

Kent Academic Repository

Full text document (pdf)

Citation for published version

Abrahamson, V. and Jensen, Jan and Springett, Kate and Mohamed, Sakel (2016) Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: a qualitative study. *Disability and Rehabilitation*, 39 (17). pp. 1683-1694. ISSN 0963-8288.

DOI

<https://doi.org/10.1080/09638288.2016.1211755>

Link to record in KAR

<http://kar.kent.ac.uk/56964/>

Document Version

Author's Accepted Manuscript

Copyright & reuse

Content in the Kent Academic Repository is made available for research purposes. Unless otherwise stated all content is protected by copyright and in the absence of an open licence (eg Creative Commons), permissions for further reuse of content should be sought from the publisher, author or other copyright holder.

Versions of research

The version in the Kent Academic Repository may differ from the final published version.

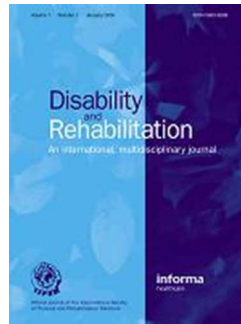
Users are advised to check <http://kar.kent.ac.uk> for the status of the paper. **Users should always cite the published version of record.**

Enquiries

For any further enquiries regarding the licence status of this document, please contact:

researchsupport@kent.ac.uk

If you believe this document infringes copyright then please contact the KAR admin team with the take-down information provided at <http://kar.kent.ac.uk/contact.html>



Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: a qualitative study

Journal:	<i>Disability and Rehabilitation</i>
Manuscript ID	TIDS-08-2015-009.R1
Manuscript Type:	Research Paper
Keywords:	traumatic brain injury, integrated care, community rehabilitation

SCHOLARONE™
Manuscripts

view

IMPLICATIONS FOR REHABILITATION

1. Traumatic Brain Injury (TBI) is a major cause of long-term disability. It can affect all areas of daily life and significantly reduce quality of life for both patient and carer.
2. Professionals appear to underestimate the change in abilities and impact on daily life once patients return home. Community services maintain a short-term focus whereas patients and carers want to look further ahead; this dissonance adds to anxiety.
3. The study's findings on service fragmentation indicate an urgent need for better integration within health services and across health, social care and voluntary sectors.
4. A link person/case manager who oversees the patient journey from admission onwards would help improve integrated care and ensure the patient, and carer, are at the centre of service provision.

1
2
3 **Experiences of patients with traumatic brain injury and their carers during transition from**
4
5 **in-patient rehabilitation to the community: a qualitative study**
6
7

8
9 **ABSTRACT**
10

11 **Purpose:** To explore the experiences of individuals who have had a severe TBI and their carers in the
12 first month post-discharge from in-patient rehabilitation into living in the community.
13
14

15 **Method:** Using a qualitative approach underpinned by critical realism we explored the narratives of
16 ten patients and nine carers using semi-structured interviews approximately one month post-
17 discharge. Thematic analysis was carried out independently by two researchers.
18
19

20 **Results:** Firstly, perceptions of support were mixed but many patients and carers felt unsupported in
21 the inpatient phase, during transitions between units and when preparing for discharge. Secondly,
22 they struggled to accept a new reality of changed abilities, loss of roles and loss of autonomy. Thirdly,
23 early experiences post-discharge exacerbated fears for the future.
24
25
26
27
28
29

30 **Conclusions:** Most patients and carers struggled to identify a cohesive plan that supported their
31 transition to living in the community. Access to services required much persistence on the part of
32 carers and tended to be short-term and therefore did not meet their long term needs. We propose the
33 need for a case manager to be involved at an early stage of their rehabilitation and act as a key point
34 for information and access to on-going rehabilitation and other support services.
35
36
37
38
39
40
41
42
43

44 **198 words**
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

INTRODUCTION

Traumatic Brain Injury (TBI) is a major cause of long-term disability. In 2013-14 there were 162,544 hospital admissions for TBI in the UK, a rate of 254 per 100,000 population [1], similar to a European aggregate of 262 per 100,000 [2]. While high quality prevalence data is scarce [3], secondary sources suggest there are 0.76m [4] to one million [5] adults living with a TBI in the UK. Severe TBI can result in profound long-term disability that affects all areas of daily life with significant repercussions on psychological adjustment, subjective well-being, quality of life, life satisfaction and community integration [6-8].

The transition from hospital to home is a relatively new area of research but an important phase where individuals and their families develop greater awareness of the injury's impact on daily life [9]. It is the point at which responsibility for care shifts from health care services to family caregivers [10]. It often involves a change in social roles and responsibilities for patient and carer [10] and from our own clinical experience appears to be a time when patients and carers feel particularly vulnerable and unsupported by statutory services. To facilitate transition healthcare professionals need to understand the patient, their family and their social context; identify ongoing health and rehabilitation needs; and access and implement required services [11]. This requires effective co-ordination to ensure all services are in place and both patient and carer have been involved in decision making as equal partners [12]. A well-managed transition has the potential to drive the adjustment process and the early stages of community reintegration [13]. However a recent qualitative review of the experience of discharge from hospital to home for patients with acquired brain injury (ABI) which included those with stroke, TBI and dementia found that carers reported a lack of involvement in the discharge process and insufficient communication about the patient's condition and care [11].

Levack et al's [6] comprehensive metasynthesis of qualitative research (1965-2009) identified 23 studies representing the views of 263 people with mild to severe TBI. All studies manifested 'a clear

1
2
3 expression of deeply felt loss associated with TBI' [6] and three themes were constructed to represent
4
5 this loss. The first, a disconnect with pre-injury self, represented a loss of connection with who one
6
7 had been pre-injury which related to memory loss, lack of independence and loss of valued roles. This
8
9 linked to the second theme, mind/body disconnect, which encapsulated impairments of body
10
11 structure and function and lack of control over certain functional abilities. The third theme, social
12
13 disconnect was most pertinent to those with severe injury who found their social world and
14
15 opportunities for new relationships had shrunk, in part due to stigmatisation. Associated with this
16
17 were the emotional sequelae including grief, regret, anxiety, powerlessness and low self-esteem [6].
18
19 However common outcome measures tend not to measure these concepts and focus instead on
20
21 functional outcomes [6]. Thus there is likely to be disconnection between what is measured as an
22
23 indication of successful rehabilitation, the identification of ongoing or unmet need, and the lived
24
25 experience of patient and carer [14].
26
27
28
29
30

31 From the carer's perspective much of the literature focuses on the burden of caring [15, 16] but few
32
33 studies focus on factors associated with a positive outcome [17]. For carers of those with TBI such
34
35 factors included good family functioning, good coping skills and good social support while negative
36
37 factors included the reverse with associated high levels of emotional distress [17]. However it is
38
39 unclear what interventions would support carers to maximise their coping skills in the transitional
40
41 period post-discharge.
42
43
44
45

46 Policies

47
48 The policy background includes the National Service Framework for Long-term Conditions [18], the
49
50 Darzi Report [19], the Health and Social Care Act [20] and the NHS Mandate [21]. All were drivers for
51
52 change in the care of those with long-term conditions and emphasised high quality and person-
53
54 centred care, listening to the patient voice, long-term support for patients and carers, and integrated
55
56 service provision. 'Patient experience' is listed as one of three mandatory targets used to measure
57
58
59

1
2
3 improvement in the Health and Social Care Act [20], is emphasized strongly in the NHS Mandate [21]
4
5 and was given the same emphasis as *safety* and *clinical effectiveness* in the Darzi report [19]. The
6
7 Royal College of Physicians report on rehabilitation medicine [22] was driven by these policy
8
9 aspirations and the care pathway for TBI, a model of best practice, emphasised long-term support,
10
11 community reintegration, a single point of contact, integrated care planning and multi-agency care
12
13 **(Figure 1).**
14
15
16
17

18 Many people do not have ongoing access to appropriate services and the patient pathway still
19
20 demonstrates significant weaknesses [23] despite the emphasis on integrated care. This approach
21
22 requires whole system working across organisational boundaries to 'improve patient care and
23
24 experience through improved co-ordination' [24]. There are different models, levels and intensities of
25
26 integration and no universal approach [25] but the key attributes include strong leadership with strong
27
28 shared values and goals across services; political and financial alignment between organisations;
29
30 shared information systems; and the patient and carer at the forefront and engaged in all aspects of
31
32 care [24].
33
34
35
36

37 ***[insert Figure 1 about here]***
38

39 Current Practice

40
41 The care pathway up to the discharge point from secondary care is well defined. However, over the
42
43 past decade there has been little progress in the provision of integrated care and individually tailored
44
45 long-term services for those with severe TBI in the community [26] despite the research focus on
46
47 community reintegration [27], continuity of care [28, 29] and integrated care [30, 31]. It is essential to
48
49 understand the experiences and perceptions of patients and carers during the transitional phase to
50
51 inform improvements to service delivery to meet their needs [10]. Although there is some relevant
52
53 literature [9, 10, 32-35] studies often conflate mild, moderate and severe TBI [6, 17, 35-37], use a
54
55 sample with mixed brain injury diagnoses [11, 17], adhere to quantitative measures [16, 36, 37] or do
56
57
58
59

