

Walsh, R Stephen and Crawley, Lorraine and Dagnall, Neil and Fortune, Donal G (2020) The man who used to shrug – one man's lived experience of TBI. NeuroRehabilitation. pp. 1-14. ISSN 1053-8135

**Downloaded from:** http://e-space.mmu.ac.uk/626194/

Version: Accepted Version

Publisher: IOS Press

DOI: https://doi.org/10.3233/nre-203079

Please cite the published version

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# The man who used to shrug – one man'slived experience of TBI

R. Stephen Walsh\*, Lorraine Crawley, Neil Dagnall and Donal G. Fortune

#### 6 Abstract.

- 7 BACKGROUND: Stress is common to the experience of TBI. Stressors challenge physical and psychological coping abilities
- and undermine wellbeing. Brain injury constitutes a specific chronic stressor. An issue that hinders the usefulness of a stress-
- <sup>9</sup> based approach to brain injury is a lack of semantic clarity attaching to the term stress. A more precise conceptualisation of
   <sup>10</sup> stress that embraces experienced uncertainty is allostasis.
- **OBJECTIVE:** An emerging body of research, collectively identifiable as 'the social cure' literature, shows that the groups
- 12 that people belong to can promote adjustment, coping, and well-being amongst individuals confronted with injuries, illnesses,
- traumas, and stressors. The idea is deceptively simple, yet extraordinarily useful: the sense of self that individuals derive
- from belonging to social groups plays a key role in determining health and well-being. The objective of this research was to
- apply a social cure perspective to a consideration of an individual's lived experience of TBI.
- METHODS: In a novel application of interpretative phenomenological analysis (IPA) this research has investigated one person's lived experience in a single case study of traumatic brain injury.
- 18 **RESULTS:** Paradox, shifting perspectives and self under stress, linked by uncertainty, were the themes identified.
- 19 CONCLUSIONS: A relational approach must be key to TBI rehabilitation.
- 20 Keywords: IPA, TBI, rehabilitation, phenomenology, brain injury, social cure, relational

# **1. Introduction and literature review**

In-depth examination of the single case has a long 22 and fruitful history in cognitive and clinical neuropsy-23 chology (McPherson & Della Sala, 2019). Indeed, 24 discussing memory, Shallice writes that "most of the 25 greatest scientific advances from neuropsychologi-26 cal investigations has come from studies of a single 27 patient, or less frequently, a few similar patients, each 28 treated as individuals" (Shallice 2019, p.1). A key 29 strength of the single case in the current context is that 30 it permits an increased understanding of how an indi-31 vidual with brain injury experiences the world. The 32

research presented herein demonstrates that uncertainty is the fulcrum on which one survivor's lived experience of traumatic brain injury (TBI) pivots. Once, in his own words, our participant used to be a man who shrugged things off. Now, uncertainty, experienced as a consequence of living with brain injury, has rendered that old shrugging-self eclipsed by a more precarious self. Accordingly, the authors suggest that mitigation of uncertainty should be key to effective rehabilitation following TBI. The primary challenge faced by the researchers in writing this report was to present the reality of uncertainty, as it manifests in the lived experience of our participant, and those around him, in a frame possessing sufficient conceptual rigour. Therefore this paper is guided by the concept of allostasis, specifically the view that coping with stress requires production of

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strategies that can mitigate uncertainty about the
 future. In employing IPA the authors provide insights
 into one survivor's attempt to adjust following a
 severe TBI. The purpose of this paper is, through
 focusing intensely on one person's lived experience,
 to produce transferable knowledge that may usefully
 be applied in both clinical and research contexts.

57 1.1. Brain injury

TBI is a leading cause of death and disability in 58 young adults throughout the world: fifty million peo-59 ple experience a TBI every year, with an estimated 60 yearly cost of \$US400 billion (Maas et al., 2017). 61 TBI may significantly impact a person's social, cog-62 nitive, emotional and behavioural functioning, which 63 may hamper a return to previous roles (Hoofien et al., 64 2001). Issues of identity and mood are key aspects 65 of medium to long-term outcome following injury 66 (Scholten et al., 2016), and are arguably more impor-67 tant to the individual than their functional outcome. 68

# 69 1.2. Allostasis and allostatic load

Stress is common to the experience of TBI (e.g., 70 Oureshi et al., 2019). Cannon (1932) was one of 71 the first academics to apply the concept of stress 72 to homeostasis in humans (Romero, Dickens, & 73 Cyr, 2008). The idea, borrowed from engineering, 74 acknowledges that external pressures affect people. 75 Explicitly, stress-causing agents (stressors) if acute 76 or prolonged, challenge physical and psychologi-77 cal coping abilities and undermine wellbeing. From 78 this perspective, brain injury represents a specific 79 chronic stressor (Walsh, Fortune, Gallagher, & Mul-80 doon, 2014). Noting this, Walsh et al. (2014) posit that 81 the integrated social identity model of stress (Haslam, 82 2004) is pertinent to the study of acquired brain injury 83 (ABI). The model emphasises the need for theorists to 84 consider social and contextual factors that traditional 85 approaches often neglect. This is especially true with 86 individualised conditions such as brain injury, where 87 there is a tendency to focus on the person. The 88 integrated social identity model of stress provides 89 an alternative approach by viewing groups as cen-90 tral to the experience and perception of brain injury 91 and resulting stress (Muldoon, Schmid, & Downes, 92 2009). This approach is also relevant to under-93 standing related concepts, and explicitly perceived 94 control (Lazarus & Folkman, 1984). Other integral 95 concepts within the extant stress literature related 96 to ABI, and ABI rehabilitation, include moving 97

beyond individualism, group memberships, social identities, context, and perceived control.

