

2023-04-06

The Secondary Impact of Mild Traumatic Brain Injury: An Interpretative Phenomenological Analysis of the Experiences of Family Members

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<http://hdl.handle.net/10026.1/20496>

10.1177/10664807231164421

The Family Journal

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The Family Journal

The Secondary Impact of Mild Traumatic Brain Injury: An Interpretative Phenomenological Analysis of the Experiences of Family Members

Journal:	<i>The Family Journal</i>
Manuscript ID	Draft
Manuscript Type:	Qualitative
Keywords:	Traumatic brain injury, Family, Ambiguous loss, Mild traumatic brain injury, Interpretative phenomenological analysis
Abstract:	<p>Mild traumatic brain injury (mTBI), with symptoms beyond three months, may be more common than previously believed, but is poorly understood. This has resulted in contradictory and confused information for service users, which has had an impact on those with mTBI and their families. This qualitative study aimed to improve understanding of the lived experiences of families of people with mTBI, with symptoms beyond three months. It extends a previous study, which focussed on all degrees of traumatic brain injury (TBI) (mild, moderate and severe). Four individuals participated in semi-structured, virtual interviews. Following an interpretative phenomenological analysis (IPA), three superordinate themes were identified: 1) going round in circles, 2) the second secondary impact, and 3) dialogue with myself. Findings indicate that families of people with mTBI, with symptoms beyond three months, may experience many of the same challenges as families of people with moderate or severe TBI, albeit at a lesser intensity. This includes difficulty making sense of TBI and challenges to their identity, both of which mirror the comparator TBI study findings. However, findings also indicated that this group may experience different challenges to families of people with moderate or severe TBI, aspects of which have not previously been reported. Feelings of ambiguous loss may be increased by incongruity between information provided and families' experiences, and by the varied availability and content of information. Implications for service providers are that consistent, transparent and realistic information and education may aid adjustment and assist families to support people with mTBI.</p>

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4 **The Secondary Impact of Mild Traumatic Brain Injury: An Interpretative**
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6 **Phenomenological Analysis of the Experiences of Family Members**
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10 **Introduction**
11

12 “...grief is hard enough anyway, but when you don’t know the truth, everything freezes and
13 you can’t move on.” Hare (2011).
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15
16
17 Traumatic brain injury (TBI) is defined as damage to the brain by an external, mechanical
18 force (Polinder et al., 2018). Under the Mayo criteria (Malec et al., 2007) severity of TBI is
19 classified from mild to moderate and severe, with mild traumatic brain injury (mTBI) defined
20 by loss of consciousness of less than 30 minutes, post-traumatic anterograde amnesia for less
21 than 24 hours or skull fracture with the dura intact. mTBI is common, and represents a global
22 public health issue (Brazinova et al., 2021). The World Health Organisation (WHO)
23 estimates that, worldwide, between 100 and 300 people per 100,000 receive medical
24 assistance for mTBI annually (Holm et al., 2005). The WHO recommends adopting a bio-
25 psycho-social model for rehabilitation (Glintborg, 2019), with families playing a key role in
26 providing support, and facilitating patient education and adaptation (Bannon et al., 2020).
27
28 The importance of family in mTBI recovery is highlighted in a causal loop diagram (CLD)
29 (Kenzie et al., 2018), which seeks to facilitate understanding of the challenges and complex
30 interplay between the biological, psychological and social in mTBI recovery. As the CLD
31 illustrates, the social dynamics of mTBI recovery are complex, with a strong link between
32 supportive relationships, resilience and coping. Surveys of those with mTBI have found that
33 social support predicts lower symptom reporting (Quan Zeng et al., 2016; Temple et al.,
34 2016) and increased satisfaction with life (Seidl et al., 2015). However, mTBI can negatively
35 impact family functioning, causing disruption to relationships with the person with mTBI
36 (Jones et al., 2020; Nelson et al., 2019; Orff et al., 2016; Pugh et al., 2018).
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3 Families support mTBI recovery both practically (Kerrigan & Giza, 2019) and emotionally
4 (Azman et al., 2020). Those with mTBI are not always aware of their symptoms, so it is
5
6 important that families are educated about mTBI (Quatman-Yates et al., 2020), in order to
7
8 provide an informant perspective to clinicians (Marshall et al., 2015). Families can also
9
10 increase self-awareness and comprehension of the condition (Cichon et al., 2015) and serve
11
12 as an important external reference point, which helps people with mTBI make sense of the
13
14 changes they have experienced (Snell et al., 2017). Despite their importance in recovery,
15
16 families of people with mTBI have reported feeling left out of rehabilitation by medical
17
18 services, resulting in frustration and a perceived lack of empathy (Hyatt et al., 2014).
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24
25 Ambiguous loss theory (ALT) has potential to explain the experiences of carers of people
26
27 with TBI (Kreutzer et al., 2016). ALT contends that a lack of narrative, which is consistent
28
29 with experience makes it harder to adjust to loss, increasing and prolonging distress (Dahl &
30
31 Boss, 2020). ALT asserts that a phenomenon can exist, even if medical services cannot
32
33 measure it, and should be recognised phenomenologically, regardless (Boss, 2007). The goal
34
35 (consistent with the CLD) is to maximise resilience (Boss, 2018). An important factor in
36
37 families supporting recovery may be their forming a clear concept of TBI, aiding them to
38
39 understand what to expect and when and how to help people with TBI (Fadyl et al., 2017).
40
41 Conversely, contradiction and confusion between care professionals may hinder people's
42
43 ability to recover from TBI (Fadyl et al., 2017). Recovery from acquired brain injury (ABI)
44
45 (meaning either TBI or non-TBI, e.g., cerebrovascular brain injury (Tibæk et al., 2019))
46
47 involves changes in identity for people and their family caregivers (Glintborg, 2019). Whiffin
48
49 et al. (2019) posit that family identity reconstruction after TBI is important to recovery,
50
51 requiring narrative that is congruent with participants' lived experience.
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58 Clear information is important for recovery from mTBI (Brunger et al., 2014; Minney et al.,
59
60 2019; Robinson-Freeman et al., 2020; van Gils et al., 2020) in both the acute (Prince &