1
2
3 not focus solely on the transition period [6, 15, 16, 36]. Thus there appears to be a gap in
4
5 understanding what is important and beneficial to patients with severe TBI, and their and carers, in
6
7 the context of UK healthcare in this transitional phase, and how best to meet these needs.
8
9

10 11 **Study Aims and Objectives**

12
13 Delineating the multitude of discharge destinations within the community, the range of services,
14
15 interventions and approaches, or lack thereof, formed the starting point in formulating a better
16
17 community service that ensures continuity of care for this vulnerable client group. We wanted to find
18
19 out:
20

- 21
22 1. What are the experiences of patients and their carers of the transition back home during the
23
24 first month post-discharge?
25
- 26
27 2. What gaps and/or difficulties did patients and carers encounter in service provision during this
28
29 period?
30
- 31
32 3. What did patients and carers find beneficial, and/or think would have been beneficial, in
33
34 terms of interventions and services, during this transitional phase?
35
36

37 **METHOD**

38
39 A qualitative approach was initially identified as best matched to the study aims and objectives. We
40
41 planned to explore the narratives of patients and their carers from their perspective and to create
42
43 meaning within the context of their unique experiences [38]. This accords with realism which
44
45 acknowledges that there can be different yet valid interpretations of a phenomenon based on a
46
47 particular perspective or outlook [39]. A distinctive feature is the belief that the world is independent
48
49 of our understanding of it and that 'all knowledge is partial, incomplete and fallible' [39]. Realism
50
51 accepts that knowledge is provisional and has an interpretative element but this does not equate with
52
53 an interpretivist acceptance of multiple realities [39]. Critical realism, which arose mainly from the
54
55 work of Bhaskar [40] and Sayer [41, 42] suggests 'that the world should not be conflated with our
56
57
58
59

1
2
3 experience of it' [41]. In other words, critical realism asserts that there is an independent reality 'out
4 there' but our knowledge of that reality is socially constructed. It proposes that social phenomena
5 exist in an open system where structures and mechanisms interact at different 'layers' of reality and
6 are in a constant state of flux [43].
7
8
9

10 11 12 13 **Target population and sampling**

14
15 The recruitment setting was a specialist 19-bed inpatient neurorehabilitation unit in a National Health
16 Service (NHS) teaching hospital in England which caters for patients with neurological conditions
17 including those with severe TBI. We wanted to focus on severe TBI because their (and their carer's)
18 needs are more complex than and differ to those with mild-moderate TBI and much of the literature
19 does not differentiate [17]. Thus our target population was adults aged 18 years and above admitted
20 to the unit with severe TBI as defined when initially assessed: Glasgow Coma Scale score of 8 or less at
21 time of injury; loss of consciousness for more than 24 hours; and post-traumatic amnesia of seven or
22 more days [44]. Those able to communicate and able to consent were invited to participate in the
23 study, with their carers. Carers were defined as relatives/friends who the patient regarded as their
24 main source of practical and/or emotional support; they either lived with the patient or visited
25 regularly. Patients were excluded if they had significant communication and/or cognitive impairment
26 such that they were unable to engage in conversation in a meaningful way or there were any concerns
27 about capacity to consent to interview. No one was excluded due to pre-existing conditions unless
28 they were also unable to communicate and/or consent.
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

48 Consecutive eligible patients were identified and recruited by the Consultant two weeks prior to their
49 expected discharge date. Recruitment continued until the sample size was reached. We estimated
50 that ten patients and their carers would be feasible in terms of the number of discharges within the
51 study period; that not all patients would have a partner or close relative who they would consider
52 their carer; and we were not aiming for theoretical saturation given the nature of this study. This
53
54
55
56
57
58
59

1
2
3 approach accords with qualitative research that aims to enable analytic, rather than statistical,
4
5 generalisation so that the findings can be generalised at a conceptual level higher than that of the
6
7 specific case [45]. Ten patients and nine carers were recruited between May to December 2013 and
8
9 interviewed between June 2013 and February 2014. During this period there were 111 discharges of
10
11 whom one-third were severe TBIs. As the Unit is the main centre for brain injury rehabilitation in this
12
13 geographical area the sample could be regarded as relatively representative of those who sustain a
14
15 severe TBI in this region. However we are not claiming the sample was statistically representative as
16
17 this is not relevant to qualitative research [38].
18

19 20 21 22 **Ethics and research governance**

23
24 Ethical approval was obtained from the London City and East NRES Committee and research
25
26 governance approval was obtained from the Hospital Trust. We considered the ethics of dyad versus
27
28 individual interviews. We anticipated that most participants would be married/inter-dependent
29
30 couples and it would be artificial to isolate patient from carer when the effects of brain injury,
31
32 acquired or traumatic, so clearly affect the carer and family [11, 36]. We followed the Ethics
33
34 Committee's recommendation of giving respondents the choice to be interviewed separately or
35
36 together and seven out of nine dyads opted for the latter.
37
38
39
40

41 42 **Consent**

43
44 Alongside discussion of the project the Consultant provided potential participants and carers with an
45
46 information sheet. Only those with capacity to consent were included; capacity was assessed by a
47
48 member of the multi-disciplinary team (MDT). Patients were given one week to ask questions and
49
50 decide whether or not to participate. Ten people invited to participate in the study agreed to take
51
52 part. An eleventh person agreed but moved out of area and was lost to follow up. Respondents were
53
54 then asked to consent to their contact details being given to the researcher (VA) to contact them post-
55
56 discharge. The researcher contacted participants two weeks post-discharge to arrange an interview
57
58
59
60

1
2 for approximately one month post-discharge. On the day of interview the researcher reviewed the
3
4 information sheet with participants prior to documenting consent.
5
6
7
8

9 **Data collection**

10
11 Interviews took place in the participant's own home although an alternative venue was offered. We
12
13 chose to interview approximately one month post-discharge based on clinical experience that this
14
15 transitional period is particularly difficult for patients and carers.
16
17

18
19
20 The topic guide (**Appendix 1**) was developed through a targeted review of the literature and in
21
22 consultation with patients and carers through a focus group with the local branch of Headway (eight
23
24 patients and four carers). Interviews were audio-recorded and transcribed verbatim by an
25
26 independent transcribing service. A field-guide was kept by the researcher to record observations and
27
28 ideas during and immediately after each interview and to capture the context of each interview [46].
29
30 Participants were asked for basic demographic information including marital status, living
31
32 arrangements and employment status pre- injury.
33
34
35
36

37 **Data analysis**

38
39 We chose thematic analysis because it is epistemologically neutral, compatible with a realist approach
40
41 and its flexibility allowed us to search within a data item and across the dataset 'to find repeated
42
43 patterns of meaning' using an iterative process [47]. The process was inductive, or data-driven,
44
45 because we were not trying to fit the data into a pre-existing framework [47]. However, we cannot be
46
47 entirely free of preconceptions which could influence our interpretation of the data. Therefore
48
49 analysis was carried out by two researchers (VA and JJ) in order to avoid researcher bias [48]. Each
50
51 phase was carried out separately before we compared ideas, re-visited the transcripts, and amended
52
53 after further discussion.
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

The initial phase involved familiarisation with the data by listening to the audio-recordings and repeatedly reading transcripts to appreciate the depth and breadth of material. Once familiar with all aspects of the data we each made handwritten notes on the transcripts to assist generating an initial list of ideas for coding. Phase 2 involved the production of initial codes from the data, a code being the most basic element of data. The intention was to identify interesting aspects that might form the basis of repeated patterns throughout the dataset [47]. One researcher (JJ) coded manually while the other researcher (VA) used Nvivo 10. We had a large number of codes which we organised into groups although many data extracts fitted into more than one code. Once in agreement, we updated the codes on Nvivo. At this stage all codes were retained and inconsistencies in the data were documented. Phase 3 involved organising codes into broader potential themes. Data extracts were moved under the appropriate theme and data that did not appear to 'fit' was kept under a 'miscellaneous' category [47]. Again, one researcher (JJ) did this by hand while the other researcher used Nvivo. We used visual representations to categorise codes into themes and discussed until we reached consensus and then amended on Nvivo. Phase 4 involved refining the themes and reviewing material that we had filed under 'miscellaneous'. The first stage involved looking through coded data extracts under each theme and deciding whether or not they fitted with the theme and if they formed a coherent pattern. The second stage involved considering whether the themes accurately reflected the dataset overall. We again did this independently before reaching consensus and amending on Nvivo. In phase 5 themes were named, defined and summarised. Each theme needed to have clear parameters and tell a 'story' as well as fitting into the broader narrative of the entire data. By this stage we were able to see how themes reflected individual experiences and the dataset as a whole. Phase 6 involved writing up our findings to reflect our interpretation of the data [47].