An issue that hinders the usefulness of a stressbased approach to brain injury is lack of semantic clarity. The term 'stress' requires clarification because the term denotes both the agent that causes the response, and the reaction. Furthermore, over-stimulation of an emergency response results in 'chronic stress', which is associated with stress related disease (Romero, Dickens, & Cyr, 2008). Thus, in order to use the term stress appropriately, linguistic disambiguation and operationalisation is necessary. In the present study, the authors link stress with lack of certainty. This is because uncertainty is a stressor that undermines the capacity to predict, plan, and behave efficaciously (Hogg. 2007/2016). A more precise conceptualisation of stress that embraces uncertainty is allostasis. Allostatic load is what happens in terms of neuroendocrine, cardiovascular, neuroenergetic, and emotional terms when stress responses have become chronically activated (McEwan, 1998). In the context of TBI, allostatic load describes the situation when brains, organs whose function is to reduce uncertainty, are unable to resolve uncertainty (Peters, McEwan, & Friston, 2017). Hence, allostasis is an important concept because it recognises that stressed individuals perceive themselves as lacking control (Peters, McEwan, & Friston, 2017).

Taking things further, brain injury can usefully be understood as a chronic stressor (Walsh, Fortune, Gallagher, & Muldoon, 2014). Expanding on this point, Walsh et al. (2014) argue that the integrated social identity model of stress (Haslam, 2004) highlights the importance of attending to the social and contextual factors, often neglected in individualised considerations of illness, and can thus usefully be applied to the study of TBI. Not least because the model moves beyond individualistic analyses of stress. The integrated social identity model of stress regards groups as central to the experience and perception of stress (Muldoon, Schmid, & Downes, 2009). It is also important to consider the issue of perceived control (Lazarus & Folkman, 1984); Greenaway et al. (2015) having demonstrated that social identity is a significant predictor of perceived control.

#### 1.3. The social nature of human beings

In the early twentieth century, Vygotsky and Luria, founding fathers of modern neuropsychology, strove for a unified theory of mind (Cole, Levitin & Luria, 145

2010). In more recent years, a free energy princi-148 ple has been proposed which attempts to provide 149 a unified brain theory with particular reference to 150 action, perception, and learning. Friston (2010), in 151 a consideration of the free energy principle (i.e. 152 any self-organising system that is in equilibrium 153 with its environment must minimize free energy) 154 argues that the crucial characteristic of biological 155 systems is their capacity to maintain homeostasis in 156 an environment that is perpetually subject to change. 157 Moreover, Friston argues that maintaining homeosta-158 sis requires biological agents to minimize the surprise 159 that they experience. Friston (2010) suggests that 160 there are two methods open to agents in order to 161 avoid surprising states (i.e. uncertainty): (1) Change 162 the world by acting upon it; and (2) Change their own 163 internal states. 164

#### 165 *1.4. Social identity*

Lieberman (2013) reasons that contemporary sci-166 ence, including psychology, has a blind spot for 'the 167 social'. The self is important because it is 'a super-168 highway for social influence' (Lieberman, 2013, p.9). 169 One of the most rigorous and successful ways of 170 conceptualising the self is in terms of social iden-171 tity (Tajfel, 1974), whereby a person's sense of self is 172 understood as a derivative of the groups they belong 173 to, together with the social and value significance that 174 accompanies group membership(s). 175

The social identity literature links groups and 176 stress (e.g., Muldoon & Lowe, 2012). Moreover, 177 Haslam, Jetten, Cruwys, Dingle, & Haslam (2018) 178 have developed the social identity approach into a 179 new psychology of health. This provides a strong 180 theoretical foundation for linking a range of condi-181 tions, including stress and brain injury, to the idea of 182 self. The literature also associates groups with uncer-183 tainty. Hogg (2007//2016) developed uncertainty -184 identity theory, which derives from the premise that 185 individuals are unsettled and confounded by indeter-186 minate factors, particularly when they do not know 187 how they should behave individually, or towards oth-188 ers. Hogg (2016) claims that uncertainty, because of 189 the impact it has on identity (i.e. 'self' understood 190 from a social identity point of view), makes it difficult 191 for individuals to act efficaciously. Concomitantly, 192 individuals become motivated to reduce self-relevant 193 uncertainty. 194

One particularly effective way to reduce selfrelated uncertainty is through social categorisation. The reason for this is that social categorisation provides individuals with prototypes that offer templates as to how they, and others, should behave. Prototypes based on social categorisation allow individuals to know how they should feel. Consequently, the more uncertain that one is about oneself, the more one will strive to belong to groups (Hogg, 2014).

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Wilson, Gracey, Evans, and Bateman (2009) give powerful, coherent, and persuasive voice to a clinical acknowledgement of the necessity to engage with the biological, psychological, and social aspects of rehabilitation following TBI. Emotional and identity adjustment are key to rehabilitation and, given the understanding of identity set forth in preceding paragraphs, it seems (to borrow from and paraphrase Baddeley, 1993) that a rehabilitation approach that lacks a relational aspect is akin to a vehicle without an engine because rehabilitation is about the 'bio', the 'psycho' *and* the 'social'.

# 1.5. Interpretative phenomenological analysis (IPA)

IPA has a focus on the detailed examination of human lived experience (Smith, Flowers, & Larkin, 2009). As a psychological approach, IPA is underpinned by three key areas in the philosophy of knowledge: phenomenology, hermeneutics, and idiography.

# 1.5.1. Phenomenology

Maurice Merleau-Ponty, a phenomenological philosopher, was much taken with the usefulness of applying an understanding of human nature as embodied. Crucially, for those interested in TBI and rehabilitation, Merleau-Ponty was also much taken with the idea of the intrinsically social nature of human existence. In essence, Merleau-Ponty concluded that human beings cannot exist without others (Bakewell, 2016). 'Phenomenology helps physicians. It makes it possible to consider medical symptoms as they are experienced by the patient rather than exclusively as a physical process' (Bakewell, 2016, p.42). IPA is likely the most common contemporary approach to phenomenological psychology in the UK (Langdridge, 2007).