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2
3 Bruhns, 2017) and chronic stages (Hart et al., 2018). Education can promote better social
4 support for people with mTBI by normalising relationship changes due to injury and
5 suggesting positive adaptations for the individual and their social support network (Bannon et
6 al., 2020; Klonoff, 2014). There is variation in the provision and quality of information after
7 mTBI (Norman et al., 2020; Seabury et al., 2018; Silverberg et al., 2020). Table 1 in
8 Appendix A expands on a comparison of treatment guidelines by Silverberg et al. (2020) by
9 including UK guidelines. It shows that TBI information provided under NICE guidelines is
10 not mTBI specific (Doneva, 2018), which may lead to variation and reduced care in the
11 emergency department (Choudhary et al., 2021). NICE guidelines make no mention of mTBI,
12 potentially perpetuating the lack of education about chronic phase mTBI (Hart et al., 2018).
13 Table 1 also shows that patient information is not provided under SIGN guidelines, which
14 van Gils et al. (2020) claim is clinically suboptimal. Where it is provided, information may be
15 contradictory or confusing, hampering the family's ability to support recovery (Landau &
16 Hissett, 2008; Saban et al., 2015). Information must be realistic, honest about the limitations
17 of medical knowledge (Ghosh et al., 2020), and include both verbal and written information
18 (Terblanche, 2020), to provide a reference for third parties (e.g., employers) (Gourdeau et al.,
19 2020; Graff et al., 2020; Young et al., 2005).
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43 It has been suggested that providing information results in negative patient expectations and
44 may hamper recovery (Mittenberg et al., 1992; Suhr & Gunstad, 2002; Whittaker et al.,
45 2007). However, a recent meta-analysis by Niesten et al. (2019), failed to find support for
46 these claims. Others point out that such a causal relationship has not been proven (Mah et al.,
47 2018) and stress the importance of early, realistic and accurate patient and family education
48 in mTBI recovery (Minney et al., 2019; Prince & Bruhns, 2017). Some posit that providing
49 realistic information is also important in creating trust, normalising the patient experience,
50 reducing fear, promoting self-care and, improving patient outcomes (Cavallaro, 2018; Chief
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3 Medical Officer for Scotland, 2015; Fenning et al., 2019; Snyder & Engström, 2016; Yeh,
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5 2018; Zolkefli, 2018).
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12 Commonly held views among physicians may be incongruent with the experiences of people
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14 with mTBI and their families, increasing ambiguity. A common hypothesis among physicians
15
16 is that mTBI heals within three months, and symptoms beyond that time are a) caused by
17
18 other factors (Lishman, 1988) and b) rare (15%) (Iverson, 2005; Rutherford et al., 1979;
19
20 Spinos et al., 2010; Sterr et al., 2006). However, imaging evidence (Asken et al., 2018;
21
22 Khong et al., 2016; Wallace et al., 2018; Yin et al., 2019) suggests a bio-psycho-social
23
24 approach to mTBI aetiology is more appropriate (Aliyah et al., 2018; Cole & Bailie, 2016;
25
26 Snell et al., 2016; Silverberg et al., 2015). In addition, some argue that mTBI symptoms after
27
28 three months are not rare (Brady et al., 2022; McMahon, 2014; Theadom et al., 2016; Wäljas
29
30 et al., 2015) finding that most people with mTBI still have symptoms 12 months post-injury
31
32 (Dikmen et al., 2017; Hiploylee et al., 2017; National Academies of Sciences, Engineering,
33
34 and Medicine, 2022; Nelson et al., 2019). The disease process of mTBI is also poorly
35
36 understood. While people with mTBI and their families are typically advised that the injury
37
38 was the moment of organic damage and gradual improvement follows (Masel & DeWitt,
39
40 2010), the reality is more complex (Maas, 2016), involving the unfolding of a disease process
41
42 that can lead to worsening symptoms over time, as well as recovery and periods of no change
43
44 (Chancellor et al., 2019; Michel et al., 2019; Pacheco, 2019; DeKosky & Asken, 2017;
45
46 Stocchetti & Zanier, 2016; Sullivan, 2019; Wallace et al., 2018). Reassuring assessment from
47
48 medical services may unintentionally raise false hope in people with mTBI and their families,
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50 leading to feelings of disappointment and increased frustration (Landau & Hissett, 2008)
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52 when outcomes are less positive than predicted.
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3 The impact of TBI on family members has mostly been examined in terms of
4
5 psychopathological outcomes (e.g., anxiety), although more recently there has been a
6
7 growing focus on the subjective experiences of families (Whiffin et al., 2021). Qualitative
8
9 research has been called for to reinforce quantitative research, improve clinician
10
11 understanding of the priorities of family carers of people with TBI, and assist them to
12
13 improve support for families (Kneafsey & Gawthorpe, 2004; Oyesanya, 2017). A number of
14
15 theories have been proposed to explain the importance of clear patient information,
16
17 motivation in recovery, and change in identity among people with ABI and TBI and their
18
19 families, but it is not yet clear the extent to which this applies to families of people with
20
21 mTBI with symptoms beyond three months post-injury. Hyatt et al. (2014; 2015) studied the
22
23 experiences of families of a military population with mTBI, although it is not clear how
24
25 generalisable these findings are (Stillman et al., 2020). Other studies cover all TBI severities
26
27 without distinguishing mTBI (Whiffin et al., 2021). Landau and Hissett (2008) explored
28
29 experiences of families of people with mTBI with a relationship breakdown focus, but
30
31 symptom duration was not specified. Therefore, objectives of the present study are to explore
32
33 the experiences of family members of people with mTBI symptoms that persist beyond three
34
35 months, to investigate the importance of giving information to family members through
36
37 analysing their lived experience, and to undertake comparative analysis between the findings
38
39 of the original, TBI-focussed Townshend and Norman (2018) study and the current mTBI-
40
41 focussed one.
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50 Method

