

1 'Attending to the wound and the person' –
2 Patients' Experiences and Expectations of a
3 Newly Established Traumatic Brain Injury
4 Clinic

Abstract

Primary objective: This qualitative study aimed to gain a better understanding of how medical and social services in the United Kingdom (UK) currently support patients with Traumatic Brain Injury (TBI) in the community. Further, we explored patients' wishes and expectations of a newly established TBI clinic.

Methods and procedures: We conducted semi-structured interviews with ten patients with mild to severe TBI. The interview schedule was designed to cover contacts with health services, information provided, post-discharge support, current social circumstances, expectations from the newly established brain injury service and participants' desires for any new service. Transcripts were analysed using thematic analysis.

Main results: Participants highlighted the importance of the human component of their care in fostering trusting relationships. This validates patients' experience and helps them to regain confidence. Follow-up and education are also important to patients and relatives through all stages of care, regardless of the severity of the injury. Patients strive for meaningful lives and need to be supported to engage in activities. They need hands-on support, particularly with the UK's bureaucratic welfare system.

Conclusions: There is much room for improvement in the TBI community care in the UK. Our findings support the development of a holistic service that can address the multifactorial problems patients with TBI and their families face.

Introduction

The World Health Organisation has identified Traumatic Brain Injury (TBI) as a major public health problem with enormous unmet needs for effective long-term treatment [1]. TBI is the commonest cause of death and disability in those under-40 and patients who survive are often left with long-lasting difficulties and consume large amounts of health resources [2].

In the UK, it is estimated that at least 1 million patients attend Accident and Emergency (A&E) departments following TBI each year [3] and rapid emergency responses and advances in medical technology have increased the survival rates of people sustaining a TBI [4, 5, 6].

Patients with brain injury pass through up to four phases of rehabilitation, depending on the severity of the injury: acute care; in-patient treatment and specialist rehabilitation; a transition phase, including discharge from hospital and community-based rehabilitation, and a post-return to the community phase [7, 8].

Although 80% of TBI survivors return to life in the community, care pathways are traditionally focussed on responding to acute illness [3]. After TBI, patients frequently have a wide range of cognitive, psychiatric and social problems [4, 9, 10]. Thus rehabilitation can last from several years to a lifetime, making longer-term community support an absolute necessity [8, 11].

Yet the assessment and treatment of patients with TBI, even in the acute setting, varies substantially in the UK. At present, most TBI survivors fall through the gaps of clinical mental health and neurological services, which are aimed primarily at adult mental illness, dementia or neurological illnesses.

Of particular interest is mild TBI (mTBI). Those patients, representing the vast majority of those attending emergency departments with TBI, are usually discharged without neuroimaging, neurology, psychiatry or neuropsychology reviews or specialist follow-up.

64 While most patients with mTBI recover in the first 3 months, up to one third report
65 symptoms after 6 months and may therefore benefit from long-term support [3, 12, 13].

66 Alcohol misuse is common in patients with TBI, increasing the risk of repeat injuries and
67 disability, and contributing to their long-term needs [14, 15].

68 Overall, despite considerable service requirements, there is lack of research into how
69 patients and carers experience TBI services in the UK. Internationally, several qualitative
70 studies have evaluated the experiences and service needs of TBI survivors using
71 different qualitative methodologies, such as focus groups in the USA [16] and the
72 Republic of Ireland [17], and semi-structured interviews in Canada [18, 19], Australia
73 [20, 21] and the USA [8, 22, 23].

74 Two previous studies with a specific focus on service structures have been conducted
75 [16, 17]. Using focus groups, Leith et al. [16] interviewed 21 persons with mild-to-
76 severe TBI and their family members in South Carolina, USA. They found that persons
77 with TBI and their families experienced their service system as ‘unorganized,
78 uneducated, unresponsive and uncaring.’ There was an ‘overwhelming consensus
79 regarding the need for early, continuous, comprehensive service delivery;
80 information/education; formal/informal advocacy; empowerment of persons with
81 TBI/families, and human connectedness/social belonging’ [16]. McDermott & McDonnell
82 [17] also carried out focus groups with family members of patients with acquired brain
83 injury and health professionals using an interview schedule based on the Slinky Model of
84 Rehabilitation [7] and on knowledge of current service options in the Republic of Ireland.
85 Both professionals and carers highlighted a need to build and expand current services
86 and to make information and education more available and accessible. Further, a need
87 for improved coordination and communication was identified.