RESULTS

Ten patients and nine carers were interviewed (Table 1). Three patients chose separate interviews, six chose joint interviews and one patient on his own. All were interviewed at home. Five respondents

1
2 had been working prior to their TBI and the others were retired. Their ages ranged from 48-89 years
3
4 (mean 63 years; STD 14 years). Seven respondents owned their own home, two rented privately and
5
6 one lived in social housing. Carers were a mix of spouse (4), partner (2), son (1) and close friend (2).
7
8 Respondents lived in a mix of urban or semi-rural areas.
9

10
11
12
13 **[insert Table 1 about here]**
14
15
16
17

18 Three themes were identified in relation to the research question: perceptions of support; struggling
19
20 to accept a new reality; and fear for the future. Within each theme sub-themes were identified and
21
22 these are presented separately. **Table 2** provides a summary.
23
24

25
26 **[insert Table 2 about here]**
27
28

29 **Theme 1: Perceptions of support**

30 Inpatient experiences resonated with all patients and carers. The perception of not being sufficiently
31
32 supported, or supported at all, permeated all interviews and was most pronounced in the early stages
33
34 of acute inpatient treatment and transfer to other units either within the same hospital or between
35
36 organisations. Although acute medical treatment was not in itself criticised, and often highly praised,
37
38 there were instances where patients and carers felt uninformed of their condition and treatment. In
39
40 addition there were criticisms of clinicians' understanding, level of compassion and experience. This
41
42 theme is sub-divided into *inpatient experiences*, *transitions between units* and *preparation for*
43
44 *discharge*.
45
46
47
48
49

50 ***Inpatient experiences***

51
52 Although patients were interviewed one month post-discharge most had spent many months in
53
54 hospital. The shock of the initial injury and hospital admission was uppermost in patient and carers'
55
56
57
58
59

1
2 thoughts when interviewed even after this time. While their loved one was receiving emergency care
3
4 they had to deal with all practical arrangements and cope with the shock often without support:
5

6 I've never cried so much in my...because I just had nobody to turn to (Carer 1, C1)
7

8 Carer 2 graphically described the police knocking on her door, rushing to a London hospital, being told
9 her husband was unlikely to survive, barely recognising him due to the severity of his injuries and
10
11 feeling totally unsupported:
12
13

14 Nobody made me a cup of tea. Nobody asked how the family was coping, how we was. Most of the
15
16 time, people didn't even inform me of the procedures [husband] was having. There was just that
17
18 missing link everywhere (C2)
19
20

21 This was compounded by commuting between London and home, looking after their children, the
22
23 immediate collapse of her husband's business and no one local having been informed.
24
25

26 My world had fallen apart but there was no communication with down here to alert anyone... I rung so
27
28 many people in that first month and nobody wanted to know because there was nothing official (C2)
29
30

31 Other carers also assumed that their loved one's GP would be informed and therefore able to offer
32
33 advice and support but this was not the case. All carers wanted support from staff to help make sense
34
35 of the trauma, manage their emotional response and support their loved one alongside dealing with
36
37 other demands including long journeys to hospital, family commitments, financial and legal pressures.
38
39 Instead carers felt they had to battle for information from staff who did not communicate with them,
40
41 each other, or other departments/specialities. This translated into carers feeling compelled to
42
43 advocate, at times forcefully, for their loved ones. Patients also describe their frustration at not
44
45 getting answers from staff:
46
47

48 You'd ask someone one thing and you might not see them again. And they wouldn't tell me anything
49
50 that was going on. They wouldn't answer my questions, you know? (Patient 5, P5)
51
52

53 They couldn't actually decide which team was overall going to be responsible for him...All the
54
55 specialisms are there... [but] there's not like that single point of contact (C6)
56
57
58
59
60

1
2
3 Thus negative experiences were focused around poor communication and a perceived lack of
4
5 compassion from individual staff and this tended to outweigh positive experiences:
6

7 The surgeon was amazing. The physios were unbelievably young, with no life experience, and rude, and
8
9 lacked any compassion (C2)
10

11 There was no communication. No. From day one ... I was told nothing (P3)
12

13
14 Lack of rehabilitation while waiting to be transferred to a neuro-unit soured the inpatient phase even
15
16 when acute medical care had been excellent. Respondents appreciated that they were placed on, for
17
18 example, an elderly care ward due to bed shortages but still felt aggrieved:
19

20
21 It seemed like 50% of people there were ill and the other 50% of people were waiting to die (P10)
22

23
24 There's no activities. You either sit in your bed or sit in a chair (P3)
25

26
27 I really just laid in bed or sorted myself out (P8)
28

29 Despite previous complaints there were many positive comments related to the personal qualities of
30
31 staff (compassion, patience, positive attitude) and effective team work (good communication, co-
32
33 ordination, planning and provision of information):
34

35
36 All the staff from [names of three hospitals] have all been brilliant (P4)
37

38
39 He was very, very confused and every nurse they tried to help him and they've done a very brilliant job
40
41 (C3)
42

43
44 I think the main positive is hope. Someone gives you vision, like the ... nursing staff (P7)
45
46

47 ***Transitions between units***

48
49 Several people raised concerns about transfers between units, mainly from London back home and
50
51 concerns were similar to those raised about inpatient care. Issues identified included poor
52
53 communication, insufficient planning and/or chaotic transfers with little or no warning and lack of
54
55 timely information. Long delays in transport and having to wait with no update on the delay
56
57 exacerbated distress:
58

1
2
3 It was just like, is he coming? Is he going? There's a bed. No, you can't go after half-past seven at night
4 because there's not enough doctors on the ward... .. Now we've filled the bed. Now you're back on the
5
6 waiting list again (C6)
7

8
9 Again, the need to advocate for their loved one was a common theme, with carers resorting to, for
10 example, telephoning their MP, contacting the hospital's Chief Executive and employing private
11 services. In one case the carer tried to negotiate with staff that her husband was not well enough to
12 be discharged straight home but was overruled resulting in admission to a local hospital the
13 following day:
14
15
16
17
18

19
20 He came home at 8 o'clock by ambulance and it was just the worst night of our life. He couldn't
21 breathe... He was in pain. He was distraught....He'd got pleurisy. He'd got two infected drain sites. His
22 leg had got cellulitis in it and an infection. He needed a hospital bed ... he was already getting a pressure
23 sore on the base of his spine... There was just nothing in place. They literally just threw him out one
24 night and that was it. There was no care or compassion (C2)
25
26
27
28
29

30
31 In two cases in tertiary hospitals the specialism had been focussed on other injuries and the actual
32 head injury was overlooked:
33

34
35 And the staff nurse said ... "when you get him home, if you're not happy, just refer him to the mental
36 health unit" (C2)
37
38

39
40 The thing that annoyed me the most ... because it was a general orthopaedic ward, they didn't
41 understand the head injury... And they were constantly saying to [Patient], you need to go home; you
42 shouldn't be here (C8)
43
44
45

46
47 Patients also reported feeling aggrieved that issues that were important to them were considered
48 minor by staff and not addressed to their satisfaction:
49

50
51 Please bear in mind that I had an awful lot of time on my hands so little worries became big worries in
52 that environment (P5)
53
54
55
56
57
58
59
60

1
2
3 This patient was transferred without his wallet, mobile telephone or house keys and it took
4
5 considerable time and effort for them to be forwarded. However he needed to buy food because that
6
7 provided in the hospital did not meet his special dietary requirements.
8
9

10 11 ***Preparation for discharge*** 12

13 Respondents felt the final discharge home was relatively smooth but once home there were problems
14
15 that had not been anticipated. Some were surprised at how difficult it was to adjust to being home
16
17 once the initial joy had dulled. Pre discharge home visits/leave were valued and discussed yet even so
18
19 the actual experience or implications did not appear to have been sufficiently explored nor issues
20
21 addressed:
22
23

24
25 Nobody prepared me for home...Nobody said, "Well, what are you going to do when you get there? ...I just
26
27 needed a bit more guidance on how it was going to be (P1)
28

29 You just sort of assume it's going to be like being at home (P6)
30

31 I didn't really think about it [coming home]... .. you just want to be normal again but... (P4)
32
33

34 I thought it was going to be a lot easier...I thought I was back to normal, yes. And I was nowhere near (P8)
35
36
37

38 The carer's perspective was slightly different but still had an element of surprise that things were not
39
40 as anticipated:
41
42

