

For publication please go to : WHIFFIN C .J ., BAILEY C. , ELLIS-HILL C. , JARRETT N. & HUTCHINSON P .J . (2015) Narratives of family transition during the first year post-head injury: perspectives of the non-injured members. *Journal of Advanced Nursing* 71(4), 849–859. doi: 10.1111/jan.12551

Narratives of family transition during the first year post-head injury: perspectives of the non-injured members

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Abstract

Aim. To explore the narratives created by non-injured family members in relation to themselves and their family in the first year after head injury.

Background. A head injury is a potentially devastating injury. The family responds to this injury by supporting the individual and their recovery. While the perspective of individual family members has been well documented, there is growing interest in how the family as a whole makes sense of their experiences and how these experiences change over time.

Design. Longitudinal narrative case study using unstructured in-depth interviews. Methods. Data were collected during an 18-month period (August 2009– December 2010). Nine non-injured family members from three families were recruited from an acute neurosurgical ward and individual narrative interviews were held at one, three and 12 months postinjury where participants were asked to talk about their experience of head injury. Analysis was completed on three levels: the individual; the family and between family cases with the aim of identifying a range of interwoven narrative threads.

Findings. Five interwoven narratives were identified: trauma, recovery, autobiographical, suffering and family. The narrative approach emphasized that the year post-head injury was a turbulent time for families, who were active agents in the process of change.

Conclusion. This study has shown the importance of listening to people's stories and understanding their journeys irrespective of the injured person's outcome. Change postinjury is not limited to the injured person: family members need help to understand that they too are changing as a result of their experiences.

Keywords: head injury, narrative analysis, nurses, nursing, qualitative, recovery, rehabilitation, trauma

Introduction

Annually millions of people across the world sustain head injuries (Teasdale 1995). Although the injured person can make a full recovery, an extensive range of impairments is common (Wood et al. 2005). The importance of family in the recovery process often means members are relied on to provide much of the necessary care and support (Gan et al. 2006, Degeneffe & Olney 2008). A ripple effect is a useful metaphor to conceptualize the impact this injury has in families. As the ripples radiate through family life, head injury has the potential to affect the lives of all family members in several complex ways (Gan et al. 2006).

Background

The impact that head injury has on the non-injured members of a family has been the subject of extensive investigation (Wood et al. 2005, Duff 2006). However, the literature has traditionally presented a one-dimensional view of postinjury consequences concentrating on the presence of stress, depression, anxiety and reduced quality of life (Livingston et al. 1985, Brooks et al. 1986, 1987, Blake 2008, Schoenberger et al. 2010). Although not denying the importance of such constructs, much of the literature does not demonstrate the complexity of how and why the family is so affected (Anderson et al. 2002). Researchers have therefore turned their attention to family functioning, which has emerged as a key variable in the literature (Whiffin 2012). Research has identified a correlation between unhealthy family functioning and increased strain, depression and reduced life satisfaction in a range of family members (Anderson et al. 2002, Nabors et al. 2002, Carnes & Quinn 2005, Gan et al. 2006).

However, research in head injury is predominantly drawn from retrospective and cross-sectional studies using mixed groups of participants varying in time since injury from a few months to several years. In addition, family-based investigations frequently recruit single family members and extrapolate their findings to the wider family. Where studies do recruit multiple members of the same family they rarely consider how data from the same family compare to each other. The research reported here addresses these limitations and contributes to an emerging field of family-based studies in head injury.

Conceptual framework

An investigation into the family experience of head injury required a flexible approach enabling the family to be conceptualized as a dynamic, individualized and socially constructed system. The constructivist paradigm met these criteria, firmly placing the emphasis of investigation on subjectivity and the value of exploring the difference in people's experiences (Miles & Huberman 1994).

The priorities of the constructivist paradigm are consistent with those of narrative theory and these are often used together (Sparkes & Smith 2008). Bingley et al. (2008) explain that when our normal daily life is disrupted, a story of this event is created 'stories, therefore, gain a particular relevance at times of life transition or change, seemingly as a way of 'sense-making' or attempting to reshape and manage the shifting ground of our lives' (p. 655).

The study

Aim

The aim of this study was to explore the narratives created by non-injured family members in relation to themselves and their family in the first year after head injury to a relative.

Design

This study was a longitudinal narrative case study. Case study is described as ‘an empirical inquiry that investigates a contemporary phenomenon in depth and in its real-life context, especially when the boundaries between phenomenon and context are not clearly understood.’ (Yin 2009, p.18). Furthermore, case study methodology is considered to be commensurate with the ontological assumptions of constructivist research (Appleton 2002). Therefore, each family unit was able to be conceptualized as a unique case and provided the fundamental boundedness required for case study investigations (Stake 2005).

Participants

Three family cases were recruited from an acute neurosurgical ward using purposive sampling. A case was defined as a family where a member had sustained a head injury and met the inclusion/exclusion criteria (Table 1).

Table 1 : Patient criteria

| Inclusion Criteria | Rationale | Exclusion Criteria | Rationale |
|---|---|-------------------------------------|--|
| 18 years of age or above | To recruit patients with similar journeys through the healthcare system who have access to the same/ similar services | Prior head injury | To exclude complex cases where the impact of TBI would be difficult to examine given the presence of other issues. |
| Moderate – Severe TBI | | Previous psychiatric history | |
| Will potentially require inpatient rehabilitation | | Dementia | |
| Within one month of injury | To examine experiences of acute care | Alcohol or substance abuse | |
| Admitted to a ward | To ensure phase of critical illness had passed | Living in a long-term care facility | |

The family was defined according to the principle that ‘the family is who they say they are’ (Wright & Leahey 2009, p. 60) and recruitment to the study was designed to allow families to self-select members for participation who met the inclusion criteria (Table 2).

