We are not the same people we used to be: an exploration of family biographical narratives and identity change following Traumatic Brain Injury.

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# **ABSTRACT**

Subjective changes are increasingly recognised as important in recovery and rehabilitation following traumatic brain injury. Accumulation of subjective changes overtime has led many to examine the question of ‘continuity of self’ post-injury. Vacillation between feeling the same and feeling different is common and often at odds with the medical narrative preparing individuals and families for permanent change.This position of ambiguity was examined in a qualitative narrative study. The aim of this paper is to describe the narrative structures used by uninjured members of a family to understand change. These changes relate to a. their perspective of whether and how the injured person had changed and b. whether and how they themselves had changed in the first-year post-injury. Nine uninjured family members from three families took part in three unstructured interviews during the first twelve months post-injury. In-depth narrative analysis showed how family members used biographical attendance; biographical disruption; biographical continuity and biographical reconstruction to understand change post-injury. Drawing on these findings we argue that concentrating on a narrative of change is too limiting and that engaging in biographical narratives may help humanise care provided to injured individuals and their families. Implications for research and practice are discussed.

# KEYWORDS:

Traumatic Brain Injury; Family; Rehabilitation; Identity; Change

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# INTRODUCTION

In England and Wales 1.4 million people attend emergency departments with head injuries each year and of these approximately 200,000 people are admitted to hospital (National Institute for Care and Clinical Excellence, 2014). Traumatic brain injuries (TBI) cause significant losses to individuals, families and communities and neurotrauma is identified as a global public health concern (World Health Organisation, 2017). Physical, psychological, and emotional sequelae post-injury are common (Kreutzer, Mills, & Marwitz, 2016; Ownsworth & Haslam, 2016) and life changing psycho-emotional responses extend well beyond physical recovery (Muenchberger, Kendall, & Neal, 2008). Injured persons and their families can expect a reduction in social participation and an increase in social isolation and emotional distress (Couchman, McMahon, Kelly, & Ponsford, 2014). According to Bowen et al., (2009) there are both direct and indirect consequences of TBI. Direct consequences arise from deficits in cognitive, emotional, social and behavioural functioning. Indirect effects stem from the response of significant others which Bowen et al., (2009) argue have the potential to cause a second injury.

## Impact of TBI on uninjured family members in adult populations

Studies have shown that those who care for adults with TBI are at a higher risk of developing psychological symptoms of depression, stress and anxiety (Harris, Godfrey, Partridge, & Knight, 2001; Perlesz, Kinsella, & Crowe, 2000; Riley, 2007; Rivera, Elliott, Berry, & Grant, 2008). Histroically, the stress and burden that TBI has on primarcy carers has dominated the research literature (Degeneffe, 2001). The presence of neurobehavioural sequelae in the injured adult post-TBI reliably predicts carer outcomes (Blake, 2008; Connolly & O’Dowd, 2001; Harris et al., 2001; Jackson, Turner-Stokes, Murray, Leese, & McPherson, 2009; Perlesz et al., 2000; Ponsford, Olver, Ponsford, & Nelms, 2003; Wells, Dywan, & Dumas, 2005). These studies tell us that it is not the physical demands of caring but trying to live around changes in behaviour, cognition and personality that generate the greatest sense of burden.

Where a family has been supported by two spouses and one sustains a head injury, the other must assume sole responsibility (Zeigler, 1999). Therefore spouses are generally considered to be at greater risk of stress and burden than parents (Gervasio & Kreutzer, 1997). The loss of a supportive partnership has been cited as one reason for this (Perlesz et al., 2000) in addition to a loss of intamacy and change in role from equal partner to something more akin to a parent (Gill, Sander, Robins, Mazzei, & Struchen, 2011; Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011). Therefore TBI is habitually referred to as a factor that threatens marital and family stability (Gosling & Oddy, 1999). However, Kreutzer, Marwitz, Hsu, Williams, & Riddick, (2007) found that those who were married for longer, victims of non-violent injury, older persons and those with less severe injuries reliably predicted marital stability.