43 I probably had a different set of concerns than [husband] did for coming home just because maybe of
44
45 my role... just being back together after such a long time, because it is very different, isn't it? And ... in a
46
47 hospital environment ... there's lots and lots of support, and there's somebody to ask whatever
48
49 question you've got. And when you're at home, the onus... was on *me* to be able to either answer
50
51 [husband's] questions or have an answer for both of us (C6)
52

53 He had a couple of weekend visits, but that still wasn't somehow really enough to prepare us (C1)
54
55
56
57
58
59

1
2
3 Although most discharges home went smoothly there were instances where respondents reported
4 that staff did not adequately consult them, preparations were disorganised and information was
5 limited. Again, carers felt they had to advocate for their loved one:
6
7

8
9
10 They weren't talking to each other. It just got very confusing and, in the end, I got myself into such a
11 state... ... Nobody had said to me, how do you feel about him coming home? Are you happy for him to
12 come home? (C8)
13

14
15 Every day...they call me they are so unorganised (C3)
16

17
18 I'm quite happy to badger the system until I get something sorted.... It just annoys me that I have to do
19 that ... because I don't think we should have to, because I think things should be in place (C8)
20
21

22
23 Alongside this respondents raised concerns about unidentified and/or unmet need which included
24 visual problems, continence, dietary restrictions, pain management, changes in medication, pre-
25 existing conditions (e.g. psoriasis) or concurrent injuries (e.g. shoulder dislocation) and outpatient
26 appointments. Those awaiting cranioplasty were particularly anxious about how, when and where this
27 would take place.
28
29
30
31
32

33
34
35
36 There may of course have been reasons for the above but it appeared to link with lack of timely
37 information in a format respondents found helpful to assist understanding of the injury, rehabilitation
38 and long term prognosis:
39
40
41

42
43 It's not in black and white. If it's in black and white, even though the injured one may not be able to
44 understand it, but at least they have got a perception of what's wrong with them. And if that's the case
45 then they can – like now, in my case – I can now adjust to what I know, whereas before I didn't know
46 anything so I couldn't adjust myself to it (P9)
47
48
49
50

51 52 53 **Theme 2: Struggling to accept a new reality**

54
55 This theme is divided into three sub-themes which comprise *change in abilities, loss of valued roles*
56 and *autonomy and control*. It encompasses the realisation for both parties that life post-injury is likely
57
58
59

1
2
3 to be very different to pre-injury. Whilst in hospital patients felt protected from the outside world and
4
5 able to share experiences:

6
7 You're with these people who've all got something wrong with them, you know, something similar. And
8
9 then you get back here at home and outside and you're just... the one (P4)

10
11
12 But once home the long term implications of their injury started to manifest in a manner they had not
13
14 anticipated:

15
16 I didn't have any worries about coming home. I thought I would be living at home as I lived before I
17
18 went. And it hasn't proved quite like that... (P1)

19
20
21 When you get home... it hits you a bit more... the seriousness of it all (P4)

22
23 This dissonance between pre- and post-injury was exacerbated by lack of support (Theme 1) and/or
24
25 delay in services once home (Theme 3). Respondents stated that they felt 'in limbo' and were trying to
26
27 support each other as best they could. Some tried to establish a routine and build on their inpatient
28
29 therapy but most struggled to do so.
30
31

32 33 34 ***Change in abilities***

35
36 As would be expected, all areas of function were affected and impairments included physical aspects
37
38 such as balance, co-ordination and general mobility; all areas of cognition, particularly memory and
39
40 higher level executive skills; visual and visual-perceptual impairment; and emotional sequelae which
41
42 stemmed from physical restrictions, extreme fatigue and beginning to comprehend the full impact of
43
44 their injury. This manifested in mood swings, anger, frustration and anxiety of which the carer was
45
46 most often the recipient. The emotional impact on both parties was tangible, alongside the difficulty
47
48 adjusting:
49
50

51
52 What I find more frustrating than anything, is, at this present moment in time, I cannot do what I want
53
54 to do and what I used to be able to do (P6)

1
2
3 Fatigue was more profound than anticipated and made it important to plan each day. Activity
4
5 tolerance was limited and this made it difficult to establish a daily routine:
6

7 We have to plan now... for everything we want to accomplish in a day (C6)
8

9 I'm sure if I could just get over this sleep thing. It wears you down, you know? ... last night...I think I
10
11 went to sleep about half-nine and I got up at quarter to nine, and I'm still tired (P4)
12
13

14 Managing routine daily tasks left little energy to engage in activities that respondents had previously
15
16 enjoyed, either independently or with their partner such as socialising, cycling, gardening, voluntary
17
18 work and dog walking.
19

20
21
22 Interestingly patients who chose joint interviews were particularly insightful about the effect of their
23
24 injury on their functional abilities, daily structure and relationship. Those who chose separate
25
26 interviews were slightly less insightful concerning the impact of their injury on their partner, who
27
28 especially noted changes in behaviour and/or temperament:
29
30

31 He gets mentally exhausted and tired. Very, very forgetful. He'll say things that you and I ... you'd never
32
33 dream of saying it. But he'll say it (C2)
34
35
36
37
38

39 ***Loss of valued roles***

40 The combination of change in abilities, profound fatigue and difficulty establishing a daily routine
41
42 translated into loss of valued roles particularly that of husband, parent and 'breadwinner' and made
43
44 life at times intolerable:
45
46

47 I actually took an overdose...because I didn't think that it was worth going on...because everything that
48
49 I wanted was taken away: my work, my driving, my...normality, if you like (P9)
50
51

52 Alongside this, carers found themselves struggling to look after their partner and subsume additional
53
54 tasks including running the house, managing finances, in some case continuing to work and
55
56 maintaining contact with family and friends who did not always appreciate the difficulties:
57
58
59

1
2 What I hadn't realised was quite how much attention [husband] needs... he needs supervision all the
3
4 time (C1)
5

6
7 I'm the only capable, coping adult in the house now... he isn't there, not as a husband, a friend, a lover,
8
9 a dad... (C2)
10

11 Patients who were employed wanted to return to work as soon as possible. Work was a large part of
12
13 their identity and anxiety about loss of this role was exacerbated by financial pressures including
14
15 repossession of their house and maintaining their business.
16
17

18 19 20 **Autonomy and control**

21
22 The profound change in abilities and loss of valued roles translated into an underlying tension
23
24 between patient and carer with both expressing frustration, even those who worked closely as a team.
25

26 The patient expressed frustration with their reduced freedom and their partner missed being able to
27
28 do other activities and have time apart. At times patients felt over-protected, disempowered and not
29
30 listened to:
31

32
33 People try to be a bit over helpful...Just leave me alone! Give me some space. ... I think they're trying to
34
35 be overprotective' (P3)
36

37
38 I was just someone who had to rely on everybody else (P9)
39

40 This was also reflected in comments about professionals. Some patients tried to take control of their
41
42 rehabilitation but did not feel supported in their drive for independence:
43

44
45 the physio will say things to you and it's very difficult when... someone tries to tell you something what
46
47 you know more about yourself.... she [OT] was talking to me like I was a bit of an idiot (P2)
48

49 I think there is an element of probably success in recovery at home in what skills you bring to the table
50
51 yourself (P6)
52

53 Carers were clearly aware of the need to promote their partner's independence and how hard it was
54
55 for their loved one to adapt to loss of status and control. However carers felt over whelmed by
56
57 additional demands and having no time to themselves:
58
59

1
2 He was very...very clear about saying that he felt like he wasn't doing the things he should be
3
4 doing...Yes, he's very aware of this...and I think he does feel...guilty about it (C1)

5
6
7 [the sitter] just gives me that little bit of respite ... to me, that is important that I've got to get out and
8
9 do what I need to do (C8)

10 11 12 13 **Theme 3: Fear and anxiety for the future**

14
15 This theme developed from the preceding themes. Respondents were looking towards the future with
16
17 increasing fear and anxiety exacerbated by lack of, or delay in, services commencing post-discharge.
18
19 Respondents were struggling to adjust to changed abilities and roles whilst trying to support each
20
21 other as best they could. However there was a strong need to reach towards a 'better' future but
22
23 knowing how to ameliorate the gap between now and where they wanted to be was intangible. This
24
25 theme is divided *post-discharge experiences* and *moving forward*.
26
27
28
29
30

31 ***Post-discharge experiences***

32
33 The main source of consternation was delays in services commencing, no update on when they would
34
35 commence and no point of contact. Some carers resorted to private services while others advocated
36
37 forcefully:
38
39

40 Four weeks after discharge and we haven't heard a dicky bird (C1)

41
42 If you are articulate and competent, you can access the services....some of our success is the fact that
43
44 we ... probably get that information and are resilient enough (C6)

45
46 Basically, he's been left to sit here and rot. Now if we weren't involved – because he has no family and
47
48 no next of kin... .. nothing would be happening... (C10)

