

**“They brought you back to the fact you’re not the same”:  
Sense of self after traumatic brain injury**

**Abstract**

This paper considers contexts following traumatic brain injury, exploring what may be at stake when dominant expectations predict a ‘lost’ or ‘broken’ self. I explore stories co-constructed with one young man and his mother to illustrate their personal and intersubjective understandings of identity, at times conflicting, within family interactions and when encountering normative practices of neurorehabilitation clinicians. The other relations portrayed confront this man’s narrative attempts to align his present and pre-injury self, including standard assessments delineating change, administered by healthcare professionals. I consider a need for greater attention to interaction-generated disruption to sense of self, within contemporary conceptualisations of ‘person-centred care’.

**Keywords**

Sense of self; traumatic brain injury; neurorehabilitation; counter-stories

*In the quest for scientific understanding, we end up magnifying patients' deficits until deficits are all we see. The actual person fades away.*

(Kean, 2014, pSR8)

## **Introduction**

Following a blow to the head, clinicians determine whether brain injury has occurred, seeking 'objective' evidence of brain pathology or alteration in brain function (Menon et al, 2010). Systems of classification for extent and severity of brain injury are applied by the clinician, for prognostic guidance on anticipated outcomes (Maas et al, 2011). This linear narrative is future-orientated in that assessments undertaken in the present are linked to later outcomes, which are anticipated to follow a chronological sequence understood through the "application of reason, and the exercise of science and of 'expert' knowledge" (Fisher and Goodley, 2007, p.66). In the longer term, clinical intervention after traumatic brain injury (TBI) continues this narrative with the assessment of changes in physical, cognitive and psychosocial function.

,Acknowledging a "need to be me" (Boger et al, 2015, p.18) after brain injury requires tailored consideration of subjective experience. The framing of subjectivity includes complexities of its theorising as both socioculturally constituted and individualised (Kirschner, 2013). In particular, Pickersgill et al (2011) proposed that examinations of the 'neurologic subject' have focussed on understanding of individual selves to a greater extent than on ways resources of neuroscience may construct and constrain the subjectivity of others. Brain-based' accounts of subjectivity, exploring understandings of neuroscientists, clinicians, scholars in social sciences and humanities, and the wider public, have demonstrated that the "brain is only part of the story of...social lives" (Martin, 2010, p.379). However, for

those who have experienced sudden brain injury, accounts invoke broader narratives of biographical disruption in which the brain may be “inescapably present as a consequence of its dysfunction” (Pickersgill et al, 2011, p.350).

Within this paper, I consider aspirations of ‘person-centred’ care alongside understandings of sense of self following brain injury. I seek to illustrate the factors at stake through one narrative case study, based upon stories shared by a young man who had experienced brain injury. I write from a background as a neurorehabilitation physician in which I draw on my own normative practices in becoming more “consciously aware of habitual ways of being and doing” (May, 2011, p.370). Through narrative inquiry with people who have experienced brain injury, I aim to explore relational experiences in which I am “part of the storied landscapes” under consideration (Clandinin, 2014, p. 82).

### **‘Person-centred’ tensions**

Clinical settings offer well-established domains where individuals negotiate complex social processes, their capacity for action and relational aspects of power inequalities (Hunt and May, 2017). A substantial body of literature characterises the relative powers of patients and healthcare professionals (e.g. Kemp, 2007) illustrated by the concept of epistemic injustice (Fricker, 2007) where patients may be “dismissed in their specific capacity as knowers” (Greenhalgh et al, 2015, p. 6). The challenge in hand for “grand narratives of patient-centredness” (May, 2006, p. 1025) that assume epistemological authority for the person’s own story can be anticipated through accounts gained from healthcare professionals’ perspectives:

*...a common complaint from clinicians is that patients’ speech is full of*

*irrelevant information...can be irrational, and that listening for medically relevant information precludes listening to other information conveyed in patient speech* (Carel and Kidd, 2014, p.530).