88 This study aimed to examine how medical and social services in the UK support
89 community-based patients with TBI. We also explored participants’ expectations from a
90 newly established traumatic brain injury clinic (The Hounslow Pilot Clinical Service for
91 Acquired Brain Injury). The novel service had been set up in response to lack of

92 accessible TBI outpatient care in West London and patients with TBI being referred to
93 dementia and mental health services, which struggled to provide support for these
94 patients' complex needs. It was launched in May 2015 for a funded period of 12 months
95 and was staffed with a psychiatrist, a psychologist and a community psychiatric nurse.
96 The service provided initial assessments, neuropsychological and psychiatric treatment,
97 and a novel brief alcohol liaison intervention to address any existing risks for alcohol
98 misuse. Despite more than 1000 people attending the local emergency department with
99 TBI per year, and various efforts to increase awareness amongst professionals, the new
100 clinic only received 53 referrals over one year and was not renewed beyond its pilot
101 phase.

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Methods

The study used a qualitative methodology. The London-Harrow NHS Research Ethics Committee approved the study (14/LO/2275). Semi-structured interviews were chosen, as they give an in-depth understanding of the participant's experience and (unlike focus groups) allow patients with cognitive or language difficulties to fully participate [24]. Semi-structured interviews are an established tool in qualitative TBI research and have been used to great effect in similar studies [8, 18, 19, 20, 21, 23, 25].

Participants:

Patients referred to the newly established pilot clinical service for Traumatic Brain Injury in Hounslow were invited to take part in the study. To be eligible for the study, patients needed to be at least 18 years of age, have a diagnosis of TBI, and have the ability to engage in a prolonged interview in the English language. We used maximum variation sampling [26] to construct a sample that included a range of TBI patients based on severity of brain injury (mild/moderate-severe, based on the Mayo TBI Classification System [27]), time post injury (<1 year/1 year or more), social situation (living with family/living alone), and education level (secondary education incomplete/secondary education complete and higher).

Data collection:

The first author (CM) designed a semi-structured interview protocol based on the existing literature [16, 17], clinical experience, knowledge of the current service structure. We refined the protocol through discussion with key stakeholders and the final interview schedule consisted of 9 broad questions. These questions guided participants through their experience after sustaining a TBI. Questions 1-4 asked about initial contact with health services after TBI, including information given and support. Questions 5-7

130 explored the patient's current domestic and occupational situation, as well as access to
131 services. Question 8 asked about their expectations of the newly established TBI clinic.
132 The last question was adapted from Leith et al. [16]; participants were requested to put
133 desired services into a 'wish-basket'. Individual semi-structured interviews were
134 completed with every participant at a location of the interviewee's convenience, either in
135 the outpatient clinic or at home. The interviewer was a clinician (CM), but not directly
136 involved in the patients' care. Each interview lasted about 30 minutes, was audio-
137 recorded, transcribed and anonymised. The interviewer took written notes after the
138 interview and extracted demographic data and information regarding the injury from
139 each participant's electronic medical record.

141 **Data analysis:**

142 Analysis was conducted using the 6-step approach for thematic analysis described by
143 Braun & Clark [28]. This process was completed using the software package NVivo for
144 Mac Version 10 [29]. The first author immersed himself in the data, read and re-read the
145 data set, and looked for patterns and meanings. Through this process, 18 initial codes
146 were generated. Two co-analysts (CM, YW) then coded notable features in the data set
147 and identified candidate themes. These candidate themes were regrouped several times
148 and then judged for 'external heterogeneity' (clear and identifiable distinction between
149 themes) and 'internal homogeneity' (data within the theme coheres meaningfully), per
150 Patton's dual criteria for judging themes [26]. This process was iterative and supported
151 by consulting theoretical, methodological and analytical resources. Analysts repeatedly
152 returned to the interview transcripts to ensure that identified themes truly came from
153 the data. We then clustered and integrated these themes into a reduced number of
154 categories. Methodological rigour was ensured through the application of established
155 quality criteria [30, 31]. We used several techniques to ensure transparency, credibility
156 and reliability of the themes and categories: (a) re-reading the entire dataset, to identify
157 additional data that had been missed in previous stages and to examine 'whether the