49
50
51 Once people did finally receive intermediate care (or similar) the duration and appropriateness was
52
53 questioned; respondents appreciated that services were stretched but wanted more rehabilitation
54
55 than provided.
56
57
58
59

1
2
3 Some carers needed but felt unable to ask for emotional or practical support for themselves while
4
5 others simply wanted signposting. Some expected their GP to take on this role but commented that
6
7 their GP often appeared ill-informed and unable to co-ordinate or identify follow up services:
8

9
10 I just think it's that one missing link because the intermediate care team try so, so hard. But even
11
12 they're pushed with the resources that were available... .. if there was just one person that was
13
14 dedicated to that family... .. who could co-ordinate everything (C2)

15
16 Somebody that could just say: this is who you need to speak to. I don't necessarily want someone to
17
18 actually do it for me ... but to have someone to put me on the right track (C6)

19
20 Finally, respondents talked about the difficulties managing friends and families reactions to their
21
22 changed circumstances. In some cases this was an additional stressor while for others a source of
23
24 support:
25

26
27 I think the biggest thing that I've found is trying to manage other people's emotions and other people's
28
29 expectations (C6)

30
31 So he didn't die but a massive part of him died, and I think that's the bit people don't see (C2)

32 33 34 35 36 ***Moving forward***

37
38 Closely linked with post-discharge experiences and on-going rehabilitation was patients' focus on long-
39
40 term goals. Most were receiving input from the intermediate care team (ICT) which is designed for
41
42 relatively short-term rehabilitation depending on local criteria [49]. Therapists appeared to focus on
43
44 short-term goals while patients wanted to look further ahead and challenge themselves:
45

46
47 Sometimes the physio says, "Oh, don't do this." The only person who really, really knows how you feel
48
49 is yourself. And because I've tutor supported myself, I don't think I would really, really push... Yeah, I do
50
51 push and I've always worked really hard...but I haven't gone really over the top. (P2)

52
53
54 The focus was on regaining a 'normal' life, including return to work and driving, but the gap between
55
56 now and where they wanted to be stretched ahead:
57

1
2
3 I want to get back to where I was... (P10)
4

5 I got upset yesterday when we came out of Tesco's. It just overwhelmed me... .. And I phoned my sister,
6
7 and she said it's just a wobble. I'm not having many wobbles but it was just the thought: is this me for
8
9 ever now? (P4)
10

11 I recognise possibly that I'm still recovering... But I can't go on like it forever... .. I'd like to get back to,
12
13 hopefully, work where it's actually using my mind a bit (P5)
14
15

16 Equally, carers were keen to look forward to a time where the injury was less in the foreground of
17
18 daily life and they could resume 'normal' life:
19

20 But, look, we can go on about the past forever, and what we talked about – there is no past. All there is
21
22 is every day and cracking on (C10)
23
24
25

26 **DISCUSSION**

27
28 It is widely argued that the provision of effective and efficient services depends crucially on feedback
29
30 from those who use them [50]. This study captures the perspectives of patients with severe TBI and
31
32 their carers, and addresses a gap in the literature on their experiences during the transition home and
33
34 first month post-discharge specific to our health and social care setting. In particular we wanted to
35
36 map patient and carer experiences, the difficulties they experienced and what they found beneficial
37
38 during this transitional phase in order to inform local service development.
39
40
41
42
43

44 **Experiences during the transition home and first month post-discharge**

45
46 Our first aim was to explore the experiences of patients and carers during the transition home from
47
48 hospital and first month post-discharge. All patients had complex needs that required a holistic
49
50 approach to rehabilitation [22] but respondents' care appeared to be carved across specialisms with
51
52 inconsistent and at times inadequate identification of needs. No one talked about goal setting or
53
54 making a therapy plan either pre- or post-discharge although this is a cornerstone of rehabilitation
55
56 [18]. We had anticipated that this period would be an area of concern but had not foreseen that the
57
58
59
60

1
2
3 shock of initial injury and early inpatient experiences would so dominate patients' and carers'
4 thoughts even when interviewed several months later. Many respondents expressed dissatisfaction
5 with the discharge process and delays before intermediate care or other services commenced. This
6 appeared to be exacerbated by poor communication between clinicians and patients/carers plus lack
7 of co-ordination between services. Such experiences are not uncommon [11] but are inconsistent with
8 recent guidelines that stipulate both patient and carer should be involved in decision making at all
9 stages and that care should be co-ordinated within and between services [12]. Such experiences
10 appeared to have coloured respondents' experiences and increased their anxiety. More positively,
11 patients and carers functioned together to manage ongoing impairment and work towards long-term
12 goals but they appeared isolated and wanted reassurance that they were managing their
13 rehabilitation correctly. Mostly family and friends were regarded as a source of support which accords
14 with existing literature [6, 17] but some respondents reported lack of understanding and family
15 conflict as an extra source of anxiety to manage post-discharge.
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32

33 **Difficulties with service delivery**

34
35 Our second objective was to identify what gaps and/or difficulties patients and carers encountered in
36 service provision during this period. As above, most apparent were difficulties with transfers between
37 units, discharge home and gaps in service provision. Patients reported services which had been
38 promised did not materialise or that there were long delays with no communication. Some carers did
39 not know who to contact while others spent considerable time identifying a contact and chasing them.
40
41 Respondents appeared unclear what the role of ICTs were and some reported limited therapy input
42 due to staff shortages. Alongside this study the neurorehabilitation unit was piloting an intervention to
43 increase service efficiency and reduce length of stay whereby some patients were transferred to a
44 private provider for further rehabilitation before discharge (**Figure 1**). However we did not find
45 evidence that using the Independent Sector in this way added value to the patient journey or
46 circumvented problems once home.
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5 Respondents indirectly alluded to the need for integrated care. Instead they experienced problems
6
7 with vertical integration, or integration at each stage of care within the care pathway [24] which
8
9 appeared to have a detrimental effect on adjustment in the first month home. Many wanted to know
10
11 who to contact for specific concerns that they did not consider within their general practitioner's (GP)
12
13 remit or that the GP had been unable to answer and they did not know who else to ask, for example
14
15 when they would return to work and driving. Thus inpatient, community and specialist services
16
17 appeared fragmented but perhaps this is unsurprising given that services sit under different structures
18
19 and organisations. Supported discharge and integrated care planning are essential for patients with
20
21 such complex needs [22] but our respondents experienced 'that missing link everywhere' (C2) which
22
23 increased their anxiety and fear for the future.
24
25

26
27
28 Nalder et al's [10] interviews with carers, nine months post-discharge, identified key issues as the
29
30 weight of caring, lifestyle changes, feeling unprepared for discharge and coping with the initial shock
31
32 while services failed to acknowledge their needs. We found similar issues with carers becoming
33
34 exhausted, frustrated and at times overwhelmed. Although many had received excellent support from
35
36 inpatient neuropsychology services there was a key gap on discharge.
37
38

39
40
41 Respondents commented on perceived gaps in information prior to discharge which echoes previous
42
43 research highlighting a dissonance between the extensive education and information that
44
45 professionals reported providing and the paucity of information that patients and carers reported
46
47 receiving [51]. This disparity appeared to relate to patient and carer's emotional state pre-discharge,
48
49 the amount and consistency of information, when it was provided and its relevance [51].
50
51

52
53
54 **What did patients and carers value about service delivery?**
55
56
57
58
59

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Thirdly, we wanted to find out what patients and carers found beneficial in terms of interventions and services and what they would have liked or could suggest to assist service development. Respondents valued the kindness and compassion of individual staff and were extremely appreciative of acute and specialised medical intervention. It was less clear what they valued during the transition and first month home which possibly reflects the state of uncertainty they were experiencing and that they had never been in such a situation. Patients and carers particularly valued neuropsychology support but this often stopped post-discharge. They wanted more emotional support particularly from the neuropsychologist they had seen in hospital whom they trusted and felt listened to them. The need for emotional support post-discharge is unsurprising and although our carers wanted reassurance this was not related to having 'strong negative feelings' about their loved one [16]. What was notable with our respondents was their dedication to working together to tackle the sequelae of their injury particularly those who opted for joint interviews where both respondents appeared confident to express themselves even when this involved disagreement.

Sherer et al [37] conceptualises the patient experience in terms of prognostic factors for TBI outcomes and categorises these according to those which are helpful and amenable to change, or at least management, and those which are not. The former include cognitive functioning, self-reported symptoms such as fatigue and environmental factors including access to service provision. These were all issues that respondents identified as unmet needs. For example, several couples discussed the difficulty of re-establishing a daily routine due to fatigue but did not know how to negotiate this or which service could assist. Such help falls within the remit of ICTs which employ a range of therapists but the service is generic, time limited and did not appear to meet the complex and ongoing needs of this group.