Sibling bonds are important to individuals and families as these relationships are frequently the longest a person will ever have (Degeneffe & Lynch, 2006). The long-term nature of TBI means that siblings often take over caregiving responsibilities once parents can no longer manage or have passed away (Orsillo, McCaffrey, & Fisher, 1993). Although siblings are more likely to provide affective rather than instrumental support following TBI siblings still reported higher rates of depression than would be expected of the general population (Degeneffe & Burcham, 2008; Degeneffe & Lynch, 2006). Sibling concerns related to changes in their personal relationship with the injured person, the altered function and structure of the family and their long-term responsibilities (Degeneffe & Lee, 2010; Degeneffe & Olney, 2008, 2010; D. J. Gill & Wells, 2000).

Butera-Prinzi & Perlesz (2004) and Harris & Stuart (2006) investigated the experiences of children who had a parent with a TBI. Children were found to be worried and anxious about the future of their family, they feared family disintegration and expressed concern for their mother’s suffering. Loss and grief were also present with past images of their father held in high regard and were in stark contrast to how they perceived their father post-injury (Butera-Prinzi & Perlesz, 2004). In addition Kieffer-Kristensen, Teasdale, & Bilenberg, (2011) identified post-traumatic stress symptoms in children with ABI parents. The findings of this study exemplify the vulnerability and support needs of this particular group.

## Family context in TBI

Family functioning has emerged as a key variable post-TBI. Unhealthy family functioning has been found to correlate with increased strain and depression and reduced life satisfaction for both injured and non-injured family members (Anderson, Parmenter, & Mok, 2002; Carnes & Quinn, 2005; Gan, Campbell, Gemeinhardt, & McFadden, 2006; Nabors, Seacat, & Rosenthal, 2002). The Resilience Model of Family Stress, Adjustment and Adaptation ((McCubin & McCubin, 1991) hypothesises that a positive family schema (i.e. their beliefs, values, goals and expectations) will predict effective family functioning. This hypothesis was supported in Kosciulek’s (1997) study of primary carers and concluded manageability and meaningfulness were positively correlated to family functioning. In addition, there is increasing recognition that healthy family functioning is also related to better rehabilitation outcomes for the injured person (Sady et al., 2010; Sander et al., 2002, 2003).

In the wake of TBI family relationships, lifestyles and quality of life may change both immediately and in the long-term. These changes can threaten the equilibrium of the family system (Verhaeghe, Defloor, & Grypdonck, 2005). Ownsworth and Haslam (2016) have highlighted that ‘*It is well recognised that brain injury can lead to significant loss and change in social relationships, and it is only when we understand how central they are to self-definition, that we can start to understand why such loss affects people so deeply*’ (p26). It has been argued that understanding the family context can help us to understand further how families adjust, cope and adapt post-TBI (Jumisko, Lexell, & Soderberg, 2007; Whiffin, Bailey, Ellis-Hill, Jarrett, & Hutchinson, 2015; Yeates, Henwood, Gracey, & Evans, 2007). Furthermore Couchman (2014) concluded that resolution of self-identity for the injured person was central to individual and family functioning. Therefore, the multiple contexts of individual family systems need to be explored to understand this further.

## Change in identity

Subjective experiential changes are increasingly being recognised as important in understanding recovery and rehabilitation following TBI (Abrahamson, Jensen, Springett, & Sakel, 2016; Couchman et al., 2014; Gracey et al., 2008; Muenchberger et al., 2008; Nochi, 1998; Ownsworth & Haslam, 2016). Holloway and Freshwater (2007) argue that in the presence of trauma and illness what had been assumed about our lives and our perception of the future shifts or alters completely: ‘individuals find themselves in a process of deconstructing and reconstructing [their] identity’ (p706).

By building on the concept of illness narratives by Bury (1982) Ellis-Hill, Payne, & Ward (2008) argue that acquired disability should not just be seen as a time of ‘loss’. Instead it should be seen as a time of transition which may include losses but will include gains as well as aspects that do not change at all.