themes work in relation to the dataset' [28]; (b) using two analysts (CM, YW), whereby the original analyst reviewed the data for discrepancies, errors or overstatements; (c) triangulation, with themes identified in focus groups the principal investigator (VR) conducted with members of a Headway, the UK based brain injury charity (results can be provided on request).

Results

The study included ten participants (see Table 1 for participant characteristics). The following section provides in-depth description of the categories and themes that emerged. Illustrative quotes made by participants are embedded in the text (*in italics*). Table 2 summarises the categories and themes.

Category 1: Need for information and education through the continuum of care

There was a strong consensus regarding the need for information and education in the early rehabilitation phase, when patients are about to be discharged from hospital or the emergency department.

'I know A&E are very busy, but I thought they could have (...) a bit more information, a bit more time explaining to me.' (63-year-old man)

Participants reported that information was mainly given in the form of leaflets, which outlined warning signs for acute deterioration, but didn't give information about possible medium or long-term consequences.

A 41-year-old patient wanted to know: *'What to expect afterwards, and not just a day afterwards or two days afterwards. (...) I needed information to say you can expect that. (...) The medium term expectations after a head injury, I think that's a bit unclear.'*

She expected specific information regarding diagnosis and prognosis and related the traumatic brain injury to a limb injury. *'I need information to say: You can expect that. Like for my hand. I know for the next 6 weeks I need to be a bit careful.'*

Several patients described the experience of mental and physical changes as frightening. Possibly partly influenced by clinician's own uncertainty, information of what to expect in the post-acute phase was often lacking.

205 *'I didn't know what I was going through. I didn't know what I was feeling. I*
206 *thought I was going mad.'* *'All I wanted to know was a name, of what's wrong*
207 *with me.'* *'I wish I had a centre I could go to in the beginning. That would take a*
208 *lot of the depression.'* (58-year-old woman)

209 Follow-up by professionals was described as neither immediate nor well informed. Some
210 participants reported that they didn't have any follow-up contact with their general
211 practitioner.

212 *'I had to go back to my GP, but I don't think he knew anything about it.'* (58-
213 year-old woman)

214 A diagnosis was often not given or adequately explained in the acute setting. A post-
215 discharge support session explaining possible symptoms and consequences in non-
216 medical language would relieve anxieties and give information when patients and their
217 families are ready to take it in. Only after a 63-year-old man attended the newly
218 established brain injury clinic he found: *'They put my mind at rest. (...) I came out*
219 *feeling a lot better mentally. I'm not going mad.'* Similarly, a 58-year-old woman
220 stated: *'They sort of brought the puzzle together.'*

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222 **Category 2: Lack of understanding amongst relatives and** 223 **friends and need for formal and informal advocacy**

224 Patients described that the TBI had a substantial impact on relationships with family and
225 friends. Following the initial shock, relatives often struggled to understand the patient's
226 difficulties.

227 *'They sometimes say: You are not a kid. You are a grown-up. Now you should*
228 *behave like this.'* *'They say: (...) you are mad, you are sick, you are on drugs (...).*
229 *They cannot understand this.'* (42-year-old man)

230 The lack of visible signs of injury made it difficult for others to understand the impact of
231 the TBI.

232 *'There's no visible symptoms, but I felt vulnerable and needed reassurance.' 'I*
233 *needed someone to look after me, but (...) it wasn't possible because you couldn't*
234 *see a big knob on my head; you couldn't see a big bump on my head.'* (41-year-
235 old woman)