51 Design

52
53 This study has an ideographic focus and employed interpretative phenomenological analysis
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55 (IPA) (Smith & Osbourne, 2008; Smith et al., 2009), based on an ontology of minimal
56
57 hermeneutic realism, and an interpretative epistemology (Larkin et al., 2006). It assumed that
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1
2
3 there is one, universal truth, but that that truth is interpreted by individuals, who are never
4 value free (McLeod, 2011; Willig & Rogers, 2017). The method was online semi-structured
5 interviews (Lyons & Coyle, 2007). The study is both a description and an active
6 interpretation of experiences (Alase, 2017). It sought to synthesise findings both within-
7 participants in the current study, and between-participants, through comparison with the
8 Townshend and Norman (2018) study. Qualitative studies are appropriate for extension
9 (McLeod, 2011) and insights from phenomenological research may be seen as more relevant
10 in the real world if evidenced from more than one population (Larkin et al., 2019).

21 22 **Participants**

23
24 Participants were family members of people with mTBI, whose mTBI symptoms have
25 persisted beyond 3 months. They have known the individuals with mTBI pre and post-mTBI.
26
27 Participants are all English speakers over 18. Participants were self-defining, and no evidence
28 of diagnosis was sought. Friends of people with mTBI were also sought, but none were
29 recruited. Recruitment employed purposive sampling via The University of Derby and
30 Headspace UK. In addition, participants were also sought via closed, mTBI-related Facebook
31 groups. This follows the IPA approach of seeking a small homogeneous group for within-
32 group, ideographic analysis (Pietkiewicz & Smith, 2014) and mirrors the recruitment
33 approach for the Townshend and Norman (2018) study. Four women were recruited. No
34 incentive was offered. Two were supported by UK medical services, one by US and a fourth
35 made use of both US and UK services. Demographic data regarding participants can be seen
36 in Table 2.
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Table 2

Demographic data for participants and people with mTBI

Participant Pseudonym	Participant's Current Age	Participants' Sex	Relationship To mTBI Survivor	Cause Of Injury	Time Since Injury	people with mTBI' Age At Injury	people with mTBI' Sex
Debbie	57	Female	Mother	Sports Injury	5 Years	15	Female
Carole	46	Female	Wife	Fall	15 Months	51	Male
Sarah	44	Female	Wife	Cycle Accident	5 Years	39	Male
Rebecca	58	Female	Wife	Road Traffic Accident	8 Years	46	Male

Analytical strategy

There were four interviews in total with a mean duration of 56 minutes (SD = 9 minutes).

The sessions were transcribed verbatim with MS Word and analysed in NVIVO 12. Data was analysed using IPA, (Smith & Osbourne, 2008), as employed by Townshend and Norman (2018). The themes from the Townshend and Norman (2018) study were disregarded initially

to allow fresh analysis of data from the present study. After listening to interviews and reading transcripts multiple times, transcripts were analysed in detail (Nizza et al., 2021).

Initial descriptive, linguistic and conceptual observations (Smith et al., 2009) were recorded.

A record was kept of data supporting each theme. This process was repeated for each interview, and convergences or divergences were noted (Nizza et al., 2021), new themes added or more data noted as supporting pre-existing themes. The themes were then analysed and grouped into super-ordinate themes. Themes which did not relate to super-ordinate

themes were discarded. Super-ordinate themes were tested by checking back to ensure they were reflected in the data and further quotes were identified to illustrate super-ordinate

themes. Analysis was shared with participants for participant verification (Peat, 2019). One

participant provided feedback, verifying that analysis was congruent with their experience. A second method of triangulation was employed, where a co-author reviewed the analysis. The

basis for data interpretation was recorded and made explicit in the presentation of the

analysis. A reflective diary was also used to record researcher thoughts and feelings

throughout the study process. A comparison of findings was then made between the present

mTBI study and the Townshend and Norman (2018) TBI study. This began with

demographic data before the themes were compared. Evidence in the data was sought to

support any commonalities or differences identified.