Phenomenology is a philosophical approach whose focus is on lived experience. Intentionality is a key idea for those who would harness a phenomenological approach for the purpose of psychological analysis. Intentionality is the idea that when we are conscious, there is always something that is the object of our consciousness. A thing that we are 'conscious

of'. To the perceiver, consciousness, and the object 247 of consciousness, are one (Bakewell, 2016). 248

#### 1.5.2. Hermeneutics 249

Hermeneutics is the theory of interpretation and a 250 consideration of hermeneutics highlights the iterative 251 process of a phenomenological analysis. Qualitative 252 analysis is often described in a linear fashion - mov-253 ing forward through the data. IPA analysis is not 254 linear (Smith, Flowers, & Larkin, 2009) and, as such, 255 it is worth highlighting the recursive nature of IPA 256 analysis 257

#### 1.5.3. Idiography

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Idiography, a concern with the particular, has been 259 a major influence on IPA. This concern manifests at 260 two levels. First, IPA is committed to in-depth and 261 detailed analysis of the phenomena on which it is 262 focused. Second, IPA is concerned with how expe-263 riential phenomena are understood from particular 264 perspectives. Hence the effective use of single case 265 analysis and the commitment to the single case in its 266 own right. This idiographic focus on the particular is 267 'in contrast to most psychology which is 'nomoth-268 etic' and concerned with making claims at the group 269 or population level, and with establishing general 270 laws of human behaviour' (Smith, Flowers, & Larkin, 271 2009, p.29). 272

The goal with IPA is thus not generalisable knowl-273 edge; the goal is transferable knowledge. 274

#### 2. Method 275

2.1. Research question 276

With a particular focus on stress, coping and recov-277 ery, what is the lived experience of TBI? 278

#### 2.2. Participant 279

The study recruited the participant, 'P', from 280 existing professional networks. In order to ensure 281 anonymity, the authors report only general partici-282 pant details. P is a married man, in his forties. He is 283 a father of three teenage children, who works full-284 time in a professional capacity. Two years prior to 285 the interview, the participant suffered a severe, life-286 threatening TBI following a high-speed bicycle fall 287 while participating in a race. P was wearing a helmet 288 at the time, but still sustained a serious injury to his 289

left frontal lobe. To convey a sense of the injury in his own words P reported:

'I was coming down xxx pass from the car park towards xxx going fast, because it's downhill. Erm, nobody knows what happened because nobody saw what happened. I don't remember anything happening but I came off my bike erm who knows how, and hit my head. There is speculation that I may have hit it against the wall because the wall is very close to the side of the road there. Like only a foot or so away from the wall. So if you do go over the handlebars for whatever reason, there is a good chance that you are going to hit the wall. Erm so I ended up cutting my head. So I actually had a wound, It was more than just a wound, or a bang in the head. It was actually cut open as well. So I hit something sharp. Erm, in the process and then must have skidded on my side quite a long way because the whole of my right hand side was grazed. Erm, yeah and some walkers got to me. They heard it. They heard me crash, and they got to me and they basically held me together. They basically held my head together....

So what had happened is that I'd basically, I'd, it was a complete, I dunno what you call it, whole piece of skull. It was a depressed fracture. So a whole piece of skull had snapped. About the size of a saucer I suppose. A tea cup saucer, a whole piece of skull had been broken and then pushed into my brain. And the eye socket had hinged and apparently there's some sharp bits at the back of your eye socket and that had sort of, one of those had gone up because it had hinged. It had gone up. Punctured the membrane. Gone into my brain. Erm and there was bleeding on the brain.

So it was a severe injury and basically the walkers got to me and sort of kept me together. From what I've heard, I understand there was an ambulance at the top, or not too far away anyway and the ambulance was called. I think that the second person on the scene was a nurse and then they got the road ambulance. The road ambulance basically stabilised me. Got me to xxx hospital. xxx hospital then took one look at me and said we're not touching you. And then I got airlifted to Yvy which is the head trauma centre. Erm, they cleaned me out on that Saturday and they did the big op on the Tuesday'.

#### 2.3. Interview

The interview process took place on University premises and lasted for approximately one hour during which the participant (P) read an information 339

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sheet, completed a consent form, and had the opportunity to ask questions about the research at hand.

The interview was recorded on an audio device and transcribed immediately afterwards by the interviewer (SW).

#### 346 2.5. Analysis

IPA analysis is an iterative, recursive process. As 347 such, we felt that it makes sense, adds coherence, and 348 renders our analysis more transparent, to report, and 340 discuss, our results in a manner that mirrors that in 350 which we produced them. Smith, Flowers and Larkin 351 (2009) make clear that there is no 'right' way to 352 do IPA. One advantage of the manner in which we 353 present our results in this paper, in combination with 354 method and discussion, is that it makes our sense-355 making of the participant's sense-making transparent. 356 This double hermeneutic is absolutely fundamental 357 to IPA and, in our opinion, it emphasises the golden 358 thread of narrative that runs throughout our report -359 uncertainty is at the heart of the lived experience of 360 TBI. 361

IPA analysis was conducted in the manner sug-362 gested by Smith, Flowers and Larkin (2009): 1. 363 Reading and re-reading; 2. Initial noting; 3. Devel-364 oping emergent themes; 4. Searching for connections 365 across emergent themes. In order to break the narra-366 tive flow and deconstruct the transcript we utilised a 367 suggestion that Smith et al offer and worked through 368 the transcript backwards, paragraph by paragraph, 369 as well as reading from start to finish in the usual 370 manner. 371

After working on initial coding of the transcript the first author passed on a synopsis of initial codes to the remaining authors for their input. These initial codes were accompanied by the transcript, as annotated by the first author.

Linguistic comments; comments pertaining to concepts; and descriptive comments (i.e. pertaining to meaning and concerns). All of the co-authors discussed and agreed initial coding at this stage. The initial codes are outlined below.

#### 382 2.6. Linguistic comments

There was interesting movement between the active voice and the passive voice, between engaged and detached, and between first person and third person.

Examples:

In the opening part of the interview, P talks about a whole piece of skull snapping and 'it was a severe injury'. He doesn't say 'I had' but rather 'it was'. This reflects his experience. In describing the injury he begins from a position of detachment.

Similarly, a little later, P says: 'So obviously, my brain had already processed that there was something going on'.

This seems a rather distanced way for P to speak of himself. Slightly jarring.

The language used during the interview serves to position P as passive. 'I ended up in xxx'

However, there is a shift in gear after about 5 minutes into the interview when P says: 'I had a serious confabulation'.

Not 'my brain had' or 'the injury rendered me confused' but 'I had'. It's interesting that the next sentence evidences concern with using the correct terminology. Is this about validating his experience? It later transpires that P has had previous mental health issues. Is the change of gear because he is on 'safer ground' talking about mental health than TBI?