236 Patients emphasized the importance of understanding in marital relationships.

237 *'I came out (of hospital) and (...) my partner said: I've kind of had enough of this.*
238 *So I came out and was separated from her, which was really bad.'* (65-year-old
239 man)

240 Lack of family support and understanding was recognised as a major barrier for other
241 treatments to be effective.

242 *'(Patients with TBI) Need more care from the whole family rather than from*
243 *doctors.' 'If they (family members) do not support (...) therapy has no effect. It's*
244 *useless.'* (42-year-old man)

245 Patients with TBI struggled to comprehend the physical, cognitive and mental changes.
246 They felt responsible for explaining this to their family members, but were unable to
247 advocate for themselves. Professional informal or formal advocacy was lacking.

248 *'I didn't know what was going on. They didn't know what was going on.'* *'People*
249 *thought I either was putting it on or lying and this did distress me.'* (58-year-old
250 woman)

251 Withdrawal of friends and a narrowing social network was common, highlighting negative
252 attitudes of the general public towards patients with TBI.

253 *'I had friends. Now they are ignoring me.'* *'I had an accident and then everybody*
254 *was disappearing from my life.'* (22-year-old man)

255 A 42-year-old patient suggested that there should be more political pressure to promote
256 families' or the general public's understanding of TBI survivors' difficulties.

257 *'I don't think they (family members) want to understand. But if there was a law*
258 *from the council or the government, this would be a different story. They have*
259 *to.'*

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261 **Category 3: Human connectedness can relieve uncertainty** 262 **and help patients regain confidence**

263 There was consensus amongst participants with milder brain injuries that through their
264 period of acute care, the human dimension was missing. A 90-year-old man commented
265 on his treatment in the emergency department: *'They attend to the wound, but not the*
266 *person.'*

267 Participants agreed that traumatic brain injuries, regardless of severity and mode, are
268 traumatic life events. Patients and family members often underestimated emotional
269 consequences, particularly of a mild TBI.

270 *'I felt really vulnerable and I don't think my family realised, and it's kind of*
271 *knocking on now. (...) It was actually really traumatic. (...) I didn't even fracture*
272 *my skull, but the shock, the impact, was a lot bigger than that. (...) I don't think*
273 *people understand how vulnerable you feel.'* *'It was really scary. (...) I had visions*
274 *of myself having a bleed on my brain.'* (41-year-old woman)

275 Mild TBI and its potential course were poorly understood, partly due to limited
276 communication by professionals. Several participants reported a wish for more imaging
277 assessments to provide reassurance.

278 *'I would have felt better if there was a form of scan, but I can understand why*
279 *they didn't do it in terms of the radiation. But it just would have actually made a*
280 *difference. (...) I was worried about bleeding on my brain because I had blurred*

281 *vision, because my memory was affected, I would have liked (...) the MRI scan.'*
282 (41-year-old woman)

283 *'I was a bit disappointed they didn't give me a CT scan as I'm on aspirin (...) and I*
284 *thought if there's any trauma to the head, that if there was a bleed there, they*
285 *would have known. (...) So I was worried about that.'* (63-year-old man)

286 Those concerns and uncertainties were difficult to address in an acute care setting. A
287 participant would have preferred:

288 *'If someone said: Look, it's not a big injury, (...) but (it can cause) shock and*
289 *vulnerability. I don't think people understand how vulnerable you feel with a head*
290 *injury, because it can kill you. (...) I just needed someone to say: Yes, you felt*
291 *vulnerable. And a hug.'* (41-year-old woman)

292 There was consensus amongst participants that trust in family members and health care
293 professionals was crucial for regaining confidence and overcoming the consequences of
294 the injury.

295 *'Confidence comes from trust. You got to trust someone in order to get*
296 *confidence. I didn't have no confidence and I felt as though my armour had been*
297 *taken away. (...) I was (...) vulnerable and I felt frightened.'* (58-year-old woman)

298 A 41-year-old woman who had been assessed in the new brain injury clinic reported that
299 *'it made me feel a bit relieved and looked after'* and a 63-year-old man stated that in the
300 clinic *'someone's caring, you know, actually caring. (...) A&E didn't, you know, stitch you*
301 *up (and) get out sort of thing.'*

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303 **Category 4: Need for support to overcome lack of motivation,** 304 **to socialise and engage in activities**

305 Difficulties with motivation and executive function are common after traumatic brain
306 injury and were frequently described in this sample.