Two literature reviews called for a more in-depth understanding of the process and patterns of family adaptation following TBI (Perlesz, Kinsella, & Crowe, 1999; Verhaeghe et al., 2005) and progress has been made to achieve this more multi-dimensional view of the family experience. However now there is increasing interest in a more holistic understanding of change post-injury and how family centred approaches can complement rehabilitation (Foster et al., 2012). This paper continues this dialogue by examining how identifying narrative structures used by the uninjured family members contributes to understanding loss and change following TBI. We suggest that this is a new way to think about post-injury change that is therapeutic and family centred.

# AIM

This paper reports data from a larger study that investigated the effect of TBI on the uninjured members of a family in the first year following injury. The full findings of this study are reported elsewhere see Whiffin, (2012) and an exploration of how family members talked about the impact of TBI on themselves and their family was discussed in Whiffin et al (2015). However, the aim of this paper is to describe the narrative structures used by the uninjured members of a family to understand change. These changes relate to a. their perspective of whether and how the injured person had changed and b. whether and how they themselves had changed in the first year post-TBI.

# METHODS

## Participants

All participants were family members of a relative who had sustained a TBI with admission to neurointensive care. Family members were approached to take part in this study once their relative had been discharged to a ward environment. Following ethical approval by the NHS research ethics committee (REC Reference Number: 08/H0308/181) nine uninjured family members from three families consented to join this study. Of those approached to join the study only one family was unable to participate because this research required at least two members of the same family and in this instance only one family member wanted to participate. In addition, one member of case two (described below) withdrew before the final interview. It is hard to speculate on the differences between those who did participate and those who did not. It is possible these families were significantly more or less distressed than those included.

The three families are presented as cases and described below (all names and identifying characteristics have been changed).

*Case one:* Dave aged 58. The participating family members were Suzanne (spouse) aged 36 and Emma (adult daughter and step-daughter to Suzanne) aged 27. The injury was caused by a fall of six/seven meters; it was unknown how long it was until he was found. Dave sustained a severe TBI, fractured base of skull, cerebral oedema and a fractured leg. Dave was admitted to neuro-critical care where he was intubated and sedated for approximately ten days. He was subsequently transferred to a specialist neurological ward and assessed for rehabilitation but no beds were available. Dave then self-discharged at one month post-injury.

*Case two:* Abigail aged 19. The participating family members wereDiane (mother) aged 54, Bill (father) aged 55 and Lucy (older sibling) aged 22. Abigail was involved in a road traffic accident as a pedestrian and sustained a severe TBI with a fractured skull and fractured leg. Abigail required neuro-surgery and was admitted to neuro-critical care intubated and sedated. Abigail was admitted to a specialist neurological ward, then discharged home just over one month post-injury.

*Case three:* Tracey aged 27. The participating family members were Mike (spouse) aged 29, Kate (mother) aged 54, Peter (father) aged 54, and Helen (older sibling) aged 27. Tracey was in a road traffic accident and sustained a severe TBI, diffuse axonal injury, intracranial haemorrhage and cerebral oedema. Tracey was then admitted to neuro-critical care to be intubated and sedated. Tracey was admitted to a specialist neurological ward one month after injury followed by a period of in-patient rehabilitation. Tracey was discharged home approximately three months post-injury.

At one year post-injury all injured persons had resumed most activities of daily living, including return to work, with some minor residual deficits apparent. Such an outcome would be classified by the Glasgow Outcome Score as a ‘good recovery’ (Jennett & Bond, 1975).

## Design

This study used social constructivism and narrative theory as its conceptual framework. The social constructivist paradigm views reality as relative to those experiencing it and proposes that experience is created, shaped and constructed through social interaction and individual interpretation (Denzin, Norman, Lincoln, 2011). The assumption therefore is that the experience of being in the world is never singular or objective. Within research this allows several different perspectives to be examined so that a deeper understanding can be reached about how individuals make sense of their experiences. The priorities of the constructivist paradigm align to those of narrative theory and Sparkes & Smith (2008) explain these are commonly used together.