The turn to ‘person-centred care’ promises greater importance of subjectivity within clinical encounters, in which “the needs, circumstances and preferences of the individual receiving care” are the focus (Health Foundation, 2014, p. 6). Although a multi-dimensional concept (Leplege et al, 2007), person-centred care models are generally based upon principles of individuality and mutual respect, an interdependent relationship between health and well-being, and attention to a person’s wider social and cultural background (Health Foundation, 2014; Harding et al, 2015). Progression of this approach - currently an ideal - into mainstream clinical practice is yet to be realised, requiring fundamental changes in services, roles and relationships. Advocates emphasise a need for a shift in clinical mind-set, from standard practice of “doing ‘to’ or ‘for’ people” (Health Foundation, 2014, p.3), towards greater understanding of patients as people, and to prioritise this approach as much as the practical or technical routines undertaken (Britten et al, 2016).

Contemporary practices of neurorehabilitation are underpinned by beliefs that individuals will actively engage in interventions, collaborate with healthcare professionals, and work towards achieving specified goals (Cummins, 2016). Neurorehabilitation therefore illustrates practical and theoretical difficulties within the ‘rhetoric’ of person-centred approaches (Leplege, 2007): an ambiguity where the patient is positioned as both object and agent of intended action. Furthermore, routines of practice may be acting as a defence against anxieties of the clinician-

patient relationship (Menzies-Lyth, 1998), such as the application of tools for assessment that delegate “a leadership role to the [healthcare professional], reifying their professional authority during their interactions with patients and families” (Gardner and Cribb, 2016, p. 7). In contrast, a concept of ‘belonging’ encompasses “a person-centred, dynamic and complex approach and that understands people as active participants” (May, 2011, p.367).

### **Rehabilitating ‘the self’**

TClinical approaches to neurorehabilitation after brain injury first seek to assess deficits, such as cognitive impairment and mood change (Wongvatunyu and Porter, 2008). This deficit focus is associated with assumptions relating to loss of self (Nochi, 1998; Sivertsen and Normann, 2015), where where the idea of ‘self’ is an “opaque label” (Medved and Brockmeier, 2008, p. 471). The loss of self concept falls within narratives of ‘biographical disruption’, introduced by Michael Bury in 1982, proposing that experience of ill health can disrupt a person’s own biography and sense of self (Bury, 1982). This argument has dominated accounts of experience of long term conditions (e.g., Wright, 2011), with disruption then extending to intersubjective life, changing the ways intersubjective processes are played out (Jackson, 1998). Following TBI, disruption to sense of self is frequently attributed to “a brain that has suddenly become strange” (Medved and Brockmeier, 2008, p.470), or is associated with changes in experiences of self that may be demoted to damaged regions of brain functioning (Craik et al, 2017). Where people appear reluctant to accept clinical definitions or attributions of change, they may be deemed to have a ‘lack of insight’ that has arisen from the brain injury, or they may attract a clinical label of “recalcitrant and/or non-compliant”, compared with patients who actively

construe their experiences as resulting from the clinical condition (Blackman, 2007, p.12).

Following assessment of deficit, rehabilitative approaches seek to build insight into proposed changes sustained to sense of self (Fleming et al, 1996; Kovareky et al 2007; Ylvisaker et al, 2008), for enabling work on “reconstruction of self” to commence (Lennon et al, 2014. p.27). Neurorehabilitation has been considered to:

*...contribute in some way to rebuilding a person’s self-identity regardless of the aspect of functioning focused on (e.g., mobility, speech or memory)*

(Ownsworth, 2014, p. 1).