307 *'I don't feel (able) to meet people. I don't feel able to go out (...) because I just*
308 *want to be alone.'* *'I felt much safer and happier (at home). My bed was my*
309 *friend.'* *'I don't do anything. Just sleep, eat, sleep, eat, sleep, eat, that's it.'* (58-
310 year-old woman)

311 *'I currently spend my time with the radio and sleep largely, which is a shame*
312 *because I ignore the wonderful weather we're having at the moment.'* (65-year-
313 old man)

314 A strong desire for a normal life was reported across the sample of patients. A patient
315 described his experience of meeting uninjured people in everyday situations: *'They are*
316 *enjoying (life), they are playing (with) each other. (...) I just start crying why I can't do*
317 *that, because I just had a head injury.'* (22-year-old man)

318 A key theme was that supporting the patient's motivation would make a major difference
319 to the patients' quality of life.

320 *'Head injury people, they don't feel to do anything. They need someone who can*
321 *push them.'* *'Just make them run, make them walk and have fun!'* (22-year-old
322 man)

323 It was emphasised that in the transition and early community life stages, intervention
324 should take place in the patients' home and encompass both motivational and emotional
325 support.

326 *'Somebody to talk to. Somebody who could be your crutch for that time that you*
327 *have no legs. Somebody to tell you that you are not going mad.'* (58-year-old
328 woman)

329 Participants also alluded to the benefits of care navigation and suggested provision of a
330 phone crisis line.

331 *'I forget appointments a lot of the time. I forget a lot of things in my life.'* (22-
332 year-old man)

Alcohol use was mentioned as a particular area of concern. Speaking about addressing alcohol problems, which already existed pre-TBI, a 65-year-old man stated *'it's equally hard, maybe harder.'* A 63-year-old man commented on a brief alcohol intervention provided by the brain injury clinic: *'It's a good idea (...) it could help someone who's an alcoholic or may turn into an alcoholic because of a head injury.'*

Category 5: Employers and social service lack expertise. This leads to financial pressures

Several participants highlighted the lack of support by employers and social services, particularly in the transition and community life phases. There was consensus that the needs of the studied patient group were poorly understood and unsolvable demands were made.

'I needed help all the time there and they made me redundant.' (42-year-old man)

'(Employers) don't take much notice of what the doctors say.' 'I'm supposed to go back next week and I'm a bit worried because how agitated I get when I'm out, especially if I have to concentrate on anything.' 'No one cares at work. There's no compassion when you're ill: you're either ill or you work.' (63-year-old man)

This and high bureaucratic thresholds lead to a substantial financial burden.

'I can't be dealing with the paper work and I am not dealing with it. (...) I am just burying my head in the sand.' (58-year-old woman)

Social and housing services lacked expertise to address the needs of patients with TBI. A 22-year-old man recounted inadequate accommodation affecting his recovery.

'Things are getting worse in that room, because the room is spinning and I am spinning as well, because it is too small. (...) You can measure my room by hand.'

358 *(...) I just bang my head to a wall or just hit myself or hurt myself (...) just to go*
359 *away from here.' 'It's just like jail where I am living now.'*

360 Although a social worker had been allocated, the patient stated: *'I don't know what they*
361 *do, because he didn't help me a lot to change my room'* and lack of TBI specific
362 knowledge in the social care sector was an overarching theme.