Narrative traditions view people as innate story tellers and when faced with a disruption to normal daily life stories about this event are created (Bingley, Thomas, Brown, Reeve, & Payne, 2008). Stories are therefore important at times of transition or change and are viewed as instruments to make sense of events that reshape our lives. The way these narratives are crafted reveals something about the meaning attributed to them (Bruner, 1990). In *Acts of Meaning* Jerome Bruner called for the field of psychology to return to more human concerns of meaning making and its importance to ‘being in the world’. Bruner (1990) stated ‘I have been at great pains to argue […] that one of the most ubiquitous and powerful discourse forms in human communication is *narrative*’ (p77).

## Procedure

Participants completed three unstructured narrative interviews: one, three and twelve months post-injury. Narrative interviews are an open form of interview designed around what the participants wish to talk about. Wengraf & Chamberlayne (2006) provide a structure for such interviews comprised of three stages: Stage One: invite the participant to talk about their experience; Stage Two, ask follow-up questions based on response, and Stage Three, ask additional questions based on issues not initially raised. All interviews were conducted by the first author (CW) and participants were asked to choose an appropriate location. Subsequently the interviews were completed either at the hospital (in a research facility), their place of work or in their own home. Twenty-six interviews were conducted (one participant withdrew prior to the final interview). Interviews lasted on average 90 minutes (range between 40 and 137 minutes).

## Data analysis

Interviews were transcribed by the first author (CW) into a word document. Interviews were listened to several times and transcripts were then read and re-read. An in-depth narrative analysis was then conducted. Approaches to narrative inquiry include specific research strategies that consider how the re-telling of events and experiences can reveal more about the experience than simply identifying a factual account (Bingley et al., 2008). In this narrative form, the story is not broken into small pieces or fragmented into thematic categories. Instead the textual data collected are treated more holistically and attempts are made to reconstruct a whole story (Riessman & Quinney, 2005). Therefore during the analysis participant’s accounts were ‘re-storied’ into a format that would allow chronology, context and causal links to be revealed (Creswell, 2013). This process allowed life before, life now and life after to be illuminated. This temporality is a hallmark of narrative inquiry and reveals how people have made sense of events they have experienced.

Analysis then continued to move beyond the re-storied account towards something more meaningful. This interpretation was heavily influenced by the Life Thread Model which conceptualises the whole as comprising of a number of narrative threads (Ellis-Hill et al., 2008). The analysis was conducted at three levels: 1. exploring the structures of individual narratives; 2. how these linked with the narratives of other members of the same family; and 3. how the three overall family narrative structures were similar or different to each other. Although the first author (CW) was responsible for the primary analysis of data all authors contributed to the interpretation of data and agreed on final findings. For a detailed discussion of data analysis procedures please see Whiffin (2012) and Whiffin, Bailey, Ellis-Hill, & Jarrett (2014).

# RESULTS

Data that referred directly to the recovery of the injured relative revealed how the uninjured family members understood identity and change. The findings showed that family members had a lot of narrative work to do post-injury; by which we mean they needed to understand their own sense of self post-injury as well as making sense of the identity and character of their injured relative. It is this narrative understanding of change that is the focus of this paper.

The writings of Bury (1982) G Williams (1984) and S J Williams (2000) were particularly influential in identifying the narrative structures in this study. Narrative structures refer to the order we assign to the stories we tell about our lives. Through these structures we convey the meaning of the story and illustrate to others how we have made sense of events in our lives. Following data analysis four narrative structures were identified in this study: biographical attendance; biographical disruption; biographical continuity and biographical reconstruction.

We have defined biographical attendance as a process of using narratives to maintain the injured person’s identity at times when the person was unable to fully express it themselves. This is a new narrative structured that has not yet, to our knowledge, been discussed in the literature previously.

Biographical disruption is defined as a process by which people reconsider who they think they are, and will be in the future. Bury (1982) used biographical disruption to describe how people viewed themselves in the context of a long-term illness. As such illness had ‘disrupted’ their sense of self and for some disconnected them from their anticipated future. This concept aligns well to TBI if we are to believe that change post-injury can disrupt the present and future concept of self. However, ‘disruption’ suggests change can only occur in one direction.