As changes in aspects of function are arguably not sufficient to alter a fundamental sense of self, the rationale for focus on such components with an expectation of reconstructing a sense of self requires further consideration. Narratives of rehabilitation held by healthcare professionals, family members and people receiving the service not only portray the processes and practices involved, but also influence their possible trajectories (Medved and Brockmeier, 2011). Clinical routines and interactions may “impart implicit messages and explicit testimonies that state, You have changed” (Charmaz, 2002a, p. 40S). Furthermore, the master narrative of ‘lost’ or ‘broken’ self produces a particular identity for those with the label ‘patient with TBI’ that risks overriding unique personal characteristics and resources, instead introducing a negative sense of self that may be difficult to reverse (Charmaz, 2002a). Furthermore, alterations in a person’s narrative fluency, when representing of self to others after TBI, may meet with an expectation of “listener burden” (Biddle et al, 1996, p.447). Assumptions around impaired narrative ability may then deprioritise the person’s own subjective account, while those interacting may insufficiently

acknowledge the ways in which their support may co-construct or constrain the person's self-narrative.

In the remainder of this paper, I seek to illustrate the tensions outlined through one case study of a young adult who has experienced TBI, interviewed with his mother, encompassing the under-examined stage of experience following hospital discharge (Wilde, 2014). Their co-constructed stories portray synergies and conflict within family roles and when encountering normative practices of healthcare professionals. This work is based on a narrative study that I conducted in London, United Kingdom, between 2015 and 2017, involving a total of ten participants who had experienced TBI, whom I interviewed together with another person they identified as important to them. This article draws from the experiences of one dyad; other findings have been presented elsewhere (Author anonymised, 2016)<sup>1</sup>. Through a narrative approach to interviewing, I aim to explore complexities involved in experiences of TBI through accounts that were not a sum of answers to questions. In addition, the research study design took account of criticisms of the narrative approach, regarding potential prioritisation of individual stories over interpersonal aspects, through dyadic interviewing (Woods et al, 2011a, p. 402).

### **A narrative case study**

This case study is based upon a 19-year-old man, Toby, who had sustained TBI due to a bicycle accident several months previously. I had one prior clinical involvement with this man on his own, in my professional capacity as a rehabilitation physician, but no further clinical contact. I subsequently visited him at his family home, after he had consented to participate in this study, with his family members present and his mother joined the discussion. The complexity of interactions between a person with

TBI and family members (who may be taking carer roles) requires consideration within the context of family life, rather than in the clinical gaze of the healthcare or research setting that prioritise clinical perspectives (Lachman, 2013). The interview was conducted more in line with a conversation rather than following structured topic guide, thereby integrating social interactions within the research (Medved, 2007). This analysis considers construction of stories relating to individual and collective sense of self, with a focus on interactions with healthcare professionals who were providing clinical support following TBI. The analysis of the accounts is inductive and holistic, not necessarily guided by topics anticipated by the researcher.

I understand the narrative interview to be a site where all participants are encouraged to acknowledge themselves “as particular kinds of subjects”, who are in ongoing formation within constrained subject positions (Bonham and Bacchi, 2017, p.3). Narrative, understood in terms of its function (why is the story being told; Bradby, 2017) inevitably differs when told in a research interview compared with a clinical interaction. The difference encompasses expectations of each participant of the way the interaction can unfold, and the story that can be told. Through narrative interviewing, I seek understandings of these differences and the particular collaboration within a research interview, contrasted with a clinical encounter. I aim to “open a place and time of reflection” where participants’ stories take their own preferred form (Charmaz, 2002b, p. 319), in contrast to the clinical interactions within healthcare service restrictions of time, setting, professional agenda and processes.

Two roles of the role I have brought to this research, those of clinician and of qualitative researcher, raise ethical and methodological issues for consideration.

Kuehner (2016), described anxiety that can accompany research that confronts us with others, and thus with ourselves. The dual roles introduced tension for myself and potentially intersubjectively with participants; particularly an incipient concern around ‘exploiting’ experiences for the purposes of the research. Working with this anxiety has contributed to a deeper awareness of subject positions, their fluidity and what else might be possible within interactions.