363 *'I think they're not skilled enough to be helpful in that department (...). They have*
364 *to be skilled in a particular way they're not used to. I mean, I'm just another*
365 *injury.'* (65-year-old man)

366 Social and financial pressures were identified as a major obstacle to recovery.

367 *'You know in these days it's very hard with the finances. Everything is hard. I'm*
368 *just going on.'* (27-year-old woman)

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Discussion

This study aimed to explore the experiences of patients who were referred to a newly established community-based TBI service. This study highlights participants' desire for greater information concerning the potential medium and long-term consequences of TBI, particularly in the transition period from hospital/emergency department to home, when patients and their families are trying to come to terms with acute changes in their lives. TBIs, regardless of severity, can be traumatic, suggesting a need for medium to long term follow-up and support.

There was consensus that disagreements with relatives are very distressing and hinder recovery. Often neither the patients nor their family members understand the patient's difficulties fully, aggravated by the fact that the person with brain injury may appear entirely healthy. Patients may be unable to communicate their impairments to relatives and our study indicates that professional advocacy is frequently lacking.

Although patients reported being generally satisfied with the care they receive from acute medical services, some participants concluded that the human component of immediate care was lacking. Brain imaging, such as CT or MRI scans, can give some reassurance, but this may also be misleading in that they frequently fail to reveal underlying mild brain injury. Our study indicates that follow-up in a specialist TBI clinic relieves uncertainties and helps patients regain confidence. Participants reported a strong desire to live a meaningful life, which they often fail to accomplish, as the injury causes lack of drive or energy to engage in activities. Existing services, primary care, social care and employers are often experienced as ill-informed and unsupportive. In particular, participants in this study stressed that social services and employers often aggravate patients' situations through unmanageable bureaucracy. This may lead to financial pressures and inadequate housing situations that impede recovery.

Participants in our study emphasised that information given about the diagnosis and its consequences is often inadequate. Lack of information giving is rarely grounded in professionals' unwillingness, but rather in uncertainty of prognosis. In a qualitative Canadian study [18], clinicians stated that information provision was limited, as they were unsure about the 'clinical evolution' of the patient and worried about giving false hopes or unnecessarily upsetting the family. In a US study [23], some patients were never given a diagnosis of TBI. One patient in our study stated '*All I wanted was a name*' and described a struggle to gain understanding from relatives, employer and welfare services. While the US patients described going on a journey looking for answers from neurologists, family practitioners or psychologists, participants in this study did not seem to have the drive or support to actively seek help.

Marginalisation, a shrinking social network and increasing relationship difficulties, as found in our study, are consistently reported in the international literature [16, 19, 23, 25, 32]. For some participants of our study, although years had gone by since the injury, a social network had not been re-established, and if family was present, the burden of care often lay with them. Participants also experienced a 'vicious cycle', as described by Lefebvre et al. [19], of exclusion triggering addictive behaviours and depressive affects that ultimately make the person more socially isolated. This cycle can be interrupted when the patient encounters a health professional giving psychological support. A community-based TBI clinic seems to be ideally placed to assume this role.

The lack of advocacy portrayed in our study is a recurrent theme in the literature. Leith et al. [16] described patients with TBI as 'walking wounded' (p. 1204), as others are not aware of their often invisible behavioural and cognitive deficits. The general public tends to overestimate the abilities of those with such indiscernible disabilities. Participants in this study stressed that social services and employers often appear to aggravate patients' situation through a level of frequently unmanageable bureaucracy. This was emphasised in this cohort to a larger degree than in previous research, and might be

specific to the UK context. Marginalisation and inadequate advocacy are grounded in negative biases and prejudicial attitudes towards patients with TBI held by both professionals [33] and the general public [34]. Mental health problems, as reported by the majority of patients in this study, as well as physical disabilities and epilepsy associated with TBI, are heavily stigmatised. There is no doubt that this additional discrimination impacts on the social experience [35].

One patient in this study described his experience of the emergency department as: *'They attended the wound, but not the person'*, which highlighted the frequent absence of a human dimension in the care of TBI survivors. Lefebvre et al. [18] echo this, reporting that patients with TBI often feel like 'an object of care' (p. 589). To foster confident relationships between health care professionals and patients, respect and openness as well as clear communication are necessary [18]. Patients who had attended the TBI clinic emphasized its pivotal role in relieving anxieties present at hospital discharge. In an Australian mixed-methods study [36], 70% of carers reported feeling anxious on discharge. Our study identified a need for clear, understandable information through all phases of care.