Results

Three superordinate themes were identified in the study. These were: Going round in circles, The "second" secondary impact and Dialogue with myself. A table of final superordinate themes and subordinate themes are shown in Table 3. Each theme is outlined in turn below, with detailed descriptions and quotes to illustrate themes.

Table 3

Superordinate themes and subordinate themes

Present study	
Superordinate theme	Subordinate themes
Going round in circles	It was easier when they had cancer The medical maze Sense making in a medical information vacuum
The "second" secondary impact	It's just in your head, you can't have anymore time off I have to fight all their battles 'cause they won't fight them themselves
Dialogue with myself	Shoulda, woulda, coulda. Who are they and who am I in all this?

Theme 1: Going round in circles

Going round in circles captures the lack of meaningful direction expressed by participants as they try to navigate the medical system to seek information, treatment and try to support their loved ones living with a mTBI in their recovery.

It was easier when they had cancer

This subordinate theme captures how participants' experience of mTBI compared to supporting people with other illnesses (real, or in "Debbie's" case an imagined other illness).

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2
3 “Carole” observed that accessing services for mTBI had “*just been awful*” compared to when
4
5 her husband had cancer:
6
7

8 It was easier when he had cancer, because there's the support systems out there
9
10 ... it's all just so vague.
11
12

13 This negative comparison with a life-threatening illness suggests they experience the
14
15 “*vagueness, the limbo*” (Carole) as a major impediment to supporting recovery.
16
17

18 All four participants had family who were people with mTBI with symptoms lasting more
19
20 than 3 months.
21
22

23 I just don't see that there's a flow chart of what you should do first and where
24
25 you should go if you don't get better in the first three weeks to three months. (Debbie)
26
27

28 Participants' language indicates “*frustration*” (“Rebecca”, Carole and Debbie) with how
29
30 “*difficult*” (“Sarah”) it is to access medical support. There is a sense that the absence of clear
31
32 diagnosis, treatment pathway or prognosis leaves participants feeling that they are in “*limbo*”
33
34 (Carole).
35
36
37

38 Rebecca regretted that the mTBI was invisible and voiced frustration that the usual prompts
39
40 for understanding were missing.
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44 ...you see a sling, you understand what's going on.
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46

47 The visible sling contrasted with the less visible, cognitive issues that Rebecca experienced
48
49 her husband struggling with while planning for a train journey. Unable to explain to him that
50
51 they needed to get on the train, Rebecca “*had to watch the train drive away.*” This phrase
52
53 evokes a sense of helplessness felt by Rebecca, and the situation she describes hints at the
54
55 extra challenge Rebecca faces advocating for her husband due to his less visible mTBI
56
57 symptoms.
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3 The repeated reference to limbo denotes an experienced lack of direction from medical
4 professionals. Conceptually, it indicates a hampered need to be working towards recovery
5 with clear information from medical professionals about the starting point (diagnosis),
6 journey (treatment pathway) and destination (prognosis). None of the participants talked of
7 hope. The negative comparison participants made with the clearer treatment pathways of
8 other illnesses implies a sense of loss that mTBI treatment is so much harder to navigate.
9

17 Navigating the Medical Maze

20 All participants talked about the challenges they had navigating medical services. This
21 subordinate theme captures participants' sense of the "*battle*" (Rebecca) to be validated by
22 the medical profession and other systems, and to find treatment. It describes how their
23 experience of a "*lack of information and lack of support for the medical side is awful*"
24 (Carole). Conceptually, the participants described their experience in terms of movement
25 around a system, getting "*stuck*" (Carole) and "*going round in circles*" (Carole).
26
27

28 This search is frustrating and adds to the burden of caring and advocating for the person with
29 mTBI. It is clear from their comparisons with other experiences of medical services that the
30 battle and onus on them to search is unexpected and onerous.
31
32

42 Sense Making in a Medical Information Vacuum

45 This theme reflects how the lack of a narrative that is congruent with their experience from
46 medical services leaves participants in an information vacuum. Participants report being left
47 in limbo when they do not experience the prompt recovery predicted by medical providers.
48
49

52 Participants perceived information as "*misinformation*" (Debbie) if it was not congruent with
53 their experience, leaving them "*not knowing what to believe*" (Debbie). They could not use
54 incongruent information to make sense of their experience, so participants tried to fill the
55 vacuum themselves. However, participants were aware they are not medical specialists and
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3 therefore lack the knowledge and capacity to make informed decisions. Rebecca states she is
4
5 “willing to pay but I don’t know who to choose” or “who’s good”. Similarly, Debbie is left
6
7 asking “what avenue do I take?”. Rebecca thus describes herself as “Floundering about trying
8
9 to get the right reports ready.”
10
11

12
13 “*Floundering*” evokes a sense of trying one’s best but finding it “*exhausting*” (Sarah) and
14
15 knowing that one lacks ability. This has a cost to participants' mental wellbeing, as well as
16
17 creating an additional burden.
18
19

20
21 It's overwhelming... You just can't think what to do next... It's hard, it's
22
23 mentally draining. (Carole)
24
25

26 Rebecca was relieved to find someone who validated their experience, and made her husband
27
28 realise “Actually no. I'm not going mad. I've got a brain injury.” Rebecca described this
29
30 validation as “Brilliant because it's something that. To nail it on. Other than that, it's just been
31
32 as if you were making it up.”
33
34