Our respondents also wanted to focus on return to work or activities of similar value but commented that services had a very short-term focus that did not support such aspirations. Nalder et al [9]

1
2
3 identified key events relevant to the transition phase and found a positive perception of the transition
4
5 was associated with return to work, independent use of transport and accommodation change. A
6
7 negative perception was associated with financial strain and problems accessing services. That the
8
9 timing of such events was extremely varied within the first six months post-discharge is not surprising
10
11 given the nature of TBI but highlights the importance of flexible and responsive services tailored to
12
13 individual need [9].
14
15

16 17 18 **Study Limitations**

19
20 The study sample was small and although relatively representative of the geographical area it was not
21
22 fully representative of the UK population with TBI in terms of age and ethnicity. This limitation is
23
24 common to qualitative research and reflects its focus on respondents' narratives rather than statistical
25
26 outcomes. In addition, we did not have funding for interpreters and could not include those with
27
28 severe aphasia. We chose to include only those with severe TBI and the experience of those with mild-
29
30 moderate injuries may be different. The follow-up period was intentionally short, in accordance with
31
32 the study aims. Consequently the findings are a 'snapshot' of respondent experiences at a particular
33
34 point in time.
35
36

37
38
39 The analysis was conducted by two researchers, both occupational therapists with experience of TBI. It
40
41 could be argued that our professional perspective might have influenced analysis but efforts were
42
43 made to avoid bias including use of a field log, independent analysis, comparison of coding and
44
45 adherence to Braun & Clarke's [47] guidelines. Some respondents had compensation claims pending
46
47 but we did not set out to compare those who did versus those who did not. However it became
48
49 apparent that this was relevant in terms of access to follow-up services and addressing financial
50
51 difficulties and it may have been useful to differentiate. Similarly, data analysis could be criticised for
52
53 insufficient attention to the interaction between patient and carer in joint interviews, and insufficient
54
55
56
57
58
59
60

1
2
3 separation of patient versus carer data, however the approach taken was in-line with the purpose of
4
5 the study and how the findings can be translated into practice.
6
7

8
9 Finally, the findings need to be considered within the context of health and social care provision in our
10
11 setting because services vary considerably across the UK. This was part of the rationale – to identify
12
13 problems specific to the area and ways of ameliorating them, with the long-term aim of developing a
14
15 care pathway that supports equity across the UK.
16
17

18 19 20 **Conclusions and recommendations**

21
22 Our study has filled a gap in knowledge surrounding the experience of patients who have had a severe
23
24 TBI and their carers in the first-month post-discharge in our health care setting. Best practice
25
26 recommends that there is a single point of contact, joint health and social service planning, multi-
27
28 agency care and long-term support [22] but respondents did not experience this. The first month
29
30 home was an emotionally loaded time where experiences as an inpatient, during transitions and
31
32 discharge home resonated strongly. Clinicians, patients and carers appeared to underestimate the
33
34 change in abilities and impact on daily life once home. Both patients and carers struggled to adapt to
35
36 new roles and responsibilities and were grieving for what had been lost. This was emotionally
37
38 demanding and required more support than was available. In addition community based NHS services
39
40 focused on short-term goals whereas patients had aspirations for the future which were not
41
42 sufficiently acknowledged. This dissonance added to anxiety and fear of what the future holds for
43
44 them. Lessons that emerged include:
45
46

- 47
48 • The value of making explicit the lessons of home leave and exploring their implications with
49
50 patient and carer before and in preparation for discharge.
- 51
52 • All patients should have a comprehensive needs assessment and goal setting as part of discharge
53
54 planning and this should take into account their carer's needs.
55
56
57
58
59

- The importance of a focus on the patient's long-term goals from the beginning and especially in the immediate post-discharge phase. Patients were particularly concerned about return to work and driving.
- A case manager or link worker as a first and ongoing point of contact would be ideally placed to facilitate integrated care and ensure patient and carer are at the forefront of decisions from inpatient admission onwards.
- Long term emotional/psychological support is essential for patient and carer. It is important to recognise that needs differ at different stages of the recovery process.

Case management models have existed for some time in the independent sector and there are other models [22]. Although a recent systematic review of services for people with ABI found insufficient evidence to draw conclusions regarding case management for people with TBI [52] a case manager should enable 'well-planned and timely transfer between services to ensure optimal use of limited resources', oversee the patient journey from admission onwards and support and advocate for patient and carer [22]. Future research needs to ascertain what model of case management is best suited to this client group; what local contextual issues affect process and outcomes; and what is best practice in terms promoting integrated care and providing a cost-effective service.

8169 words

Acknowledgements: [REDACTED]

Declaration of interest: The authors report no declaration of interest.

REC Ref 13/LO/0117

R&D Ref 105284

References

- 1
2
3 [1] Acquired brain injury. The numbers behind the hidden disability [Internet]; c2015. Available from:
4 <https://www.headway.org.uk/statistics-resources.aspx>.
5
6 [2] Peeters W, van den Brande R, Polinder S, Brazinova A, Steyerberg EW, Lingsma HF, Maas AI.
7 Epidemiology of traumatic brain injury in europe. *Acta Neurochir* 2015;157(10):1683-96.
8
9 [3] Roozenbeek B, Maas AI, Menon DK. Changing patterns in the epidemiology of traumatic brain
10 injury. *Nature Reviews Neurology* 2013;9(4):231-6.
11
12 [4] Tennant A. Epidemiology of traumatic brain injury. project number 030/ 0067. Leeds: University of
13 Leeds; 2005.
14
15 [5] Counting the cost of the rehabilitation postcode lottery for road crash victims [Internet]; c2013
16 [cited 2015 5/22/2015]. Available from: [http://www.irwinmitchell.com/personal/personal-injury-](http://www.irwinmitchell.com/personal/personal-injury-compensation/rehabilitation/postcode-lottery-of-rehabilitation)
17 [compensation/rehabilitation/postcode-lottery-of-rehabilitation](http://www.irwinmitchell.com/personal/personal-injury-compensation/rehabilitation/postcode-lottery-of-rehabilitation).
18
19 [6] Levack WM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain
20 injury: A metasynthesis of qualitative research. *Disability & Rehabilitation* 2010;32(12):986-99.
21
22 [7] Schönberger M, Ponsford J, McKay A, Wong D, Spitz G, Harrington H, Mealings M. Development
23 and predictors of psychological adjustment during the course of community-based rehabilitation
24 of traumatic brain injury: A preliminary study. *Neuropsychological Rehabilitation* 2014;24(2):202-
25 19.
26
27 [8] Williams MW, Rapport LJ, Millis SR, Hanks RA. Psychosocial outcomes after traumatic brain injury:
28 Life satisfaction, community integration, and distress. *Rehabilitation Psychology* 2014;59(3):298.
29
30 [9] Nalder E, Fleming J, Cornwell P, Foster M, Haines T. Factors associated with the occurrence of
31 sentinel events during transition from hospital to home for individuals with traumatic brain
32 injury. *J Rehabil Med* 2012;44(10):837-44.
33
34 [10] Nalder E, Fleming J, Cornwell P, Foster M. Linked lives: The experiences of family caregivers during
35 the transition from hospital to home following traumatic brain injury. *Brain Impairment*
36 2012;13(01):108-22.
37
38 [11] Piccenna L, Lannin NA, Gruen R, Pattuwage L, Bragge P. The experience of discharge for patients
39 with an acquired brain injury from the inpatient to the community setting: A qualitative review.
40 *Brain Injury* 2016:1-11.
41
42 [12] Transition between inpatient hospital settings and community or care home settings for adults
43 with social care needs (NG27) [Internet]; c2015. Available from:
44 <http://nice.org.uk/guidance/ng27>.
45
46 [13] Turner BJ, Fleming J, Ownsworth T, Cornwell P. Perceived service and support needs during
47 transition from hospital to home following acquired brain injury. *Disabil Rehabil* 2011 05/01;
48 2015/06;33(10):818-29.
49
50 [14] Gray J, Lie ML, Murtagh MJ, Ford GA, McMeekin P, Thomson RG. Health state descriptions to elicit
51 stroke values: Do they reflect patient experience of stroke? *BMC Health Services Research*
52 2014;14(1):573.
53
54
55
56
57
58
59
60