It is notable that, excepting on one occasion, the language P used for family members might be read as rather distant and does not use any names. 'My wife', 'she,' 'they,' 'the kids,' 'my mother,' are the order of the day. It may be that this language is indicative of distance, or detachment.

A line that jumped off the page at us on first reading the transcript is where P says that he latches on to 'an idea then peck people's heads about it'. This is a most vivid use of language and it serves to position P as both engaged, and as an outsider poking in. It is reminiscent of Socrates and the gadfly. Perhaps we are reading too much into this line, but it does convey a somewhat ominous feeling of discomfort to the reader.

When linking his experience of TBI to his depression, P takes possession of the narrative:

'I equate (TBI) as very similar to my experiences with depression'.

It may be that the same thing is at play here as in the section mentioned earlier where there was the shift in gear to 'I'.

As the interview proceeds we move back to the more passive version of P.

'My personality is quite project-focused'.

Not 'I am....', instead, P is quoting himself. He is very much in the observer role here and it conveys

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an impression of unemotional detachment from thethoughts described. Almost cold.

'I'm not going to let this little brain injury thingstop me....'

P refers to his marriage as 'the relationship'.

442 Not 'my relationship'/' my marriage' etc. Again,
443 this might be perceived as detachment. Also, there is
evidence of loss (on the family's part) behind the way
language was deployed here.

As the interview approaches the half-way point we have another shift of gear back to 'I'. This shift was prompted by the question about uncertainty and we think it is because the device of 'project focus' is being used to position P as having some element of control over his life and circumstances.

'I can keep going a bit more'

It seems that positioning and control is also behind
P's description of what was a life- threatening and
life-altering TBI as a

'serious bump on the head'

### 457 2.7. Concepts

There were some fascinating concepts in this transcript.

The first concept we picked out was the concept of
project and project focus. For example, P says that 'I
see my life in terms of projects'

Across the entirety of this interview, uncertainty loomed large and it is interesting how the concepts of the project and uncertainty are almost oppositional, or counterbalancing, in terms of each other. The impression we derived from the transcript is of finely balanced coping:

"It may be a bounce back reaction and it's like 469 I'm on my second life now so I'm just going to go 470 for it. But there is that niggling idea that I've dam-471 aged my brain. Whether that's noticeable on a day 472 to day level and whether that has any effect on 473 any future deterioration of any sort. I don't know. 474 But there's part of me that goes ... It just give you 475 that sense of mortality and it's like I don't know 476 how much longer I've got with a fully functioning 477 mental capacity. So you kind of have a project and 478 this is like what I want to achieve now because 479 its, I don't know, just in terms of work, it's like 480 thinking through to retirement at 65 is like I 481 don't know if I have that long left. That might be 482 something that everyone thinks at my age, or not, 483 I don't know. But from my perspective it's like 484 I don't know how many good years I've got". 485

A second concept that we identified in the transcript is the link to depression. At several points, P links his previous experience of depression with his current experience of TBI:

"But then I see it's (i.e. the TBI) very similar as to when I was diagnosed with the depression. People start or at least it feels like they start treating me differently because they now see you as a medical case and in both of these I've always argued, it's like stop medicalising me"

"And it feels the same with my depression"

There is also a conceptualisation of the person that is both social and personal. There is, on the one hand, a thread invoking an almost unconscious need for recognition of context, and a holistic view of P's being in the world, running through the entire transcript. On the other hand, there is a view that P is very much an individual. It seems that this was evident to P who felt the need to express it explicitly at the end of the interview:

"Another thing I want to say is that the whole person-centred element is quite erm current. And you know you get quite person-centred learning and person-centred counselling. So just from my experience the whole person-centred approach to dealing with brain injury and listening to their experience. What I struggle with medically is that the medical system focuses on the patient and it is all about the patient and patient care. And fails to see a more holistic view in terms of the family and the kids. So if I go to the doctor and say I've had a brain injury, they'll say 'ok' and I'll deal with you and they may listen to you. But the family and the kids, they're their own problem. Not part of the solution and the listening process".

Perceptions and differences in perceptions figured prominently in the interview: P sees his injury as a predominantly physical thing. For his family, it's a psychological event. P is blasé about it whereas for his family it is traumatic. For P it is a progression, and for his family it is a triggering event:

"I see it more as a progression thing rather than a purely post injury before and after because I see there were things happening in my life, in me and my relationship prior to the accident. Whereas I think they tend to see it, they have the accident very much as a, an event that triggered things. Whereas I see there was an event, and it may have 492

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triggered things, changed things, but it may have
just accelerated what was already happening and
I see it within a much longer time frame"

There is also a divergence of perspectives: For the family the injury was a shared, traumatic experience. Whereas for P it is experienced as a distant event:

<sup>541</sup> "I'm sort of distant from it in a way because they
<sup>542</sup> don't talk to me that much and when I try to ask
<sup>543</sup> them then there seems to be this conflict about
<sup>544</sup> what they say they're thinking and what my wife
<sup>545</sup> says is reporting to me what they're thinking. It's
<sup>546</sup> just a big muddy".

Then there are the differences with regard to P's immediate family and those one step removed who see his as a miraculous recovery:

"There's a bit of conflict between her and my 550 family because my mum is like 'oh what a mirac-551 ulous recovery,' you know, we're all so pleased 552 and Mary (pseudonym) is like 'You should try 553 living with him'. (Both Laugh). It's not all roses. 554 So that has led to a bit of a fall out as well. Because 555 its perspective and how close. Anyone who is like 556 one step removed from me seems to think like I'm 557 fine". 558

# 2.8. Descriptive comments (Meanings and concerns)

The TBI has some overlap with P's experience of 561 depression in terms of what it means to him. But the 562 different use of language around each suggests that 563 the depression has been processed in a way that the 564 TBI has not. For example, P tended to use the first 565 person when speaking about his depression and the 566 third person when speaking about his TBI. Is it that 567 the depression is experienced as resolved? 568

#### 2.8.1. Uncertainty

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A couple of years after his accident, P returned to 570 compete in, and complete, the event in which he had 571 suffered the TBI. It may be that P's return to the event 572 where he almost died means significantly more to him 573 than the mere 'box to be ticked' that he talked about 574 in the interview, or a consequence of 'project focus'. 575 P's description of the event he was taking part in at the 576 time of his injury as 'The bruiser' is, perhaps, telling. 577 We think that P's description of the accident as a phys-578 ical event for him but as a psychologically traumatic 579 one for his family is also telling. The accident means 580

different things to different people. There is considerable uncertainty attaching to it. There seemed, to us, to be scant overt emotion attaching to the TBI from P's perspective. However, we could not help but wonder, on reading the transcript, whether the repetition of the event may not have had something to do with a desire to resolve and reduce uncertainty. Even if this processing was taking place outside of conscious awareness.