35
36 The strong relief at being believed reveals the cost to her sense of self-worth of not having
37
38 been believed previously.
39
40

41 Theme 2: The "second" secondary impact
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44 The "*second*" secondary impact refers to the impact that family report from dealing with
45
46 systems that do not seem to understand their reality. This impact is called The “*second*”
47
48 secondary impact because there is an impact on the family of people with mTBI which is
49
50 secondary to the primary impact on people with mTBI themselves, but there is another
51
52 “*second*” layer of impact on family from not being understood or believed.
53
54
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56 It's Just in Your Head, You Can't Have Any More Time Off
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3 This subordinate theme captures the additional impact on participants of not being believed
4 or understood. One way this manifests itself is in participants' experience of a "*battle*"
5 (Rebecca) or "*fight*" (Carole) (words used repeatedly) with systems (e.g., medical, employers,
6 school) that don't recognise the injury.
7
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12
13 His work have been horrifically bad throughout the whole thing. (Carole)
14
15

16 Participants report they have no clear understanding for themselves and no "*proper*
17 *literature...*" they "*...could pass on to people*" (Sarah) to explain mTBI. They report that
18 they feel alienated from medical services because they feel unheard, not believed and that the
19 nuances of the condition are not understood.
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22
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24
25

26 This failure to recognise the condition is a shock to participants, as their expectation is that
27 medical services and systems will not only recognise injury, but be sympathetic and
28 supportive. When this does not happen there is disappointment and anger.
29
30
31
32

33 One of the people at work said to him "Shit happens." "Just get on with it."
34
35

36 That was the welfare person. (Rebecca)
37
38

39 Choosing to report the phrase "*Shit happens*" suggests Rebecca experiences an uncaring
40 system that does not understand or sympathise with her. There is a sense of being let down in
41 the language used by all participants. Their extreme language ("*horrific*") indicates shock and
42 disappointment.
43
44
45
46
47

48 I Have to Fight All Their Battles 'Cause They Won't Fight Them Himself
49
50

51 This theme summarises participants' experiences of being an advocate for the person with
52 mTBI.
53
54

55
56 You're almost suddenly thrown into being an advocate straight away. Having
57 to sign all the paperwork because he's too fuzzy to know what's going on. (Carole)
58
59
60

1
2
3 All participants express the view that people with mTBI lack the ability to fully advocate for
4 themselves. Whether it is the practicality of chasing medical referrals, the fact that people
5 with mTBI “*can't always articulate what's going on*” (Carole) or that they lack the energy to
6 struggle to access help.
7
8
9
10
11

12
13 Yeah, well he doesn't fight it. Yeah. He'll just roll over and play dead about it.
14

15 (Rebecca)
16
17

18 Participants report that medical services do not recognise the extent to which people with
19 mTBI lack capacity to self-advocate.
20
21
22

23 No, he can't do it. He's got a head injury. That is the whole point we need to. I
24 need to do it on his behalf. (Carole)
25
26
27

28 This perceived lack of appreciation of incapacity by medical services seems to create a
29 barrier to participants advocating for the person with mTBI. Medical services may not
30 recognise the lack of capacity to self-advocate but participants are all too aware, and this adds
31 to their workload and worry.
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38 Theme 3: Dialogue with myself 39

40 Dialogue with myself reflects participants' struggles to make sense of the disease process
41 through internal dialogue and revisions to their sense of self and other.
42
43
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46
47 Shoulda, Woulda, Coulda.
48

49 This subordinate theme relates all participants' regret over their earlier medical decisions.
50

51 Debbie expresses this most clearly:
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55 There were just a lot of mistakes made, that maybe caused this injury to last.
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58
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1
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3 This theme captures the hermeneutic phenomenon of participants interpreting their past
4 decisions through the lens of their present understanding. Debbie expresses regret at being
5
6 “*uneducated*” given what she knows now:
7
8

9
10 You look back and you say “woulda, coulda, shoulda”.

11
12
13 When Debbie looks back with regret, it is with the implication that she should have known
14
15 better.
16
17

18
19 I had been, if I knew, but I just, I think in the beginning of the thing you just
20
21 don't think they're not going to get better. (Debbie)
22
23

24 Participants differ in how they express regret. Unlike Debbie, Rebecca expresses anger at
25
26 medical services for not investigating brain injury and some crossness at herself for not
27
28 having thought of it. She is more forgiving of her past self than Debbie.
29
30

31
32 I think we got lulled into that sense of “*ohh it might take six months*”. (Carole)
33
34

35 Carole’s use of “*lulled*” suggests anger with herself for being fooled by medical services.
36
37 Seeing herself as foolish has implications for Carole’s self-esteem and identity.
38
39

40 I think I didn't want to go to anyone, because I want everything to be OK.
41
42

43 (Sarah)
44

45 There is a sense that Sarah too thinks she has been foolish, which seems to go against her
46
47 otherwise competent identity.
48
49

50
51 Who Are They and Who Am I in All This?
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53 This final subordinate theme describes the impact of the person with mTBI’s injury on the
54
55 participant’s identity and their perceived identity of the person with mTBI. All participants
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57 remarked on changes to the person with mTBI’s identity post injury. The person with mTBI
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3 was described as not being “*right*” (Rebecca and Sarah) and “*not really him anymore*”
4
5 (Carole). This profound change forms a significant aspect of participants’ internal dialogue.
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7 All participants recounted a change in the person with mTBI’s occupational identity. The loss
8
9 of doing work and leisure activities that the person with mTBI loved often came with a loss
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11 of social connections, leading to isolation for participants and the person with mTBI.
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15 16 **Discussion**

