation, in the post-acute phase.	Results suggested that the presence of an informal caregiver significantly raises the likelihood of access to rehabilitation services, but e once the access has been made-it doesn't significantly influence the amount of rehabilitation services used. Rehabilitation may be facilitated by the presence of caregiving as access to the rehabilitation may be refrained by administrative obstacles and family support may favour motivation for a type of care requires active patients' motivation.	Policy makers should, among other issues, consider the role of informal caregiving when designing policies for patients with disabling diseases. The presence of a caregiver appears crucial for access to rehabilitation services. Policy makers should be aware that ensuring access to these services may involve the presence of caregivers as they may have motivational and case management roles. The knowledge offered by this study should be used to design policies for facilitating access to care to patients without informal care support.

Tverdal et al, 2018	Norway	74 patients admitted to ward or intensive care unit at a trauma referral hospital within 24 h of traumatic brain injury. Mean age of participants was of 44 years (16-85 years), and 70% were male. 40% of TBI were due to road traffic incidents, and 42% were due to falls. Most injuries were mild TBIs based on GCS assessment (72%). Patients were divided into 3 groups according to the clinical care they received: (a) emergency room (EM), (b) admission (patients admitted into hospital but not in the ICU,(c) ICU patients admitted directly to the ICU from the ER or other hospital.	Describing the discharge process for patients with TBI from a trauma hospital and patients experience and overall satisfaction with care transition. To evaluate the association between discharge process, patient satisfaction, and quality of care transition. It was hypothesised that patients with more severe injuries would have lower satisfaction and quality of care.	The hypothesis was confirmed. Furthermore, findings showed the major factors affecting overall satisfaction and quality of care transition were patient experience of involvement in care transition and co-ordination of care. One third of patients reported that they were not involved in the discharge process, and/or did not experience continuity in their care transitions, hence not meeting the demands of patients-centeredness. Discharge was planned for the majority of patient in ICU but only 41% were discharged directly to a rehabilitation unit, not following the desired rehabilitation chain. Information provided from trauma hospital were often inadequate, suggesting that the discharge process was not optimal for all patients needs improving.	Patient-centeredness and involvement in healthcare decision-making improve the quality of care and patients' satisfaction of healthcare services. Therefore, it would be useful to develop interventions for healthcare professionals working with TBI that facilitate patient participation in care transitions, as well as to enable patients/proxies to take part in decision-making processes. It is also important providing information to patients/caregivers of what to expect after discharge. Patients with more severe injuries were less satisfied with transition of care and its quality. This suggest that special attention and consideration needs to be given to patients with severer injuries and their caregivers.
Tverdov at al, 2016	United States	29 family members who were involved in the care process returned substantial data to be used in the study	Perceived needs, obstacles to services, psychological distress and social problem solving of family members of persons with ABI. These family members are at a greater risk for depression, anxiety,	Primary family members were satisfied with the information and professional support. Female family members had higher levels of distress than males, but the majority were in the average range for levels of psychosocial distress.	Facilities should assess family members' needs annually, perhaps via surveys taking 20 mins or less. Awareness of resources should be increased for families as well as increased awareness for staff across disciplines.

			comatose symptoms, and social isolations and diminished life satisfaction. Identifying family members characteristics that contribute to life distress can aid in developing effective supports		
Visvanathan et al, 2019	United Kingdom	15 Stroke survivors during hospitalisation and at 6-months post-discharge	To better understand treatment decision-making in acute stroke through the exploration of experiences, views and needs of stroke survivors	Those independent pre-stroke struggled to accept long-term disability and had a stronger emotional reaction to their stroke. A wide range of unmet psychological needs were identified at post-discharge that impaired quality of life	There is a need for psychological support post-stroke, particularly among individuals who have experienced a loss of independence.
Voris et al, 2019	United States	n=7 100% female spousal carers of military veterans with PTSD and TBI, semi-structured interviews, participants ranged from 30 to 47 years of age, mean age 38	The study examines what it means to be a wife of a combat veteran who suffers from post-traumatic stress disorder (PTSD) and/or traumatic brain injury (TBI).	The findings indicated that spouses of military veterans with TBI and PTSD these women experience tremendous emotional, financial, and social challenges that arise from being the caregiver for their husbands. Spouses reported feeling isolated from and abandoned by both the military community and the civilian community. The social and emotional disconnection of the spouses e amplifies the stresses they confront in daily life—stresses that are unique to their relationship to being with a combat veteran spouse who has PTSD and/or TBI.	Recommendations primarily focus upon further research required regarding supporting the unmet needs of military spouses coping with the consequences of TBI and PTSD and the importance of including such carers in the research process. Supporting women to find and/or create positive community connections is noted and is a greater understanding of how military culture affects post-military families reintegrate into civilian life
Watkin et al, 2020	United Kingdom	172 participants with TBI, recruited >48 hours after hospital admission	The study collated return to work data at 3, 6 and 12 months post-injury	68% of moderately/severely injured and 84% of those with mild injuries returned to work following TBI. Many required adjustments or accommodations in the workplace to manage. Most participants took at least 3-4 months to return to work. Overall, 16% returned to	Further exploration of long-term return to work is required. More investment in assessment, particularly for those with mild injuries

				pre-injury levels of employment by 12 months post-injury. Those were high health related quality of life, anxiety and functional ability were more likely to achieve complete return to work. 67% reported low job contentment and reduced hours.	is required to ensure their difficulties are appropriately addressed.
Wright et al, 2016	Canada	11 Canadian adults living in the community with acquired brain injuries (ABIs). All with a minimum of 2 years post injury. 6 women and 5 men. The average age was 44 years, age range 37-58 years. All 5-42 years post injury. The injuries sustained are of a traumatic nature, such as assault or vehicle related.	Little is known about ABI patient's experiences with healthcare and decision making, and whether experiences align with patient-centred care (PCC) principles. This study looked to obtain a better understanding of how mild to moderate ABI patients in the chronic phase of recovery (i.e. minimum 2 years post-injury) experience and navigate healthcare.	Participants conveyed similar narratives, with 2 main experiences: They positively portrayed their doctors and healthcare relationships, reporting feeling lost and needing their doctor's help; The second that they negatively portrayed their doctors and their healthcare relationships – reporting being capable and therefore not needing their doctor's help. Although seemingly contradictory, these 2 main types of experiences speak to one coherent experience in which capability served as a counter-narrative to what they perceived as a global narrative of being devalued, dismissed and patronised.	Implications of these counter narratives are that they can affect the perception of experiences with healthcare services for those with ABIs. Furthermore, doctors may want to focus more on fostering a positive doctor–patient relationship by conveying that they care for and value their patients, and why simple interactions may contribute to this positive relationship. Hence, face to face meetings are important as well as a sympathetic and personal demeanour. However, this also serves to highlight the importance of doctors finding the balance between supportive and patronising. Ultimately, feeling valued, capable and cared for was what these participants valued most in their doctor, representing the kind of doctor they wanted and needed in their healthcare.
Ytterberg et al, 2019	Sweden	Seven partners (2 male, aged 60-82) of individuals 6+ years post stroke.	To explore the experiences of partners	Participants identified difficulties in adjusting to life post-stroke which involved high care needs that	The findings highlight the need for increased support for the partners of those

		*This study included some participants within the threshold of the review and some whose partners were older than 65 years when they experienced their stroke. All data was anlaysed.	of those 6+ years post-stroke	elicited levels of anxiety and caused strains of everyday life and their relationships	with have experienced strokes.