Lastly, there seems to be something pertaining to both meaning and concern in that P experiences his TBI as an event falling on the continuum of his life:

'I always used to describe myself, before I was depressed, as the man who shrugs. I used to just shrug stuff off and I didn't have any strong feelings or care. It was like if you want to do that, that's fine. I'm not bothered. And since the depression and maybe even more now, I've kind of felt like I am standing up more for myself and how that comes across is probably just rude and aggressive (laughs). Particularly if that is in contrast to how I was 15 years ago or whatever. Then it is suddenly like, you're being a bit aggressive here. Being a bit selfish and a bit self-centred and all the rest. Whereas to me it is simply like I am trying to get my point across.'

Whereas for others in P's immediate family, the event is like a light switch moment. It is clear that there is loss implied in his family's experience. It is less clear whether P is sharing that experience of loss at an emotional level.

Another very important aspect is that P is still 'a valid human being'.

For P: "one particular stress (is) around the sort of long term effects and changes, I equate as very similar to my experiences with depression. Erm, in that two things. One is that my kind of denial and inability to see how I've changed. It's clear that my wife and she reports some of our friends, see that I behave differently. And that I am somehow quite different. And that's not seen with my work colleagues. So it is only people who are close and sort of live with me or have experienced me closely see those changes that maybe even I don't see. Some of them I can accept on a kind of intellectual level. But I don't see that I am radically different now as I was then. Because that's a conflict, I think that's quite stressful. But then I see it's very similar as to when I was diagnosed with the depression. People start or at least it feels like they start treating me differently because they now see you as a medical case and in both of these I've always

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argued, it's like stop medicalising me. You're treat-632 ing me like I'm a case book and I just find that really 633 stresses me. I'm still a person. I'm still a valid human 634 being. It feels like other people are always interpret-635 ing you and analysing you through that perspective of 636 'you've got a brain injury' or 'you've behaved differ-637 ently' or 'your personality has changed' or whatever 638 it is. And it feels like you are no longer being taken 639 at face value." 640

#### **3. Themes and discussion**

IPA begins with, but should go beyond, a standard 642 thematic analysis (Brocki & Wearden, 2006). Fol-643 lowing initial coding, we identified four themes. In 644 line with the guidance offered by Braun and Clarke 645 (2006), these themes were produced/arrived at by 646 organising those codes that had been identified in the 647 first stage of analysis into bigger patterns of mean-648 ing that spoke directly to our research question. We 649 also tried to take on board the advice of Smith and 650 Osborne (2003, p.71) to imagine a magnet with some 651 of the themes pulling others in and helping to make 652 sense of them. 653

As the analysis proceeded recursively in steps, developing emergent themes and searching for connections across emergent themes merged, producing connected themes: 1. Paradox/contradiction; 2. Shifting perspectives/discontinuity; 3. Self under stress. Uncertainty was an overarching theme.

In order to keep on the phenomenological track, the 660 four aspects of life-world (temporality [experience of 661 time], spatiality [experience of space], embodiment 662 [experience of being in a body], and inter-subjectivity 663 [the relational aspect of lived experience]) guided the 664 authors. These acted as focal points during theme 665 exploration. It is also necessary to state that, in line 666 with the IPA guidance offered by Smith, Flowers, and 667 Larkin (2009), theme construction primarily derived 668 from coding notes. The purpose of conducting anal-669 ysis in this way was to facilitate breaking up of 670 transcript narrative flow. This represents a manifes-671 tation of the hermeneutic circle, where the themes 672 identified capture and reflect understanding (Smith, 673 Flowers, & Larkin, 2009). 674

#### 675 3.1. Paradox

The 'paradox' theme is important. Before coming to the specifics of the case at hand, it is worth noting that one significant, and generally unconsidered, paradox is that the experience of TBI is simultaneously intensely individual and intensely social (Walsh, Fortune, Gallagher, & Muldoon, 2014). Historically, approaches to brain injury rehabilitation have been rooted in individualism. These individualistic ways of understanding TBI were, and remain, important. However, individual selves can also be understood as reflective of social constructs which arise from social contexts. Hence, it is useful to view TBI as having a social aspect.

The social and individualistic frames for understanding TBI are not 'either/or'. Yes, it is paradoxical that TBI is both individual and social. However, Bowen, Yeates and Palmer (2010) propose that in order to understand fully what lies within the brain, neuropsychological inquiry must look outwards to social relations and context.

Furthermore, it has not escaped our notice that there is also a contradiction in our using a single case study to explore 'the social'.

In considering the lived experience of P, we find much that is paradoxical. For example, P is both detached (e.g., 'Erm, so yeah. I'm sort of distant from it in a way because they don't talk to me that much and when I try to ask them then there seems to be this conflict about what they say they're thinking and what my wife says is reporting to me what they're thinking'.) and engaged (e.g., ' I latch onto an idea then peck peoples heads about it'); active (e.g. 'I'm quite project focused. And I think I have become more so since the injury') and passive (e.g.,' So obviously, my brain had already processed that there was something going on'; 'my personality is quite project focused'); individual and social (explored further in 'self under threat' theme); ABI is seen as both a continuum with the past (e.g., 'I always used to describe myself, before I was depressed, as the man who shrugs. I used to just shrug stuff off and I didn't have any strong feelings or care. It was like if you want to do that, that's fine. I'm not bothered. And since the depression, and maybe even more now, I've kind of felt like I am standing up more for myself and how that comes across is probably just rude and aggressive (laughs). Particularly if that is in contrast to how I was 15 years ago or whatever. Then it is suddenly, like, you're being a bit aggressive here. Being a bit selfish and a bit self-centred and all the rest. Whereas to me it is simply like I am trying to get my point across.') and as a break with the past (e.g., ' And this is probably where it is a sticking point, I see it more as a progression thing rather than a purely post injury before and 729 after because I see there were things happening in my 730

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life, in me and my relationship prior to the accident.
Whereas I think they tend to see it, they have the
accident very much as a, an event that triggered
things. Whereas I see there was an event, and it may
have triggered things, changed things, but it may
have just accelerated what was already happening
and I see it within a much longer time frame').