Narrative in psychology case studies gained favour in the 1980s (Polkinghorne, 1989), and saw onward development of case studies, or case stories, as a methodology (Jones, 2011). An individual case can be defined by “an identified reason that is peculiar or particular” (Hyett, 2014, p.2), for which in-depth description and analysis aims to capture complexity within the specific context (Merriam 2009).

The qualitative case study approach within this paper is situated in a social constructivist paradigm, “focusing on how people construct knowledge or make meaning” (Merriam, 2009, p. 208), including that which is co-constructed through from the researcher’s interaction with the participants and interpretations (Merriam, 2009; Hyett, 2014). I have chosen to present this man’s story to enable consideration of a “counter-narrative of capability” as proposed by Wright et al (2016), and to explore factors that may undermine person-centredness within clinical interaction.

### **Aligning oneself**

Toby presents himself as a university student, using the present tense, to emphasise this as his current, ongoing identity when asked to talk about himself:

Interviewer: *Can you tell me a little about yourself?*

Toby: *I am 19 years of age. I study Chemistry at university. Erm, I don't really know what else to say. That's it.*

He does not include in this introduction any information relating to his injury, or the imposed break in his university studies that has resulted. His mother, however, is keen to emphasise the disruption to his identity, and his dependence:

*And then, obviously, Toby has had to have a year out so I just became his full-time carer.*

In contrast, Toby aligns his present self with himself prior to his injury, limiting disconnection with his past and seeking to diminish any questions over identity. Toby later elaborates on the silence within his initial response, illustrating his deeply felt reluctance to include the story that separates him from his peer group, and the identity of independence, recently gained through leaving home and going away to university:

*It's a bit upsetting as well to, um, see your friends carry on doing their life and basically be adults. And you're back to being pretty much a toddler, being wheeled around.*

In assessing his own progress in recovery, Toby again relates his current achievements directly to experiences that are relevant to his university study tasks, and interactions with his university-based social group:

*I feel all right, in my head. I've been doing a bit more Chemistry, I've taught a little bit of Chemistry. I've had conversations and been going back to being a bit more social like going up to uni, visiting and seeing people, and I've been all right in them sort of situations. I haven't felt uncomfortable or anything.*

Within his own account, he constructs his ability to re-establish himself back at the university as primarily due to his perseverance, with his own friends' support. Here, we might suspect he is trying to introduce distance between himself and his mother. Additionally, he is side-lining acknowledgement of external input, such as from healthcare professionals:

*It's not going to help if I tell my Mum or not, it's just, it is what it is, you just need to carry on, going to back [to university] like, next year...My friends come good through this experience, they have dealt with it very, very well. It wasn't really down to me, luckily my friends just did what they should have done.*

By comparison, Toby's mother talks about Toby's recovery taking place within the system of the whole family, while acknowledging the tensions in talking about this while in Toby's presence (and trying to gain Toby's approval for this alternative family narrative involving tensions):

*Everything, the healing process, is for all the close family as well you know, to let everyone's brain process it and come to terms with it, as well. Wouldn't*

*you agree, Toby? It is quite hard sometimes, because he gets frustrated with me. Even now he is frustrated with me.*

Following Toby's discharge to his family home, his mother had taken on the painstaking tasks required for his basic care needs, in addition to undertaking broader supportive activities and meeting emotional requirements: "I was there to do everything". His mother subsequently describes the experience of not living the life she had anticipated for herself at this stage, when "it all came crashing down on us" and contrasting the family's experience with Toby's, saying, "sometimes I think he has done better than us". She presents aspects of her own experience of looking after Toby after TBI as a continuity in her own identity as a mother, referring to herself in this context as a parent, rather than necessitating a role change to carer:

*You know, teenagers sleep all the time anyway, at the best of times, especially boys, I find. So how do you assess, from a parent's point of view, what's normal, and what it is I should be worried about?*