Biographical continuity on the other hand refers to the narratives that are not threatened in the presence of illness and the person is not disconnected from their prior self. Therefore this narrative structure sits in direct contrast to biographical disruption and explicitly challenges this discourse of loss (S. J. Williams, 2000). Finally biographical reconstruction is defined as an attempt to realign narrative order by revising our self-concept in the past, present and future (G. Williams, 1984).

We present the examples of these four narrative structures below starting with biographical attendance, then moving onto biographical disruption, biographical continuity and finally biographical reconstruction. In our findings, we explore biographical reconstruction of self and others to explore how family member’s own identities are challenged alongside that of the injured person. During this discussion, we highlight the consequence of biographical reconstruction when not all family members share the same experience and talk about this in terms of ‘narrative misalignment’. Narrative misalignment is defined as a lack of symmetry between people, events and experiences and the impact this has on their interpretation. Extracts of data are presented below from family members that illustrate these narrative structures and the context in which family members were speaking.

## Biographical Attendance:

Biographical attendance was especially noticeable within the early accounts and during periods of unconsciousness and confusion. Often the need to attend to the injured person’s identity was a direct consequence of being told by health professionals that the injured person would no longer be the same. Biographical attendance involved family members actively looking for, and describing, known character traits. Recognisable personality traits that were important to the uninjured family member were then shared with the family or others, including healthcare staff.

Suzanne noticed physical cues: ‘*When he first woke up, you know, I mean I could see that… even when he was asleep, the way he was putting his hands… and I thought… oh… yes, you know, that’s him…’ (Suzanne: First Interview)*

Emma noticed and shared how her Father spoke: ‘*he’d say ‘yes, yes, boss, yes fraulein’… and he’d say that to everyone and it was like yes well that’s the kind of thing he says, and that was such a relief…’ (Emma: First Interview)*

Lucy used biographical attendance with a family member and recalled her sister’s character: ‘*And my dad… [laughs]… he’s so blunt… ‘oh I just don’t want her to be a vegetable’ [laughs] and I was like… ‘dad… you can’t, firstly say that and secondly, she won’t’… and I had this… eternal feeling that she wouldn’t, my sister’s so flipping… feisty and such a… stubborn mule… I couldn’t ever see that leaving her… she’d just be like ‘no, I’m not gonna give into you lot’…’ (Lucy: First* *Interview)*

The process of biographical attendance helped family members in this study to make a connection to the injured person as the person they were before injury. As such, these acts helped to create positive affirmations of the future and represented the possibility for recovery even when the outcome was unknown.

## Biographical disruption.

Almost all family members talked about the possibility that their relative could be different from the person they were prior to injury. This change was either predicted by healthcare professionals in their professional discourse or was a consequence of TBI of which family members were already aware.

Suzanne predicted the consequence of biographical disruption: *‘… I was really worried that he would not be him at all… that was one of my worst fears, that you know if he’s not like his old good self, will I still love him, and will he still love us? Will he remember what we’ve been through?’ (Suzanne: First interview)*

Emma tried to make sense of the medical view: ‘*He [doctor] was like ‘oh but his personality might be affected’…and I was like ‘well…that’s quite a big deal!’ [laughs]…you know, ‘here’s your dad by the way he’s not actually your Dad ‘cause he’s completely different to the person he was before’…’ (Emma: First Interview)*

For some this threat was purely hypothetical and was not realised in the year this study was conducted. For others, possible changes were examined and explored during their portrayal of their relative’s recovery journey.

Suzanne spoke about what was different post-injury: ‘…*that’s when we sort of find that… under stress he doesn’t cope as well as before… because he’s sort of a calm person and… he would just deal with it really well… I think now he just gets really vocal and… sometimes if you walk into his office and you say something he just… BURST… or he snaps or he slams or he… breaks or… that’s something that he never used to do before…’ (Suzanne: Third Interview)*

However, these changes were not always as catastrophic as they had been led to believe but they could still be significant.