Platt (2001) discusses the use of paradox in 738 Shakespeare and argues that a recognition of the 739 paradoxical nature of the world is a prerequisite for 740 cognitive growth. According to Platt, this applies to 741 both characters and audience (intrinsically social and 742 individual!). We argue that Shakespeare, perhaps the 743 shrewdest observer of human nature to ever write in 744 the English language, picked up on something that 745 we, as psychologists focused on rehabilitation, can 746 usefully apply to thinking about rehabilitation fol-747 lowing brain injury - the idea that paradox needs to 748 be recognised in order for a person to move forward 749 and grow post TBI. 750

Vygotsky (1978) offers an extraordinarily useful 751 set of thinking tools to contemporary psychologists 752 wishing to grapple with what appears to be para-753 dox. Cole and Scribner (1978, p.6-7) report that 754 'Vygotsky saw in the methods and principles of 755 dialectical materialism a solution to key scientific 756 paradoxes facing his contemporaries'. A central tenet 757 of this method is that phenomena should be stud-758 ied and understood as processes in motion, and in 759 change. Thus, when Vygotsky speaks of his approach 760 as "developmental" this is not to be confused with 761 a theory of child development. The developmental 762 method, in Vygotsky's view, is 'the central method 763 of psychological science'. The dialectic represents 764 opposing directions of thought united in a contin-765 uous whole. This way of approaching paradox in 766 a holistic manner allows us to transcend binary 767 thinking and, in Vygotsky's view, should facilitate 768 an enhanced understanding of the human psyche 769 (Daniels, 2008). 770

As one of the research team (DF) was examin-771 ing the transcript for the first time, that hoary old 772 'two roads diverged in a yellow wood' came to their 773 mind. A question arose as to whether P's narrative 774 represented a 'real' (i.e. as others might consider it) 775 or interpersonal/intrapersonal divergence. In the spe-776 cific case of P, and the broader context of TBI cases 777 generally, these questions are there to be thought 778 through. On discussion, amongst the authors, the 779 diverging road image spoke to the image of a 'Y'. 780

One group of researchers who have spent considerable time on precisely this aspect of TBI, in terms

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of a 'Y' shaped model of the rehabilitation process, are Wilson, Gracey, Evans, and Bateman (2009). Pictured as a 'Y' the top left of the 'Y' is seen as pre-injury self-representations, and the top right of the 'Y' is seen as the self in current context. The gap between both is the experience of self under threat. Alternatively, discrepancy. Hence, the model fits easily with both Vygotskian understanding of lifespan development as process, and the Allostatic brain literature which regards stress (in this case ABI) as a generator of existential uncertainty.

It is noteworthy that TBI survivors often seem cognitively intact to interviewers (and others) and that the person with TBI does not perceive changes in themselves in the same manner that their family members do (Newby, Coetzer, Daisley, & Weatherhead, 2013). This is discussed further below. Rehabilitation, according to Wilson, Gracey, Evans, and Bateman (2009) is about bringing the discrepant arms of the 'Y' in the survivor's rehabilitation process together as TBI survivors integrate their pre- and postinjury selves, as well as those around them, and the world in general.

It is a paradox that P is both the same but different, and the reasons are both individual and social. Under the spotlight of TBI, the consequence of this unresolvable paradox is uncertainty.

Newby, Coetzer, Daisley, & Weatherhead (2013) report that disinhibition and social isolation are common following TBI. Moreover, because survivors often do not experience the same changes as those around them, others do not perceive that they require rehabilitation. This discerned continuity, as evidenced by P in this report, as well as the perception of disinhibition on the part of the family, may reflect an attempt to mitigate uncertainty. This process is thus best understood holistically. Research has shown that individuals experience greater change during times of uncertainty, and when stress is high (Tedeschi & Calhoun, 1996).

The uncertainty and stress literature (e.g., Peters, McEwan, & Friston, 2017) outlines how, in contexts where uncertainty remains unresolved, individuals encounter allostatic load. Habituation is key to wellbeing for those faced with long-term exposure to allostatic load. Probability appraisal, in turn, is key to habituation. Those who habituate do so by broadening their probability expectations of goal states divergence (Peters, McEwan, & Friston, 2017). In other words, people predict that they will often be wrong in their predictions. They become reconciled with uncertainty. 783

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Conclusion - Paradox: The certainty of uncertaintyrelieves uncertainty.

#### *3.2. Shifting perspectives*

Perspective-taking is about seeing, and appre-838 ciating, things as others do. Perspective-taking is 830 purposeful. Attempting to walk in another's shoes, 840 so to speak. Things that one can take a perspective on 841 include situations, states, and objects (Echterhoff & 842 Higgins, 2011). One reason that we take perspectives 843 is to understand others and predict their behaviour. As 844 outlined earlier in the paper, allostatic load, related 845 to uncertainty, feeds into chronically activated stress 846 responses. 847

In P's narrative, perspective-shifting attempts are 848 apparent throughout. P is concerned with how oth-849 ers see him, he shifts between 1st and 3rd person 850 when referring to himself. Considered from an allo-851 static load framework, TBI generates a tsunami of 852 uncertainty and delivers a double hit because: a) TBI 853 constitutes an existential threat to the survivor, and 854 those around them, and is thus both an acute and 855 chronic source of uncertainty; b) An important pur-856 pose of our brains is to come up with strategies that 857 reduce uncertainty. TBI impacts the organ's capacity 858 to do this. Crucially it also impacts on the capacity to 859 draw on social resources that might aid in uncertainty 860 reduction via social support. 861