However, in talking about the aspects of change she has observed in Toby's behaviour, conscious that she is in his presence, she emphasises that she is talking from an identity as his carer, rather than as his mother:

*But being a carer, you pick up on something that's not quite right, and that is hard, from a close carer's point of view.*

### **Encountering healthcare professionals**

In discussing aspects of interactions with healthcare professionals, both in the hospital setting and after return to the family home, Toby's mother positively presents those situations in which a sense of continuity had been established for Toby, showing her

own awareness of the primary importance for him of maintaining his identity as a university student:

*Even when he was in the hospital, [a healthcare professional] come round and just chatted to him and she was fantastic because she just started talking to him about what he was doing at university, so she got him. And he was reeling off stuff about Chemistry and he said afterwards, "What was she doing?" and I said, "She was assessing you but making you feel very comfortable at the same time"; she was fantastic.*

Toby's mother's account of interacting with their General Practitioner (GP) extends beyond the family's past familiarity with him as a clinical care provider, or sense of continuity of input. Instead, she emphasises the positive effect for Toby that she perceives to have resulted from the GP interacting with him as 'the same person' as prior to his injury:

*And after being in the hospital, no matter what doctors you saw, and no matter how nice they were, it was nice to see your own GP walk in and remember Toby from before, and he remembered Toby was at uni and he, he didn't remember what science, but he knew he was doing a science, and he talked to Toby as a person.*

Similarly, Toby himself describes positively those interactions with healthcare professionals in which he felt that his own interests and aptitudes were supported and understood, by "stimulating your head, rather than assessing all the time".

Toby and his mother's stories of positive interactions contrast with their accounts of healthcare professionals whom they did not perceive to have supported his own sense

of self, or his own valued aspects of identity. Instead, they describe ways in which the support received was that for ‘a person with TBI’ rather than what Toby needed at the time. In talking about his experiences of receiving support following discharge home, from healthcare professionals working in a community neurorehabilitation team, Toby highlights the assessments he was required to complete as beside the point:

*Toby: They did lots of assessments, er, yeah, to the point that they were a little bit annoying.*

*Interviewer: Can you tell me more about what you mean, about that?*

*Toby: Well, when you know you’re not right in your head, you can’t remember things, and someone keeps coming round and like, they don’t give you much advice. Well, they don’t do anything to help you get better. So it was like, “Where does this leave me? What benefit is this for me, rather than you just telling me that I’m a bit slow, what is the benefit?” It’s a bit annoying. Whether they did their job or not, I would still be in this position and the only thing it did was annoy me at the time.*

He rationalises such interactions in relation to the healthcare professionals’ own role identities and their service requirement for recording information about him as the patient, while his own personal story clashed with the need for such assessments:

*They have to do their job, of course, whether I like it or not. I just wish that they had left me alone a little bit. It was just like, nothing’s really changed, my memory’s got a little bit better but I don’t know why you need that much data...The psychologist coming round brought you back to that, brought you back to the fact that you’re not the same, you’re not thinking the same and*

*then, that goes back to like, seeing your friends at uni, like, doing their stuff.*

*So, I think it was very counter-productive.*

Toby further contrasts his experience of interactions with healthcare professionals with his own social group identity, highlighting the threat to his sense of self posed by the assessments:

*It's not nice, when like, someone's telling you that you're a bit slow and you see your friends on Facebook and things, and they're like getting on with their life, and you're being told that you can't think as well as you used to.*

Toby constructs stories about attitudes encountered with the general public differently from those in personal contexts such as healthcare interactions, for example, when being 'spoken over' while he was in a wheelchair (due to lower limb injuries), saying, "It's just discrimination really...but I mean, people get it every day". He described his strategy for coping with such incidents as trying to insert himself:

*To show your, er, to show your being to them. And just be a bit more assertive and then it does get a little bit better.*

By contrast, when giving accounts of interactions with healthcare professionals that he had felt were unhelpful to him personally, he does not perceive that to "show his being" had been a successful strategy:

*[The healthcare professional] said something quite weird, at the time...she was a bit off-ish, a bit like, "Well you're doing it, whether you like it or not", really, yeah.*

When talking about those interactions in which healthcare professionals (whom he had perceived to be unhelpful) attempted to address his ‘university student’ identity, Toby does not describe a personal sense of value from this intervention, instead considering the reference to his university studies to have been made at an inappropriately low level:

*Toby: It was basically very vague bits of advice, like, “Make sure you give yourself enough time to revise, for your exams”. And I was like, well, what’s that? What kind of advice is that? Do you not do that anyway?*

*Mother: Yeah, the report actually said that...it was the sort of thing you might say to, you know, a GCSE student, basically.*

Toby’s mother’s endorsement of his account demonstrates their collectively diminished confidence in such interactions with healthcare professionals, which by their accounts had failed to recognise him as a person and his need to be valued in this way, adequately support his stage of progress, or acknowledge his own potential resources.

His mother’s construction of the interaction as undermining supports Toby in maintaining his sense of self as a capable university student, identifying challenges that interactions described have brought him. At the same time, she introduces her own perception that he has been struggling to maintain his former level of achievement:

*Toby is a very easy-going person, and to see him that...he was quite distressed after [the healthcare encounters]. What I would say is, because so many people that these psychologists and doctors see, they have so many different abilities, but just going by the university you’re at, and what you’re studying,*

*and not being all softly spoken, because sometimes softly spoken can come across very patronising, actually it can come across extremely patronising, and when there's a 19 year old who is struggling, who is a very clever boy, you know.*

### **Family interactions**

The interactions with healthcare professionals in which Toby felt 'patronised' are viewed by his mother as problematic not only for him, but extending to other family members, by impacting on their interactions. His mother attributed responsibility for these situations to the disruption caused by the healthcare professionals, rather than to Toby:

*That does need to be a bit addressed, because it didn't help my situation afterwards. It really distressed Toby, and the family, because if Toby's distressed, he lets everyone know.*

Toby's mother portrays the work that she undertook along with other family members, not made explicit to Toby at the time, that was intended to maintain his social identity with his valued university peer group:

*We were very conscious to start off with, when Toby was really confused, we took everything away from him. We didn't want him doing anything on social media that he might be embarrassed about afterwards...he was talking to people at uni that, like he said, were carrying on with their lives, so you have got to get that balance right, that is where it can be hard at times, and you can see that he doesn't want me to mention it.*

She perceives Toby's reluctance to acknowledge that this input had been required on his behalf, noticing his reaction to the comparison she draws with his peer group.

With awareness of his sensitivities over management of his social interactions, she had called upon other resources within the family:

*This was a family discussion without Toby, because he wasn't in the right place at the time. We actually left it to his older brother, so it's like not Mum and Dad prying into his stuff. We knew that his older brother, who is 29, was probably the safest bet... so he had dealings with it all and took over his access to all his information. I don't need to see everything in his life and I was just very, very conscious of that, for our relationship afterwards. All along, I have been extremely conscious of that.*

His mother constructs this account of her decision-making outside her role as carer, while maintaining her 'mother' identity by behaving in relation to Toby's personal interactions, as she would have done in the past. Toby agrees with his mother's account, but also emphasises the way he sees the connection between himself and his university friends as overriding the intervention taken on his behalf, by his family:

*Definitely that was the right thing to do. I was talking absolute nonsense at the time, rubbish and stupid stuff. So, not that my friends would be bothered, or I'd be bothered even if my friends thought I was an idiot about it, I wouldn't be that, er, self-conscious.*

Toby also attributes the success of this aspect of handling information to his own actions and those of his friends, diminishing the role played by his family members:

*I got my eldest brother to message one of my closest friends, just to say, "oh I've been in an accident, I'll be in hospital for a little bit longer...not going to have any visitors for the moment, blah blah blah, please keep this information*