This study adds to the growing literature on consumer's preferences for delivery of health care. Participants of our study emphasised known factors underpinning consumer preferences such as availability, accessibility and accommodation [37]. In line with the international literature, patients with TBI in the UK found limited participation in the acute period of medical care acceptable, but wished for more empowerment to manage their own subsequent care in the community [38]. Participants in our study highlighted that they were often left to their own devices and needed to actively seek support. This lack of community resources is a prominent theme in the literature. Lefebvre et al. [18], who published their study more than ten years ago, were surprised to observe 'that in this era of globalisation, with public health policies intended to restore control over health issues to the population (...) little seems to have been accomplished, to date, to

formulate and set up (necessary) organisational structures' to support TBI survivors adequately (p. 595). Our study highlights that it does indeed seem that little has been achieved in the last 10 years, despite an increasing number of people who have experienced a TBI living in the community [4, 5, 6].

Although research into the service experiences of patients with TBI and their carers has been carried out in high-income countries, such as the USA [16], Ireland [17], Canada [18, 19] and Australia [36, 38], this study is the first exploring the UK context. A specific strength is the active inclusion of patients with TBI. Although some studies have interviewed community-dwelling TBI survivors independently [8, 21, 23], most other studies [18, 19, 20] conducted interviews either with inpatients in rehabilitation centres, or patients were interviewed together with their caregivers. The only comparable European study used focus groups with professionals and carers, not patients [17]. In terms of the breadth of data collected, semi-structured interviews with patients with cognitive and language difficulties generated data that was possibly less rich than that from focus groups. Nevertheless, group consensus and information overload that often occurs in focus groups [39] could be avoided, and it is likely that patients were able to speak more freely when relatives or carers were not present. A robust methodology was achieved through the application of established quality criteria [28, 30, 31] and the use of several techniques to ensure transparency, credibility and reliability of themes and categories.

Limitations

An obvious limitation of the present study is that only a small number of participants were included. However, the methodology chosen, semi-structured interviews and thematic analysis, is well-established and has been shown to reach saturation within the first 6-12 interviews [24, 40]. It has been used effectively in similar populations [18, 19, 22, 23], whereby one study [18] specifically commented that this approach reached saturation.

As this is a retrospective study, results might have been affected by recall bias. Most patients struggled to recollect what exactly happened at the time of the injury. The distraction of a detrimental life event, the inherent cognitive difficulties and other events happening at the same time might also have dimmed their recollections.

Some interviews with mild TBI patients and patients with cognitive impairment provided irrelevant answers. It was evident that some mild TBI patients who were interviewed only weeks after their injury had priorities not related to their brain injuries. Patients with cognitive impairment struggled to recall details of their care experience. This limited the richness of the data generated by these interviews [41].

Moreover, results of the study may have been influenced by selection bias. Potential sources of this possible bias include the fact that only patients referred to the TBI clinic were included, and the clinic was still in the process of adjusting its referral criteria. Although non-English speakers were excluded, the sample appears to represent ethnic diversity in the examined population.

Recommendations and conclusions

This qualitative study explored how medical and social services in the UK currently support patients with TBI in the community. Our results show that there is much room for improvement of the community support system and that education is pivotal. Patients and their families should be seen early post hospital/emergency department discharge by a competent professional to explain symptoms and put them into context. In addition, we would recommend that families receive education, e.g. via family interventions, to deal with the reality of post-injury life. Targeted supports to help TBI patients overcome lack of motivation and social exclusion, such as befriending services, or, at later stages, self-help or activity groups, could improve quality of life substantially. The potential of aggravation of existing or new onset alcohol misuse should be addressed in clinical encounters. Support with bureaucratic challenges, particularly with the employment and welfare system, from benefit advisors, social workers or trained

520 psychiatric nurses, should be part of a TBI patient's community care team. Our findings
521 endorse the development of a holistic community-based service addressing the
522 multifactorial problems patients with TBI and their families face.

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