Lucy found humour in the changes she identified: ‘*she [Mother] came in, in the morning and said to me ‘Lucy you need to do lunch for about two’ … and Abigail comes down stairs and goes ‘What’s this… you’re cooking lunch for just you and Mum’… and I was like… no Abigail not for two of us … for two o’clock! … and she went ‘oh yeah! oh yeah! … [laughs]… (Lucy: Second Interview)*

Diane showed how change was unquantifiable: ‘*I’ve said to Abigail before you know… do you think this is what you were like before or… is this something, ‘oh yes[!] she says, it was probably what I was like beforehand’… … [long pause]… she was worried she was going to wash away on holiday [said very quietly]… she’d got a li-lo… and I said to her she could sunbathe in the water… the beach we’d gone to was really calm… [but] she thought she might wash away… ’ (Diane: Third Interview)*

There was evidence that family members still had a strong sense that TBI can fundamentally change the injured person and one year after injury Suzanne illustrated her perception of her husband’s biographical disruption by describing him as ‘*a shell that you’re used to but something on the inside was different’.*

## Biographical continuity

Juxtaposed to the narratives of biographical disruption were narratives of biographical continuity. S J Williams (2000) argued that in some circumstances illness does not result in a biographical shift, and suggests that continuity not change is the dominant discourse. Such continuity relies on elements of biographical confirmation and reinforcement. In this study, we found that despite the medical discourse preparing families for change there were circumstances where change was not a dominant feature of all the accounts.

Helen wanted to affirm her sister’s biographical continuity: *‘I remember when she first came out and she’d come into town with my mum sometimes… and they’d pop in to see me here [at work] and I’d run around the office with her going ‘look, look at her’… [laughs]… like she was some like show and tell…’ [Helen: Third interview]*

Kate compared the real to the hypothetical to emphasise biographical continuity: *‘And course she’s come home and she’s come on leaps and bounds… it’s a miracle on two legs really… I mean everybody… all the doctors she speaks to they’re all amazed how well she’s doing … and when you think where we were and where she is now I mean, she’s talking about going back to work now… I mean… it just doesn’t seem possible… we’ve been so lucky… I mean we do consider ourselves lucky to have her here the way she is…’ [Kate: second interview]*

Peter revealed that biographical continuity was identified early: *No… because once she woke up and started talking she was almost instantly back to her normal self although she was obviously sort of… you know only just capable of talking… her manner and the way she’s talking and speaking to people… it hasn’t changed… it was wonderful to know it was our Tracey that was back and not… a half something of a Tracey that was back…’(Peter: Second Interview)*

Return to a pre-injury self was considered a key milestone in the injured person’s journey and this narrative of biographical continuity was used by family members to illustrate recovery had been reached.

## Biographical re-construction of self and others

G Williams (1984) argued that in the presence of chronic illness individuals re-examine their changing relationship to the world. As such illness does not necessarily ‘disrupt’ a sense of self, but it may force a re-construction of sense of self if the taken for granted world is threatened. ‘*Narrative re-construction is an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society*’ (G Williams, 1984 p.197). In this study, uninjured family members found themselves coming to terms with a life changed by TBI, and the necessity of making sense of how this experience had shaped them. However, what was significant about *their* journey was that this occurred initially in the absence of the injured person and this could leave family members feeling misaligned from each other.

 Emma talked about the change evident in herself and others*’…it’s brought me and Suzanne and the girls really close together… but if anything, my Dad’s been a bit left out on that ‘cause… [laughs] … he was just asleep for a few weeks and wakes up! [laughs]... it feels like we had a crisis and he wasn’t around and we dealt with it… but he’s not kind of benefited from all the bonding that’s gone on!’ (Emma: First Interview)*

Narratives of biographical re-construction were also evident in how family members spoke about the injured person and how they tried to repair the ruptures in the narratives of the injured person caused by TBI.

Dianne tried to reconnect her daughter to her ambitions pre-injury: *‘But she might have to change what she was planning to do… might have to be a bit of a change… but what she was doing is what she’s always wanted to do since she was about three… always… you know, every year she’s always done pantomime, she’s always done the summer season… she’s always been involved in theatres…it will come hard for her to be told that, say ‘that isn’t going to be her option any more’… she may have to re-think… … so I don’t know…[pause] … it’s difficult… (Dianne: First Interview)*

In this example, the uninjured family members remembered the importance of Abigail’s past biography, more than they felt Abigail herself did. These ambitions were also an important part of their own identity. This emphasised the interconnected nature of narratives between all injured and uninjured family members and the potential for future misalignment.