- 1
2
3 [15] Carlozzi NE, Kratz AL, Sander AM, Chiaravalloti ND, Brickell TA, Lange RT, Hahn EA, Austin A, Miner
4 JA, Tulskey DS. Health-related quality of life in caregivers of individuals with traumatic brain injury:
5 Development of a conceptual model. Arch Phys Med Rehabil 2015;96(1):105-13.
6
- 7 [16] Tverdov AH, S. McClure K, Brownsberger MG, Armstrong SL. Family needs at a post-acute
8 rehabilitation setting and suggestions for supports. Brain Injury 2016:1-10.
9
- 10 [17] Baker A, Barker S, Sampson A, Martin C. Caregiver outcomes and interventions: A systematic
11 scoping review of the traumatic brain injury and spinal cord injury literature. Clinical
12 Rehabilitation 2016 March 23.
13
- 14 [18] National service framework: long term conditions [Internet]; c2005 [cited 2014 11/26/2014].
15 Available from: [https://www.gov.uk/government/publications/quality-standards-for-supporting-
16 people-with-long-term-conditions](https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions).
17
- 18 [19] [ARCHIVED CONTENT] High quality care for all: NHS Next Stage Review final report [Internet];
19 c2008 [cited 2015 6/1/2015]. Available from:
20 [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicati
21 onsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825).
22
23
- 24 [20] Health and Social Care Act 2012 [Internet]; c2012. Available from:
25 <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>.
26
27
- 28 [21] A mandate from the Government to NHS England: April 2014 to March 2015 [Internet]; c2014.
29 Available from: <https://www.gov.uk/government/publications/nhs-mandate-2014-to-2015>.
30
- 31 [22] Medical rehabilitation in 2011 and beyond. Report of a working party [Internet]; c2010. Available
32 from: <https://www.rcplondon.ac.uk/publications/medical-rehabilitation-2011-and-beyond>.
33
- 34 [23] The Invisible Patients: Revealing the state of neurology services [Internet]; c2015 [cited 2015
35 6/1/2015]. Available from: <http://www.neural.org.uk/updates/245-invisible> patients variations
36 report.
37
- 38 [24] What is Integrated Care. An overview of integrated care in the NHS [Internet]; c2011 [cited 2015
39 6/23/2015]. Available from: <http://www.nuffieldtrust.org.uk/publications/what-integrated-care>.
40
41
- 42 [25] Optimizing scopes of practice: new models of care for a new health care system [Internet]; c2014
43 [cited 2015 6/24/2015]. Available from: [http://www.caahs-acss.ca/wp-
44 content/uploads/2014/08/Optimizing-Scopes-of-Practice_REPORT-English.pdf](http://www.caahs-acss.ca/wp-content/uploads/2014/08/Optimizing-Scopes-of-Practice_REPORT-English.pdf).
45
- 46 [26] Life after brain injury: a way forward. Manifesto for acquired brain injury, July 2012 [Internet];
47 c2012 [cited 2015 6/1/2015]. Available from: [http://ukabif.org.uk/wp-
48 content/uploads/2014/02/Life-After-Brain-Injury.pdf](http://ukabif.org.uk/wp-content/uploads/2014/02/Life-After-Brain-Injury.pdf).
49
- 50 [27] Sander AM, Clark A, Pappadis MR. What is community integration anyway? defining meaning
51 following traumatic brain injury. J Head Trauma Rehabil 2010 Mar-Apr;25(2):121-7.
52
53
- 54 [28] Aspinall F, Gridley K, Bernard S, Parker G. Promoting continuity of care for people with long-term
55 neurological conditions: The role of the neurology nurse specialist. J Adv Nurs 2012;68(10):2309-
56 19.
57
58
59

- 1
2
3 [29] Haggerty JL, Roberge D, Freeman GK, Beaulieu C. Experienced continuity of care when patients
4 see multiple clinicians: A qualitative metasummary. *Ann Fam Med* 2013 May-Jun;11(3):262-71.
5
6 [30] Kodner DL. All together now: A conceptual exploration of integrated care. *Healthc Q* 2009;13 Spec
7 No:6-15.
8
9 [31] Co-ordinated care for people with complex chronic conditions [Internet]; c2013 [cited 2015
10 6/23/2015]. Available from: <http://www.kingsfund.org.uk/publications/co-ordinated-care-people-complex-chronic-conditions>.
11
12
13 [32] Nalder E, Fleming J, Cornwell P, Shields C, Foster M. Reflections on life: Experiences of individuals
14 with brain injury during the transition from hospital to home. *Brain Inj* 2013 10/01;
15 2015/06;27(11):1294-303.
16
17
18 [33] Whiffin CJ, Bailey C, Ellis-Hill C, Jarrett N, Hutchinson PJ. Narratives of family transition during the
19 first year post-head injury: Perspectives of the non-injured members. *J Adv Nurs* 2015;71(4):849-
20 59.
21
22
23 [34] Nalder E, Fleming J, Cornwell P, Foster M, Skidmore E, Bottari C, Dawson DR. Sentinel events
24 during the transition from hospital to home: A longitudinal study of women with traumatic brain
25 injury. *Arch Phys Med Rehabil* 2016;97(2):S46-53.
26
27 [35] Conneeley AL. Transitions and brain injury: A qualitative study exploring the journey of people
28 with traumatic brain injury. *Brain Impairment* 2012;13(01):72-84.
29
30 [36] Brands I, Stapert S, Köhler S, Wade D, van Heugten C. Life goal attainment in the adaptation
31 process after acquired brain injury: The influence of self-efficacy and of flexibility and tenacity in
32 goal pursuit. *Clinical Rehabilitation* 2015 June 01;29(6):611-22.
33
34 [37] Sherer M, Sander AM, Nick TG, Melguizo MS, Tulsy DS, Kisala P, Hanks R, Novack TA. Key
35 dimensions of impairment, self-report, and environmental supports in persons with traumatic
36 brain injury. *Rehabilitation Psychology* 2015;60(2):138.
37
38 [38] Hesse-Biber SN, Leavy P. The practice of qualitative research. Second edition. ed. Thousand Oaks,
39 Calif.: SAGE; 2011. .
40
41 [39] Maxwell JA. A realist approach for qualitative research. Thousands Oaks, CA: Sage; 2012. .
42
43 [40] Bhaskar R. A realist theory of science. Hassocks, Sussex: Harvester Press; 1978. ID:
44 44KEN_Voyager446818.
45
46 [41] Sayer RA. Realism and social science. Thousand Oaks, Calif.: Sage; 2000. ID: dedupmrg14721441;
47 Includes bibliographical references (pages 189]-199) and index.
48
49 [42] Sayer A. Method in social science: A realist approach. Second ed. London: Routledge; 1992. .
50
51 [43] Clark AM, Lissel SL, Davis C. Complex critical realism: Tenets and application in nursing research.
52 *ANS Adv Nurs Sci* 2008 Oct-Dec;31(4):E67-79.
53
54
55
56
57
58
59
60

- 1
2
3 [44] Head injury: Triage, assessment, investigation and early management of head injury in children,
4 young people and adults. NICE clinical guidelines 176 [Internet]; c2014 [cited 2015 6/1/2015].
5 Available from: <http://www.nice.org.uk/guidance/cg176>.
6
- 7 [45] Yin RK. Case study research: Design and methods. Fifth ed. Thousand Oaks, Calif.; London: SAGE;
8 2014. ID: 44KEN_Voyager572343; Includes bibliographical references (pages 167-174) and index.
9
- 10 [46] Emerson RM, Fretz RI, Shaw LL. Writing ethnographic fieldnotes. Second ed. Chicago: The
11 University of Chicago Press; 2011. .
12
- 13 [47] Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology
14 2006;3(2):77-101.
15
- 16 [48] Morse JM. Critical analysis of strategies for determining rigor in qualitative inquiry. Qualitative
17 Health Research 2015:1-11.
18
- 19 [49] National service framework for older people [Internet]: Department of Health; c2001 [cited 2014
20 Nov 11th]. Available from:
21 [https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198033/Nation](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198033/National_Service_Framework_for_Older_People.pdf)
22 [al_Service_Framework_for_Older_People.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198033/Nation).
23
24
- 25 [50] Kneebone II, Hull SL, McGurk R, Cropley M. Reliability and validity of the neurorehabilitation
26 experience questionnaire for inpatients. Neurorehabil Neural Repair 2012 Sep;26(7):834-41.
27
- 28 [51] Paterson B, Kieloch B, Gmiterek J. 'They never told us anything': Postdischarge instruction for
29 families of persons with brain injuries. Rehabilitation Nursing : The Official Journal of the
30 Association of Rehabilitation Nurses 2001;26(2):48.
31
32
- 33 [52] Laver K, Lannin NA, Bragge P, Hunter P, Holland AE, Tavender E, O'Connor D, Khan F, Teasell R,
34 Gruen R. Organising health care services for people with an acquired brain injury: An overview of
35 systematic reviews and randomised controlled trials. BMC Health Services Research 2014;14(1):1.
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49