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18 This IPA study aimed to explore the experiences of families of people with mTBI symptoms
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20 that persist beyond three months. Data from semi-structured interviews with participants was
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22 summarised into three superordinate themes: 1) Going round in circles, 2) The "second"
23
24 secondary impact and 3) Dialogue with myself. The study compared findings with
25
26 Townshend and Norman (2018) which focussed on people with mild, moderate and severe
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28 TBI. All the Townshend and Norman (2018) themes were mapped to themes in the present
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30 study. Findings indicate that families of people with mTBI, where symptoms last more than
31
32 three months, may experience many of the same challenges as families of people with
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34 moderate or severe TBI, albeit at a lesser intensity. This includes difficulty making sense of
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36 TBI and challenges to their identity, which mirrors the findings of Townshend and Norman
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38 (2018). In addition, they may experience some challenges in a different way to families of
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40 people with moderate or severe TBI. These challenges are not present in the Townshend and
41
42 Norman (2018) findings. For example, they may feel frustration, caused by lack of congruity
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44 between patient education and their experience. Also their experience of ambiguous loss may
45
46 be further complicated by the lack of availability and quality of information about mTBI. The
47
48 quest for information and care is experienced by all participants and this is widely reported
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50 among families of people with mTBI (Carlozzi et al., 2016; Landau & Hisset, 2008; Hyatt et
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52 al., 2014). Chronic phase support is more frequently provided to people with moderate or
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3 severe TBI and their families, whose needs for rehabilitation are greater and more complex
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5 (Hart et al., 2018; Graff et al., 2018).
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8 As predicted by ALT (Boss, 2007; Boss, 2018; Dahl & Boss, 2020), participants experienced
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10 an inability to adjust to a new normal due to the ambiguity of their loss. This is consistent
11
12 with findings by Landau and Hissett (2008), and consistent, but less extreme than, findings in
13
14 families of populations that included more severe TBI (Giovannetti et al., 2015; O’Keeffe et
15
16 al., 2020; ThØgersen & Glintborg, 2020). Participants also appeared demotivated by the lack
17
18 of clear patient information, as predicted by Self Determination Theory (Adams et al., 2017;
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20 Kusec et al., 2019; Ryan & Deci, 2019). This echoes the findings in an mTBI population by
21
22 Auclair-Pilote et al. (2021), who speculated that poor patient education led to diminished
23
24 competence, which was a causal factor in lower motivation for recovery. This finding raises
25
26 the possibility that confusion may demotivate people with mTBI, as well as their families.
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32 This may be further explained by Identity Process Theory (IPT) (Breakwell, 1986; Jaspal &
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34 Breakwell, 2014), which understands identity after change in terms of assimilation of change
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36 and evaluation. As has been discussed, identity disruption in family caregiving is common
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38 (Cooper, 2021; Eifert et al., 2015). TBI represents an existential change for people and their
39
40 families that requires a reconstruction of identity (Glintborg et al., 2018; Whiffin et al.,
41
42 2019). Consistent with IPT and findings from Landau and Hissett (2008), all participants
43
44 reported being hampered in assimilating change due to a lack of narrative from medical
45
46 services that was congruent with their experience. Participants also reported feeling
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48 negatively evaluated by medical services and not feeling believed or supported, which IPT
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50 predicts would further hamper their ability to assimilate change. This negative evaluation and
51
52 lack of congruent narrative was not reflected in the themes of the Townshend and Norman
53
54 (2018) study.
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3 Consistent with Social Identity Theory (SIT) (Scheepers & Ellemers, 2019; Tajfel, 1974), the
4
5 poor evaluation and lack of understanding by medical services (salient others) reported by
6
7 participants may also hamper the families' ability to maintain or reconstruct their identity
8
9 post injury. The impact of injury on family member identity was a major finding of the
10
11 Townshend and Norman (2018) study. It was mirrored in the present study, albeit to a lesser
12
13 extent (possibly because the present study focussed on less severe TBI). In the present study,
14
15 there was more emphasis on the impact on wider socialising and the resulting isolation.
16
17 Participants' lives were changed in terms of self-image, family role, relationships and social
18
19 group membership. SIT predicts that social groups are important in identity formation and
20
21 self-esteem (Scheepers & Ellemers, 2019; Tajfel, 1974). Participants experienced a negative
22
23 impact on their identity from leaving groups post-injury. Another common findings with
24
25 Townshend and Norman (2018) was the reference to people with TBI being off-centre and
26
27 them but not them, consistent with qualitative findings by Saban et al. (2015). TBI is