## Biographical misalignment

Most commonly in narrative research the individual’s story is preserved and prioritised. However, this study considered both the individual’s story and how this was understood within a family context. What the data suggested was that the symmetry between narratives in families was important. Where events and experiences were shared and subsequent narratives created were similar, or aligned, family members felt closer, united, and pulled inwards. However, we used the term narrative misalignment to describe the consequences of sharing physical spaces, events and experiences but developing differing interpretations of these. The consequences of this misalignment were feelings of isolation within families. These misaligned narratives emphasised the division within families and illustrated how the family could be pulling apart.

Mike revealed how he thought his wife would always be a step removed from their experiences as a family: *‘even though she was awake she was probably still in some sort of a coma… and that’s quite strange because… the experiences that… we had together with her awake… she can’t remember… it’s really, really odd, it’s almost as if there was another life running alongside… that she had no part of… and ultimately she lost… two or three months of her life… but she was there… and we’ve all got very vivid memories of it…’(Mike: Third Interview)*

Emma described how not sharing her step-mothers experience was leaving Suzanne feeling vulnerable and isolated: *‘… so I think that was quite horrible for Suzanne and then these changes in temper and mood and short fuses that she’s told me about… if no one else witnesses it or… no one else sees it… that must be pretty tough…’ (Emma: Third Interview)*

# DISCUSSION

Our findings revealed how biographical attendance, biographical disruption, biographical continuity and biographical reconstruction can help to understand why and how families are so affected by TBI. The data revealed complex and interwoven processes in understanding change post-TBI for the whole family. We also illustrated how narrative misalignment creates distance between its members which can undermine cohesion within families. Such narratives have great potential to increase understanding of outcome for patients and families over and above objective measures.

In a meta-synthesis of TBI research loss and reconstruction of self-identity and personhood were common themes post-TBI (Levack, Kayes, & Fadyl, 2010). In a grounded theory study of ten individuals who had sustained a TBI Nochi (1998) concluded that individuals fundamentally revised their ‘self-narrative by changing the appearance of their past and future’ (p.1797). More recently Abrahamson (2016) interviewed 41 brain injured individuals and their family member and identified a ‘disintegration of self-identity’ and understanding that life post-injury would be very different. Furthermore Muenchberger (2008) examined identity transition in six individuals with TBI and described TBI as a dynamic journey with a constant interplay between pre-and-post injury comparisons, and while there were negative outcomes there were also positives to be taken from the experience. This research reflects a growing interest in self-concept following TBI (Gracey & Ownsworth, 2012; Ownsworth & Haslam, 2016) and our findings resonate with this literature.

However, only a small number of studies consider how uninjured family members contribute to understanding loss and change following TBI (Abrahamson et al., 2016; Couchman et al., 2014). By exploring biographical attendance, disruption, continuity and reconstruction in the context of TBI this study contributes to the literature on self-concept by proposing a different way to think about change post-injury. We suggest that identity change in a narrative sense is about how we learn to understand ourselves in the world and the sort of worlds we create. Galvin and Todres (2012) suggest using this lifeworld approach allows service providers to support people to feel valued as whole human beings.

Although our research was completed with uninjured family members and not the injured person it shows the complexity of change post-injury and that family members are active agents in this process. Where families provide the main social and support networks for injured persons it is reasonable to assume that narratives of the uninjured members influence how the injured person makes sense of the events they have experienced post-injury. However, this assumption needs testing in future research.