*and don't tell anyone else, just tell these bits of information", and they were just great.*

His mother negotiates a balance between her provision of support, and allowing Toby to experience a feeling of being in control, saying "I was trying to give him back a little bit". This was physically demonstrated through her chosen position within the interview at the family home, in which she sat across the room somewhat outside of the interviewing dyad, rather than joining the table to sit next to Toby. However, the negotiation illustrates tensions within her own role identities: becoming Toby's carer had brought re-connections to previous aspects of her role as the mother of a child and adolescent:

*I was like happy but sad, because I had Toby as like a ten-year-old Toby back again, just for a few weeks, and it was lovely. I knew it wasn't right, but it was lovely, just to get that little bit of him again. Then we got the stroppy thirteen-year-old Toby again.*

Within the interaction between Toby and his mother, factors relevant to the "history of the mother-child relationship" resurface, bringing differing meanings to each of them (Riley and Balloo, 2016 p. 1067). In constructing her account, she expresses her awareness that Toby does not want to hear her talk about her own observations of these changes in him:

*I don't think he's, he's definitely not 100%...and he doesn't like me saying that, just by his face, and he's going to give me an ear-bashing later.*

In Toby's own account of this period referred to by his mother, he tries to interpret the differences between his own subjective experience and the changes he was hearing about from others, acknowledging the potential for deficit by drawing on a metaphor of growing up:

*It's hard to say because it's like anything, when you're a child, you don't realise you're getting taller or anything.*

Here he demonstrates his experience of brain injury as an unattended component of his reflexive self, rather than a cause for a disrupted identity (Pickersgill et al, 2011).

## **Discussion**

Dominant discourses, when left unexamined and unproblematised, shape what is taken to be 'normal', leaving assumptions about who does what unchallenged (Selland, 2017). Interventions in neurorehabilitation follow a linear narrative, aimed at identifying, assessing and monitoring physical, cognitive, emotional or behavioural deficits (Wongvatunyu and Porter, 2008). 'Disciplinary power', enacted through team roles and tools, target predefined aspects of function, rendering them "discernible, and potentially malleable", according to the healthcare professionals' priorities (Gardner, 2016, p.15). Within neurorehabilitation practice, healthcare professionals' legitimisation may be sought through claims to systems of knowledge within "neuro-territory" (Kirschner, 2013, p.225), accessing neuroscientific knowledge (Rose and Abi-Rached, 2013). Despite the progress that the individual and family make, perceptions of professional assessments may be associated with struggle and failure that undermine self-esteem (which may then be measured, to assess the effect of interventions that are applied to the person to improve it (Fisher and Goodley, 2007)). In highlighting aspects of change following TBI, clinical interactions potentially

disrupt continuity of self, or “reduce the whole inner person” to one of the assessed components (Gelech and Desjardins, 2010, p. 68).

Through one case study, I have considered some interactional contexts of narrative (re)construction following traumatic brain injury, in which sense of self may feel threatened despite subjective attempts to maintain a ‘continuity narrative’ (Medved and Brockmeier, 2008; Atkin et al, 2010). The accounts from one young man who experienced brain injury, and his mother, have highlighted interactions that challenge his intention to maintain his present identity as a valued and capable member of his social group. His family and friends supported his sense of belonging to this group, for example managing his use of social media soon after his injury in a way that would be ‘acceptable’ to his broader network. Experiences of belonging are dynamic (May, 2011) and are “about what you have in common with some people and what differentiates you from others” (Weeks, 1990, p. 88). Toby perceived standard assessments administered by healthcare professionals as unhelpful, in the way they delineated change that rendered him ‘different’ to his peers, conflicting with the continuity of self that he personally felt he needed to maintain.