One way that TBI can influence the capacity to 862 draw on social resources is via damage to those 863 regions of the brain that impact a person's capacity 864 to mentalise effectively damage which impacts a per-865 son's capacities to mentalise (i.e. decode the mental 866 states of others; Bowen, Yeates, & Palmer, 2010). We 867 perceived, perhaps mistakenly, some lack of capac-868 ity to appreciate the perspective of those close to P, 869 associated with comments where P expressed frus-870 tration with being regarded as a 'medical case' and 871 'different'. 872

P also referenced his experience of cognitive-873 behavioural therapy (CBT) from his pre-TBI 874 depression: "when I had my depression, I did a CBT 875 course which is supposed to help. I maybe didn't take 876 it as seriously as I could but there were elements of it 877 that were useful at the time. But my wife says that I 878 became much more aggressive as a result of it. Now 879 I think we also have friends who did couples coun-880 selling prior to that and that was all about erm one of 881 them being more assertive and I think she frames my 882 CBT course in the same frame as their couples coun-883 selling and she has in her head that I was supposed to 884

come back from the CBT more assertive and says I was more aggressive. That wasn't what the CBT was about but that is how she was interpreting"

This lead us to a consideration of how engagement with a formal therapy prior to a brain injury may influence the reaction and coping with a lifethreatening event, i.e. the brain injury itself. There was some blunting of affect discernible in the transcript which could be attributed to the TBI and/or perhaps the influence of a pre-TBI depression; P presented awareness of 'doing' as a coping mechanism however the 'feeling' was not as apparent. It is noticeable that P refers to the depression as 'my depression' which implies an ownership or internalization of it and he also acknowledged that there were aspects of the CBT which he found useful during that time. It could be that the CBT provided an alternative explanation from the medical model and therefore the 'label' under the psychiatric classification system could be challenged and under his control. P also referenced throughout the script his action-oriented personality and there could be a link with actionorientation and the implementation of behavioural activation strategies that are prevalent in CBT as a response mechanism. The use of actions can give a sense of control, particularly when someone is coping with dys-executive changes brought about by a brain injury (Evans, Emslie, & Wilson, 1998). There is less evidence in the script of application of the CBT cognitive skill strategies to the TBI. The TBI itself is presented in a more medical light through the linguistic presentation of how it occurred and its impact. Another possible reason for presenting the TBI in a medical light may be that the CBT became a stressor as the perceived external reaction to it (from his wife) was one of reproach and therefore, altering cognitive and, in turn, communication style, may have been consciously avoided. P also highlighted in his own words a common criticism in the literature of the CBT approach in that in some cases it may become overly focused on formulations at the individual level of experience (Gaudiano, 2008) and that it made him consider a more 'holistic' approach in terms of addressing relationship issues-i.e. that therapy would include significant others in the context of a systemic approach.

A person's capacity to navigate their social world is compromised by TBI because it upsets delicate social ecosystems in subtle ways (e.g. Newby, Coetzer, Daisley, & Weatherhead, 2013). We can see this in P's transcript, for example, in a section where he says that, following the TBI, 'I felt that I was fine 930

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apart from the tiredness. My wife says that I have 937 changed and that I was a lot different. She says that 938 I, kids have noticed differences as well. When I talk 939 to my kids, they say that it is not that different. My 940 wife is saying that it is more different than they have 941 said. But there's a whole different perspectives thing 942 going on'. We can see that, in line with the obser-943 vation made by Newby et al, the TBI is a manifest 944 source of uncertainty. 945

On the descriptive side, it seems that there is the 946 appearance of some emotional detachment and the 947 almost clinical description of the TBI event as if 948 from a third party perspective. Might the 949 engagement with therapy pre-TBI have influenced 950 current cop-ing style? Or is there a worry that if the 951 emotions are experienced, then the depression may 952 re-emerge?It does come across as being more part of 953 a nar-rative than a specific event and there is a sense 954 of almost annovance at other's reactions. On consid-955 ering the transcripts, we were drawn to the coping 956 responses; doing the projects (e.g." my personality is 957 quite project focused") yet we also made reference 958 to retreating (I think we've both kind of retreated to 959 our safe spaces, which is not interactive); we can see 960 that P seems to be engaging with the practical - but 961 not the interpersonal. 962

It is often the case that people close to TBI survivors experience changes that the survivor does not. It is also clear that there are biological, psychological, and social aspects to the complex emotions (on all sides) associated with TBI (Newby, Coetzer, Daisley, & Weatherhead. 2013).

In order to most effectively address allostatic load, 969 in a rehabilitation context, we argue that the clini-970 cal focus needs to be on relational approaches (i.e. as per Bowen, Yeates, & Palmer, 2010). Social con-972 text and relationships are therefore vital. We need to 973 ensure that the capacity for shifting perspectives is as 974 functional as possible 975

#### 3.3. Self under stress 976

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It is clear from the transcript that P embodies a self under stress. This is not at all unusual in the context of TBI.

At this point, it is important and necessary to out-980 line exactly what we mean when using the word 981 'self'. In the contemporary neuropsychological reha-982 bilitation literature ideas of personality have been 983 superseded by concepts of cognitive representations 984 of 'self' (Yeates, Gracey, & Collicutt McGrath, 985 2008). Within the social identity approach, Simon 986

(2004, p.9) suggests that multiple possible identities emerge from interaction between individual brains and their environments. Simon (2004) deploys the idea of identity in a broad sense to cover phenomena, and processes, discussed by others under the heading 'self' (Simon, 2004, p.2). We have followed Simon's lead with regard to defining 'self' and 'identity' in this paper.

So, identity can be understood as the product of self-interpretation processes which take place as the result of social interaction (Simon, 2004). Hence we are dealing with what might be regarded as a dialectic (or paradox) where one pole of the concept of self is social, and the other is individual.

Social identities are those selves, based on valued group memberships, that constitute who, as individuals, it is that each of us understand ourselves to be. At our base, each of us has social identities, selves, that are relational and founded upon relationships.

Walsh, Fortune, Gallagher, and Muldoon (2014) argue that in order for identities to be viable following TBI, survivors must be able to perform their identities. It may be that this performative aspect of identity was the driver of P's re-participation in a race that had almost killed him on his previous attempt. Hogg (2016) discusses social identity in the context of existential threat and it is relevant that the idea of social identity itself, and social identity as a body of theory, was born out of existential threat in the theory founder's own life<sup>1</sup>.