We examined the narrative alignment in families and found that narrative misalignment in families can be painful and may mean families find it hard to stay together because they are living different realities. Not sharing realities may lead to individuals feeling they are isolated from the rest of the family. Figure 1 illustrates the narrative alignment of families pre-injury, making an assumption that families have a shared sense of narrative order, and suggests the injured member moves out of the shared narrative during illness. Our findings resonate with those by Couchman (2014) who found in a population of individuals with acquired brain injuries that ‘conflicts and gulf’ between members (p.823) damaged family relationships. This feeling of misalignment of past, present and future may contribute to intangible and ambiguous losses that have been reported post-TBI (Abrahamson et al., 2016; Kreutzer et al., 2016). Further research is required to understand narrative alignment pre-injury and how families help to preserve, sustain or realign narrative order for the whole family post-injury.

Ellis-Hill et al. (2008) argue that in rehabilitation following stroke physical recovery is prioritised above social and emotional domains. In a similar way traditional rehabilitation following TBI concentrates on impairment and ability or activity and social participation in isolation from each other (Gracey et al., 2008). In contrast Ellis-Hill et al. (2008) suggest that the Life Thread Model could enhance current practice and research. The Life Thread Model represents the stories, or strands, of our everyday selves. In an intact thread our past, present and future lives are connected and this connection/continuity grounds our sense of self. Continuity is essential for wellbeing but illness or injury can displace continuity as the future becomes disconnected from the past and present. In the Life Thread Model this is represented by threads breaking and fraying. In contrast to a model of loss, life threads enable us to see ourselves as comprised of a number of different stories. In the presence of disability some threads may inevitably need to be tied off. However, positive approaches to rehabilitation will find ways to reconnect these threads thereby increasing the individual’s positive sense of self. In addition, it is also important to understand the threads that were never broken by illness and enable the individual to see what has not been lost.

In the context of our study the Life Thread Model can help to further understand family member’s narratives. Biographical attendance can be viewed as family members holding together the frayed threads that look like they may break in the wake of TBI. Family members are usually the first to recognise when threads do break and this is understood as a form of biographical disruption. Biographical reconstruction then helps to understand how family members themselves are changing following TBI and also how they help to sustain the self-concept of the injured person. Family members also have a role in biographical continuity by recognising threads from the past and present that remain connected to the future. In this context family members can be considered ‘guardians *of self-concept’* during periods of biographical attendance, and then active agents in the process of biographical disruption, continuity and reconstruction. Recognising and working with these positive representations may allow healthcare practitioners to learn about the meanings created by the person and their family and allow collaborative ways of working with the whole family.

# LIMITATIONS

Despite the fact that this was a small study of three families and therefore is not generalisable the communicative power of this research lies in the comprehensive analysis of three interviews with nine family members resulting in an in-depth examination of family context that would not be achieved with a larger more representable sample size. It could also be argued that asking individuals to compare their present self with their past self may result in an idealisation of their pre-injury self (Ponsford, Kelly, & Couchman, 2014). However, narratives do not have to be accurate representations of what took place (Carter, 2008) because they are accurate representations of how the teller has made sense of what took place. As such it is the process of identifying cause and meaning that is important.

## Conclusion

In this paper, we have argued that change is not a one-dimensional concept, nor is it static or should it be viewed as an end point in the journey of recovery post-injury. We identified biographical attendance, disruption, continuity and reconstruction of self and others as key aspects of the experience of family members post-TBI, and as indications that change is a multifaceted concept. Narrow characterisations of this experience as a form of loss may be unhelpful and dehumanising. We therefore propose a shift in the discourse in research and practice literature away from loss and towards transition, with greater recognition of the role that uninjured family members play in making sense of change post-injury.

Family members are too frequently treated as witnesses to the illness journey rather than as people embarking on a journey of their own. However, we have shown that family members do embark on their own journey, that they themselves are changing as a result of injury and that they are also active agents in making sense of ‘self-concept’ for the injured person. However, it is important to recognise that often families may experience a form of misalignment post-injury, and that ways of helping the families to realign and re-construct themselves post-injury may be a helpful strategy for rehabilitation. Future research should examine how families help to preserve, sustain or realign narrative order both for themselves and the whole family. Understanding how healthcare practitioners can support families to re-construct their identities in a meaningful way post injury should be prioritised.

**Declaration of Interest**

No conflict of interest is declared

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Figure 1: Narrative Alignment