Table 1: Respondent details

	Male (M)/ Female (F)	Age	Interviewed with	Housing	Social context: life pre-TBI and key concerns at time of interview
1	M	81	Wife ¹	Owner occupied house in a village.	Pre-injury this retired couple were very active, had individual and joint leisure pursuits, and particularly enjoyed belonging to a cycling group. Their children did not live locally and their social network was limited. The husband sustained a TBI when cycling but the police did not press charges; his wife was pursuing a personal injuries claim. His wife felt unable to leave him alone for more than ten minutes due to impairments with mobility, memory and cognition.
2	M	49	Wife ¹	Owner occupied house in a village.	This married couple had teenage children but no close family or friends in the area. The husband ran his own business and employed a large number of staff whilst his wife managed everything at home. He sustained extremely severe injuries and his business collapsed with major financial repercussions. His wife was struggling to cope with practical, financial and parenting issues. His key concerns were reduced mobility; pain; fatigue; impaired memory and cognition; difficulty self-regulating his emotions and speech; return to work and financial issues.
3	M	70	Partner (co-	Owner occupied flat	Pre-injury this retired businessman was in good health, very active and had friends in the

Table 1: respondent details_6th April 2016

			habiting) ¹	in town.	area. His younger partner attended to all domestic concerns and had family close by. His main concerns were impaired memory and not being allowed to drive; his partner was concerned about his intermittent confusion and difficult regulating his emotions.
4	F	64	Son	Council house on the outskirts of town.	Pre-injury this woman was very independent and active spending several hours per day walking her dogs and cooking. She was widowed and lived with both her sons, one of whom worked. Friends and family were local and close-knit. Her key concerns were lack of physical endurance; fatigue; loss of autonomy in terms of running the house, walking the dogs and going out by herself; and emotional sequelae in part related to waiting for cranioplasty.
5	M	51	Partner (lives close by)	Privately rented room in a house, suburban area.	Pre-injury this man worked full-time and had been in the same job for many years. He got on well with his landlady and his girlfriend lived locally. His main interests outside work were walking around town and socialising in his local pub. His main concerns were fatigue; fear of further head trauma while awaiting cranioplasty; and return to work.
6	M	48	Wife	Owner occupied flat on a new estate on the outskirts of town.	A professional couple who both worked full-time pre-injury and had recently moved from a house to the current flat which had enabled her to take unpaid leave to care for her husband. They had a reliable network of friends but limited contact with his family due to injury related issues. His main concerns were fatigue and reduced physical endurance

Table 1: respondent details_6th April 2016

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49

					which was making it difficult to re-establish a daily routine; return to employment; and resuming driving.
7	M	89	Friend/son-in-law ²	Owner occupied house in town.	Pre-injury he lived alone in his own house with good family support. He could only walk short distances inside with a mobility aid due to a previous fall and arthritis. Since discharge his son-in-law had been staying overnight and a friend was acting as carer in the daytime. His main concerns were reduced mobility; poor hearing and vision (pre-existing); and not being allowed to drive.
8	M	69	Wife	Privately rented flat on a busy main road in town.	Pre-injury they were a very active retired couple with individual and joint leisure pursuits and both were involved with voluntary work. They had regular contact with their daughter and grand-daughter. Both had worked for the NHS and related their recent experiences to their past work life. His main concerns were ongoing headaches and fatigue; anxiety (as the TBI had occurred outside their flat); impaired memory; and resuming valued activities.
9	M	63	N/A	Owner occupied house in a semi-rural area.	Pre-injury this man was active and healthy. His partner lived locally. They both worked full-time and enjoyed gardening, walking the dog and socialising. They had friends in the area but not family. His main concerns were associated orthopaedic injuries causing significant pain and impaired mobility; poor concentration and memory; low mood and

Table 1: respondent details_6th April 2016

					fatigue; and being unable to return to work or driving. He had an ongoing compensation claim.
10	M	48	Best friend	Owner occupied flat on a new estate on the outskirts of town.	Pre-injury this man worked full-time running a business with his best friends. He lived on his own while his girlfriend lived several hours drive away. Little contact with his family. His main concerns were reduced physical strength and an upper limb injury; language impairment; emotional lability; moving house to be closer to friends; and waiting for cranioplasty.

- ¹. Patient & carer interviewed separately
- ². Son-in-law came in part way through interview

N.B. details of injury and other specifics have been omitted to protect confidentiality

Table 1: respondent details_6th April 2016

Table 2: Summary of themes and sub-themes

1. Perceptions of support	2. Struggling to accept a new reality	3. Fear for the future
<ul style="list-style-type: none">• Inpatient experiences• Transitions between units• Preparation for discharge	<ul style="list-style-type: none">• Change in abilities• Loss of valued roles• Autonomy and control	<ul style="list-style-type: none">• Post-discharge experiences• Moving forward

For Peer Review

Figure 2: Summary of themes and sub-themes_4 Apr 2016

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Figure 1: Clinical pathway for traumatic or acquired brain injury [22]

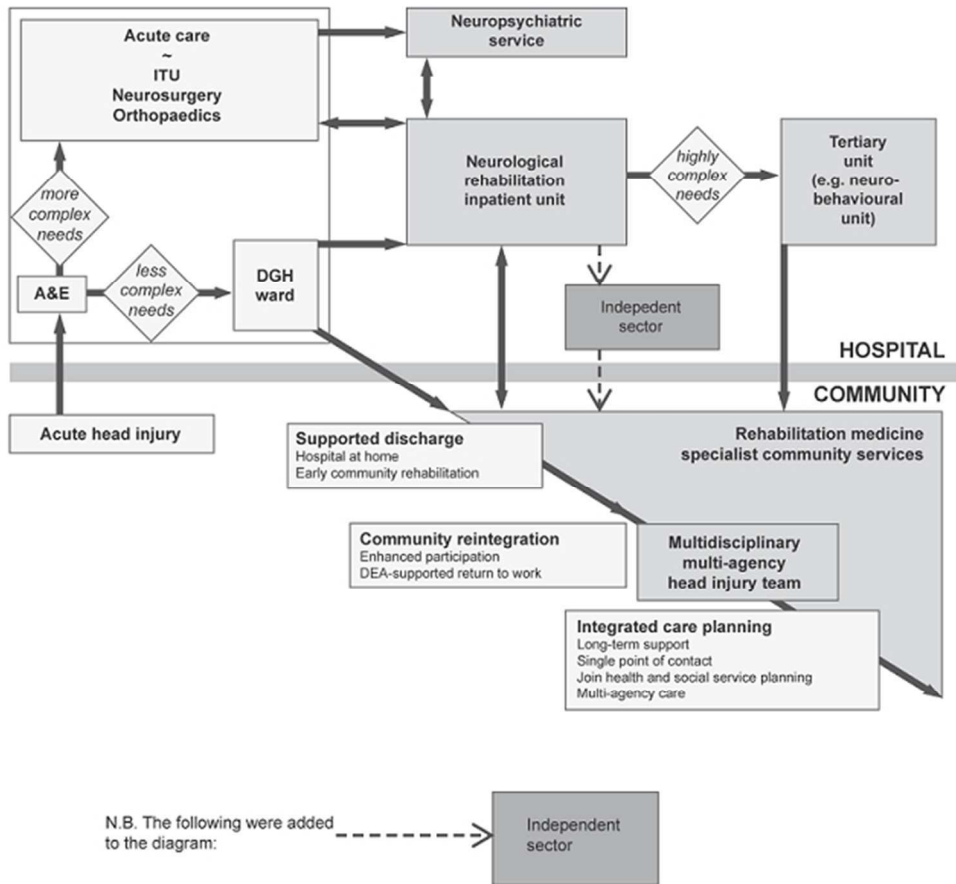


Figure 1: Clinical pathway for traumatic or acquired brain injury
173x177mm (96 x 96 DPI)

Appendix 1: Topic guide

1. Can you tell me about your experiences so far?

Initial interview prompts:

- What did you think when you were told you were being discharged home?
- What happened when you left the rehabilitation unit?
- What is it like being back at home?

Follow up interview prompts:

- How did staff prepare you for going home?
- What concerns did you have about going home?
- Were you able to discuss these concerns with anyone?
- Did you have any (unexpected) difficulties when home?
- What do you most enjoy about being home?

2. What support or services have you both had?

Prompt:

- What do you think of this support/service?
- What did or did not work well?
- What else would you have found helpful?

3. Can you tell me a little bit about your relationship and how things have changed since the injury? (give **both** participants time to talk)

- Who did most of the domestic chores?
- Do you both drive?
- How much did you go out and about?
- What was your social life like?

1
2
3
4
5 **4. What activities would you like to resume?** E.g. working, driving
6

7 Prompt:

- 8
- 9 • What are the barriers to doing so?
 - 10
 - 11 • What/who/how would help you get back to doing these things?
 - 12
 - 13
 - 14
 - 15

16 **5. Do you have any other suggestions or comments?**

- 17
- 18 • Around the time of going home?
 - 19
 - 20 • On the services you have received and/or would like to receive?
 - 21
 - 22 • What you may have found beneficial?
 - 23
 - 24 • What support you anticipate you may need in the next year?
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60