Following TBI, the neuropsychological rehabilitation literature "consistently shows that TBI devastates relationships of all kinds" (Newby, Coetzer, Daisley, & Weatherhead, 2013, p.272.). Hence, according to Newby et al. (p.123) identities (or self-constructs) are rendered fragile and left threatened by TBI.

Threatened identity is linked to the experience of uncertainty and people are motivated to reduce uncertainty (Hogg, 2016). Furthermore, as outlined earlier in this paper, uncertainty is intrinsic to the experience of allostatic load. It may well be that the experience of uncertainty ties into P's projects (e.g. "I see my life in terms of projects. The whole doing the same event (after the injury) was a project. It was a big project, and I was just very focused on that. It wasn't a catharsis thing. I didn't do it because it, because I had to do it, it was because previously it was on my

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<sup>&</sup>lt;sup>1</sup>The founder of Social Identity Theory, Henri Tajfel, was a Polish Jew who survived imprisonment by the Nazis as a consequence of hiding his Jewish identity.

tick list") and in terms of psychology, factors relating 1035 to efficacy (e.g. Bandura, 1995). 1036

Hogg (2016, p.10) suggests that social categorisation is 'particularly effective at reducing uncertainty because it furnishes group prototypes that describe how people (including self) will and ought to behave and interact with each other'. To a significant degree, being able to competently self-categorise reduces uncertainty because the groups that we belong to prescribe our behaviour when acting as members of those groups. Conceptually, this is very close to the metaphoric identity mapping (e.g. Ylvisaker et al., 2008) with which many of us are more familiar.

Indeed, it may well be that there is utility in assessing social categorisation skills in order to reduce uncertainty for those living with TBI (based on Hogg, 2016)

Ontologically, human beings are social creatures 1052 (e.g. Daniels, Cole, & Wertsch, 2007) and most use-1053 fully in terms of TBI rehabilitation, according to Simon (2004), people are most usefully understood in terms of process, rather than essence. Relatedly, we need to think in terms of people rather than brains - people have relationships with other people, brains don't. This point manifests powerfully in the current 1059 paper when P talks about himself not being a medical 1060 case and still being a 'valid human being'

" So one particular stress around the sort of long 1062 term effects and changes, I equate as very sim-1063 ilar to my experiences with depression. Erm, in 1064 that 2 things. One is that my kind of denial and 1065 inability to see how I've changed. It's clear that 1066 my wife, and she reports some of our friends, see 1067 that I behave differently. And that I am somehow 1068 quite different. And that's not seen with my work 1069 colleagues. So it is only people who are close 1070 and sort of live with me or have experienced me 1071 closely see those changes that maybe even I don't 1072 see. Some of them I can accept on a kind of intel-1073 lectual level. But I don't see that I am radically 1074 different now as I was then. Because that's a con-1075 flict, I think that's quite stressful. But then I see it's 1076 very similar as to when I was diagnosed with the 1077 depression. People start, or at least it feels like 1078 they start, treating me differently because they 1079 now see you as a medical case and in both of 1080 these I've always argued, it's like 'stop medical-1081 ising me.' You're treating me like I'm a case book 1082 and I just find that really stresses me. I'm still 1083 a person. I'm still a valid human being. It feels 1084 like other people are always interpreting you and 1085

analysing you through that perspective of 'you've got a brain injury' or 'you've behaved differently' or 'your personality has changed' or whatever it is. And it feels like you are no longer being taken at face value."

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This tension between being a 'valid human being' and being a 'medical case' also shows that, as well as being exceedingly uncertain, the internalised perspectives and judgements of others have a huge voice in P's experience. This tension is adding to the uncertainty that is hovering with regard to physical and psychological integrity, mortality, and the myriad other issues facing P.

We know from the literature that a person's adjustment to life post TBI is dynamic. As such, relationships are important and, we argue, in thinking about adjustment, we need to adopt a relational approach. A relational approach that commences with the survivor's relationship with himself or herself (Newby, Coetzer, Daisley. & Weatherhead, 2013).

P describes his experience of TBI as akin to his diagnosis with depression. P perceives that people are treating him differently because he's a 'medical case'. Again, this experience conveys the impression of threat and uncertainty.

Luders, Jonas, Fritsche, & Agroskin (2016) report that social exclusion has been found to increase aggressive behaviour. We get the sense from the transcript that, probably unintentionally, P feels that he has been, to some degree, marginalised. Luders et al. (2016) argue that even in unfavourable situations, highlighting potential benefits, and highlighting different ways of appraising the threat might change the perceived nature of threat and thereby help prevent negative outcomes. In other recent research, Greenaway et al., (2014) report that reminding people that they have some control over potentially threatening events eliminated threat effects.

#### 4. Conclusion

The key goal of this report is not to generate gen-1126 eralisable knowledge. Rather, the intent was (is) to 1127 develop transferable knowledge that might be use-1128 fully applied in both clinical and research contexts. 1129

There are many moving parts evident to those 1130 focused on a consideration of the lived experience 1131 of individuals who have experienced TBI. Paradox, 1132 shifting perspectives and self under stress were all to 1133

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the fore in the transcripts that were the basis for this
study. The thread that bound these factors together
was uncertainty.

In contemplating the apparent tension between a 1137 need to focus on the individual, and the social, in 1138 the context of rehabilitation following TBI, we were 1139 faced with a question as to where the line should 1140 be drawn between individual and social psychology. 1141 Our conclusion, and our argument, is that, rather than 1142 conceiving of the individual and social as binary 1143 opposites, rehabilitation should approach the indi-1144 vidual and social as dialectic components of lived 1145 experience. A relational approach that considers the 1146 relationships a given person has, as well as the pres-1147 ence (or sometimes the absence) of significant others 1148 within rehabilitation, is required. 1149

Furthermore, because of the prominence of uncer-1150 tainty in the lived experience of P, it is our conclusion 1151 that reducing uncertainty (allostasis) must be a key 1152 component of post-TBI rehabilitation. This last point 1153 in particular is crucial. Based on the evidence pre-1154 sented in this report, we suggest that key components 1155 in this endeavour are likely to be social identities and 1156 self-categorisations: both of the TBI survivor, and 1157 those around them. 1158

#### 1159 **Conflict of interest**

1160 None to report.

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