28
29 experienced as an invisible injury by families in both studies. This invisibility adds to the
30
31 person with mTBI's challenge of being understood and supported by medical services
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33 (Childers & Hux, 2016). As discussed, patient education often sets the expectation of
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35 recovery within three months (Torbay and South Devon Trust, 2018; University Hospitals
36
37 Birmingham Trust, 2018), despite recent findings that most people with mTBI experience
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39 symptoms beyond then (Hiplylee et al., 2017; Nelson et al., 2019; Dikmen et al., 2017;
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41 Theadom et al., 2018; McInnes et al., 2017). Townshend and Norman (2018) describe
42
43 "repeated stages of unrealised hope for improvement" (p.13), which was also articulated by
44
45 participants in the present mTBI study, albeit from a particular perspective. Participants
46
47 described the gap between the recovery trajectory they understood from medical services, and
48
49 their experience. By contrast, the Townshend and Norman (2018) study described a hoped-
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51 for recovery, but did not refer to expectations set in patient information being at odds with
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3 participants' experiences. This possibly explains why the sense of injustice and anger
4
5 regarding the quest for care in the present findings and elsewhere (Carlozzi et al., 2016;
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7 Landau & Hisset, 2008) is absent from the Townshend and Norman (2018) study. The
8
9 concept of a battle for care and information is also missing. Participants in the present study
10
11 experience care ending after three months. Koehmstedt et al. (2018) suggest that the ideal
12
13 TBI caregiver information would be part of a long-term care plan, although it is not clear how
14
15 this relates to mTBI, since Koehmstedt et al. did not discuss severity of TBI. For the families
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17 of people with TBI in the Townshend and Norman (2018) study, patient education is
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19 perceived as inadequate for them to fully participate in recovery. In the present study it is
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21 experienced as inadequate, but also confusing, leading participants to feel frustration
22
23 consistent with the Landau and Hissett (2008) study of people with mTBI and their families.
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26 Participants struggled to make sense of the disease process, and experienced guilt at missing
27
28 earlier opportunities to support the person with mTBI. This echoed findings that symptoms
29
30 develop and change over time (Tenovuo et al., 2021) and information (Silverberg et al., 2020)
31
32 and medical support can be sporadic (Holloway et al., 2019), leaving caregivers of people
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34 with TBI to make the best decisions they can, while being aware that they lack capacity
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36 (Graff et al., 2018; Koehmstedt et al., 2018). For participants, this seemed to create a fertile
37
38 ground for hindsight guilt (hindsight bias (Klein et al., 2017; Fischhoff, 1975) resulting in
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40 guilt), where past decisions are interpreted as though participants had had present knowledge.
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42 Participants feel guilty, because they feel they should have known better. Such guilt can lead
43
44 to poorer functioning and reduced quality of life (Griffin et al., 2019). Also, while
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46 Townshend and Norman (2018) and the present study both discuss the challenge of reduced
47
48 capacity of the person with TBI, only the current study findings suggest advocating for
49
50 people with mTBI is a challenge. This is, however, articulated in other literature surrounding
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52 TBI and mental capacity and appears to be because the reduced capacity of people with TBI
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3 to self-advocate is not recognised by medical services due to the relative invisibility of their
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5 injury (Holloway & Norman, 2022; Moore et al., 2019; Norman, 2016).
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8 Ambiguous treatment pathways were discussed by all participants but not mentioned in
9
10 Townshend and Norman (2018), suggesting some ambiguity may be specific to mTBI. As
11
12 discussed, ALT (Dahl & Boss, 2020) predicts that adjustment to loss requires ambiguity to be
13
14 clarified or at least accepted. However, current mTBI patient information may not support
15
16 that. Patient information is not always provided (Norman et al., 2020; Seabury et al., 2018;
17
18 Silverberg et al., 2020) and where it is, patient education (Torbay and South Devon Trust,
19
20 2018; University Hospitals Birmingham Trust, 2018) does not reflect the current, partial
21
22 understanding of mTBI (Maas et al., 2017; Mayer et al., 2017; Nguyen et al., 2016; Pozzato
23
24 et al., 2020; Sharp & Jenkins, 2015). In this context, Norman et al. (2020) have called for an
25
26 acceptance of what we do not know for the benefit of people with TBI and their families.
27
28 Such information would be a basis for realistic conversations with providers (Chief Medical
29
30 Officer for Scotland, 2015; Fenning et al., 2019), which may assist families to adjust to the
31
32 injury (Cavallaro, 2018; Hyatt et al., 2014; Landau & Hissett, 2008; Snyder & Engström,
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34 2016; Yeh, 2018; Zolkefli, 2018) and maximise their resilience to live with ambiguity,
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36 consistent with ALT (Boss, 2018).
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43 **Reflexivity**