Toby’s mother’s account of becoming his carer demonstrated impact on her own ‘life projects and everyday concerns’ (Mattingley, 2010), portraying tensions encountered when attempting to support her son’s own valued identity, while also fulfilling her

roles as his mother and carer, largely without input from healthcare professionals. In negotiating this balance, she instead drew on family resources as a strategy to uphold values and approaches that underlie the continuity of her relationship with her son and collective interests of the family.

Much of what is said in an interview may appear to be nothing new, or as common sense, as researcher and participant positions are produced within the discursive practices that render what is said possible. Of note, is how it became possible for Toby to talk as he did within the research interview compared to within clinical encounters that focussed on change after TBI, demonstrating the fluidity of subject positioning (Bonham and Bacchi, 2017). The transformative potential within ways of being and becoming depend on flexibility in how stories are heard and are later formed and distributed, whether by researcher, healthcare professional, family member.

Longstanding debates have addressed assumptions of lack of parity between biomedical and narrative ways of knowing, including, as summarised by Bruner, that “stories happen to people who know how to tell them” (1987, p. 691). Healthcare professionals are afforded ‘epistemic privilege’ through their training and clinical expertise (Carel and Kidd, 2014), while the person with TBI “may be regarded as cognitively unreliable, emotionally compromised, existentially unstable or otherwise epistemically unreliable” (Carel and Kidd, 2014, p.532), in the “messy, idiosyncratic, and unpredictable world of a particular person in a particular family context (or, for

some, in a context of social isolation and/or abandonment by family)” (Greenhalgh et al, 2015, p. 1).

Recognition of the role of narrative and sense of self for healthcare professionals may facilitate an intersubjective ‘hinge’ for more helpful interactions (Csordas, 2008) in which participants recognise one another as co-authors of their ideas and negotiate collective understandings (Marková, 2003). For such collaboration, “some kind of strategic reduction (of one’s own concepts...) is usually the price of entry” (Callard and Fitzgerald, 2016, p.56). This case story suggests that recognition of the socially negotiated nature of coping, and its impact on individual and collective narratives of identity, may uncover otherwise ‘hidden’ resources in individuals and networks, and enable more tailored ways of supporting people after brain injury. Here, family members may be simultaneously supportive, while also needing to question the individual with TBI’s own account of their identity and functioning.

A future area of exploration in this research will include exploration of impact on family collective identity when, for families in which a member has sustained TBI, the narrative assumption of ‘broken self’ may be interpreted as a narrative of tragedy for the family. Narratives may instead demonstrate positive growth, through the family’s shared response to the challenge and containing multiple competing strands of emotional and practical aspects of support, shaped by those involved (Riley and Balloo, 2016).

## **Conclusion**

This paper has engaged with the question of how sense of self may feel supported or threatened following traumatic brain injury, with focus on encounters with healthcare professionals and within family interactions. It has demonstrated the need for understanding of how people make sense of themselves, before constructing a ‘self’ that is assumed to be disrupted after brain injury (Medved and Brockmeier, 2008). The co-constructed stories of the case study have illustrated ways in which responsiveness to individual circumstances and identity are valued within input from healthcare professionals who use a less instrumental approach and are more willing to engage in personal and social network narratives, configuring alternative forms of collaborative interaction. I suggest that the clinical approach to assessment and monitoring of ‘patient deficits’ conflicts with the ‘person-centred’ aspiration of aligning with what matters to people for living well and acting in their own situations (Burton et al, 2017). Furthermore, it risks intervention-generated disruption to sense of self. Healthcare professionals’ incorporation of sense of self and narrative as therapeutic tools, neglected in the clinical encounter within UK practice, offer enhanced intersubjective experience.

## **Notes**

<sup>1</sup>Ethical approval to conduct this research was granted by the National Research Ethics Service (NRES) Committee - London City & East (REC reference: 15/LO/0525). Pseudonyms are used and personal identifiers have been replaced to render participants non-recognisable, without alteration of original meanings within the accounts (Kaiser, 2009).



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