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45 The researcher is a person with mTBI, with symptoms that have persisted beyond three
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47 months post-injury. Rather than using Epoché to fence off this experience, IPA has allowed
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49 the researcher to consciously use their experience, to interpret the participants' interpretation
50
51 of their experience. In this way, a double hermeneutic approach has been taken (Eatough &
52
53 Smith, 2017). By making these assumptions explicit and documenting reflection and
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55 decisions made during the study, the researcher aims to maximise transparency and enable
56
57 critical review (Peat, 2019).
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Limitations

Since this was an IPA study, a homogenous sample was sought (Smith & Osbourne, 2008; Smith et al., 2009). All participants were civilian, English speaking, adult, white, women and educational attainment and mental health data was not collected. Also, this research focussed on families, whereas people with mTBI may have other support, or none.

Conclusion

This qualitative study aimed to explore the experiences of family members of someone with mTBI symptoms that persist beyond three months. It sought to extend and compare findings of the Townshend and Norman (2018) study, which focussed on all severities of TBI. Through extending that study to examine mTBI, the present study has found that families of people with mTBI, where symptoms last more than three months, may experience many of the same challenges as families of people with moderate or severe TBI, albeit at a lesser intensity. This includes difficulty making sense of TBI and challenges to their identity. They may experience different challenges to families of people with moderate or severe TBI, such as frustration caused by lack of congruity between patient education and their experience. Although they may experience ambiguous loss, in common with families of people with moderate and severe TBI, their experience of ambiguity may be exacerbated by a lack of clear mTBI patient information. Expectations set by patient education may be unrealistic and based on outdated research. Patient education that includes an acceptance of what we do not know, may benefit families of people with mTBI by reducing ambiguity, helping them to adjust to the injury, have realistic conversations with medical services and maximise their resilience to living with remaining ambiguity. Findings suggest that people with mTBI may not always have capacity to fully self-advocate. Families may benefit from medical services facilitating family advocacy. More research is needed to explore how generalisable these findings are and to develop theory in this area.

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Appendix A - Management Recommendations

Table 1

Recommendation number/location and strength

Variable	ONF	CDC	VA/DoD	CISG	NICE	SIGN
Prompt diagnostic evaluation	1.1 (A)	C	2 (Strong)	Pg. 3-4	22(Weak) Not mTBI specific	No advice
No routine neuroimaging	1.3 (A)	1A/1B, 2 (B)	3 (Weak)	C	23 (Weak) Not mTBI specific	3.3.6
No clinical use of serum biomarkers	C	6 (R)	3 (Weak)	Pg. 5	No advice (research proposed, 24 but not mTBI specific)	No advice
Advice to rest for 1-3 d post injury	3.4 (A)	13A (B)	C+	Pg. 5	No advice	No advice
Guidance on gradual stepwise return to preinjury activities	3.4 (A), 12.3 (A)	13B, 13D (B)	C+	Pg. 5, 7	25 (Weak) Not mTBI specific	C
Early education for patient/family	2.3 (A), 2.6 (A)	7A/7B (B), 12 (A)	11, 15, 22 (Weak)	C	23 (Weak) Not mTBI specific	No advice but reassurance about symptoms should be offered. 3.4.1
Use validated symptom scales for initial assessment and to track recovery	4.1 (C)	5A, 10B (B)	C	Pg. 3, 4, 7	No advice	No advice
Neuropsychological assessment to investigate persistent (>30d) cognitive symptoms	9.4 (A)	19C (C)	17 (Weak)	C	No advice	No advice. Cognitive assessment not recommended 3.3.3
Referral to specialist or higher level of care for slow to recover patients (>10-14d for adult athletes, >30d for others)	2.4 (C)	11B/15F (B)	21 (Weak)	Pg. 5	No advice	No recommendation but may be considered. 3.4.3

Note. C, consistent with but not explicitly recommended in guideline/statement.

CDC, Centers for Disease Control and Prevention Guideline on the Diagnosis and Management of Mild Traumatic Brain Injury Among Children. Lumba-Brown et al. (2018). Strength of recommendations: A, almost always should be followed; B, usually should be followed; C, may sometimes be followed; R, intervention generally should not be done outside of a research setting; U, insufficient evidence.

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3 CISG, Consensus Statement on Concussion in Sport—the 5th International Conference on Concussion in Sport. McCrory et al. (2017).
4 Strength of recommendations: Not applicable.
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6 ONF, Ontario Neurotrauma Foundation (2018). Guideline for Concussion/Mild Traumatic Brain Injury & Persistent Symptoms. Levels of
7 evidence: A, ≥1 randomized controlled trial, meta-analysis, or systematic review; B, ≥1 cohort comparison, case study, or other type of
8 experimental study; C, expert opinion, experience, or consensus panel.
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12 NICE, National Institute for Care and Clinical Excellence, (2019). Head injury: assessment and early management.
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15 SIGN, Scottish Intercollegiate Guidelines Network, (2013). SIGN 130 • Brain injury rehabilitation in adults.
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18 VA/DoD, Department of Veterans Affairs/Department of Defense (2016) Clinical Practice Guideline for the Management of Concussion-
19 Mild Traumatic Brain Injury. Strength of recommendations: Strong For, Weak For, Strong Against, Weak Against.
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21 *Recommendation is repeated in 4.5 and 12.5.
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32 [imaging&path=view%3A/pathways/head-injury/assessment-in-the-emergency-department-for-patients-with-head-injury.xml](https://pathways.nice.org.uk/pathways/head-injury/assessment-in-the-emergency-department-for-patients-with-head-injury.xml)
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5 [circulating-biomarker-s100b-to-rule-out-signi-2](https://www.nice.org.uk/researchrecommendation/using-biomarkers-to-diagnose-brain-injury-in-adults-with-medium-risk-indications-for-brain-injury-under-the-2014-nice-ct-head-injury-guidance-what-is-the-clinical-and-cost-effectiveness-of-using-the-diagnostic-circulating-biomarker-s100b-to-rule-out-signi-2)
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10 25 <https://www.nice.org.uk/guidance/cg176/ifp/chapter/Leaving-the-hospital>
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13 *Note.* Reprinted from Management of Concussion and Mild Traumatic Brain Injury: A Synthesis of Practice Guidelines. By Silverberg et
14 al. (2020). *Archives of Physical Medicine and Rehabilitation*, 101(2), 382-393. SIGN and NICE assessment added by the researcher.
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