Table 2: Non-injured family member inclusion criteria

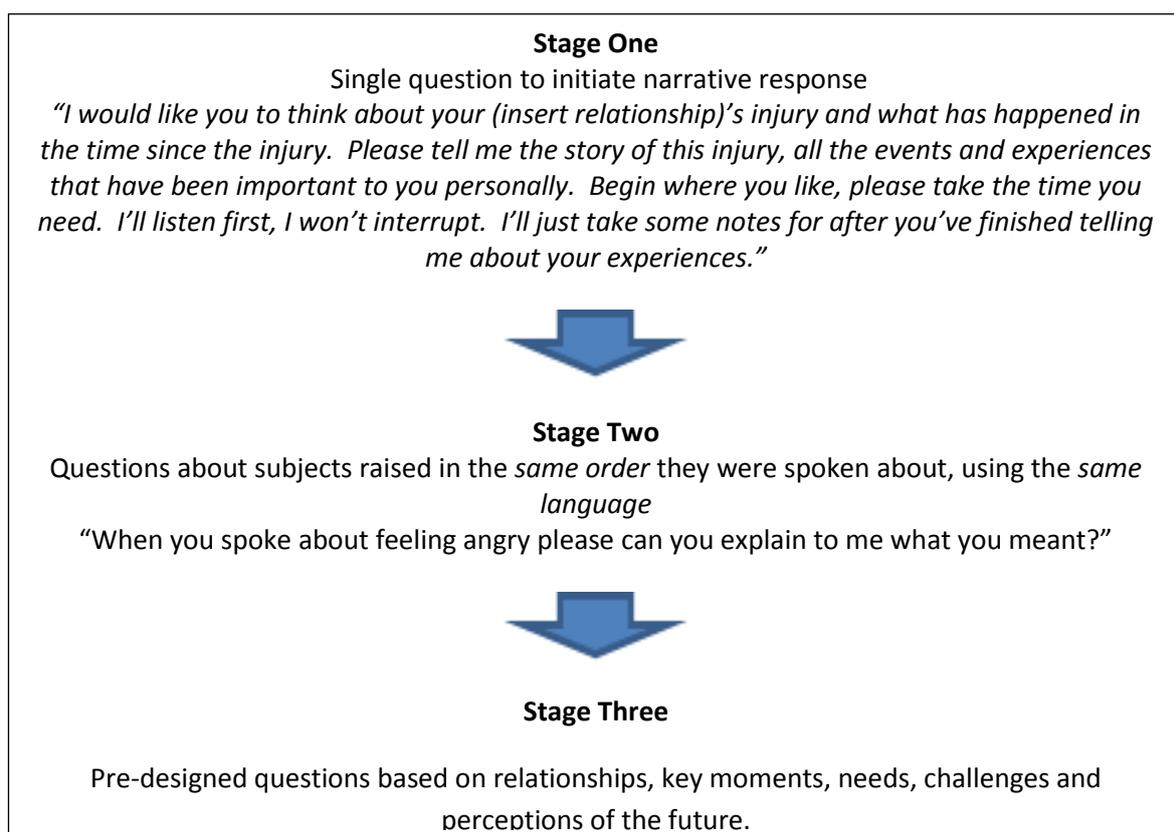
| |
|---|
| 18 years of age or older |
| Able to provide informed consent |
| Informed of the patient’s diagnosis |
| Available to participate in face to face interviews |

Participants were first approached by the clinical nurse practitioner and those who expressed an interest in taking part completed a reply slip. The lead author (CW) then made contact to introduce themselves and the study.

Data collection

Data were collected using unstructured narrative interviews following an adapted three stage process by Wengraf and Chamberlayne (2006) (Figure 1).

Figure1 Interview framework



This interview was piloted and no changes were necessary. Interviews were completed at the location requested by family members including; a hospital based clinical research facility, their home or place of work. Interviews were conducted by the lead author (CW), a senior lecturer and Registered Nurse with training in interview technique and clinical experience of head injury. Nine family members completed a total of 26 interviews (one participant withdrew before the final interview) lasting on average 90 minutes (range 40–137 minutes). Interviews were audio recorded and field notes were maintained.

Ethical considerations

Research Ethics Committee approval for this study was granted by the Ethics Committee in October 2008 (REC Reference Number: 08/H0308/181).

All patients had the opportunity to provide informed consent that would allow their family members to take part. At the start of the study, all patients lacked capacity and family members were recruited to the study without their agreement. However, when patients regained capacity they were asked about their family member's continued participation; each patient agreed and provided written informed consent. Participation was voluntary and participants could withdraw at any time. Pseudonyms were used throughout the research and identifying details changed. As a support mechanism postinterview participants were signposted to Headway's helpline, a charitable organization supporting families affected by brain injury.

Data analysis

Interviews were transcribed verbatim into a word document with attention paid to pauses, sighs and emotional responses to ensure original emphasis was not lost. Data were then explored using methods consistent with an in-depth narrative analysis. To this end, data were treated holistically to maintain and reconstruct a whole story (Riessman & Quinney 2005). Riessman (2008) stated that 'a good narrative analysis prompts the reader to think beyond the surface of a text and there is a move towards a broader commentary' (p. 3).

Data were therefore analysed to examine the 'temporality' of the experience which was considered to be life before injury, life now and life after. However, individual levels of analysis were necessary before it was possible to build an overall narrative relevant to all family members. These levels included the individual account at each data collection point, the family unit as a whole and a comparison between family cases [for a detailed account of the data analysis process see Whiffin (2012) and Whiffin et al. (2014)]. The analysis was then able to move beyond a simple representation of what was said towards a demonstration of how narratives were used to portray the storyteller's biographical sense of self, others and the family system.

Informing the analysis was the Life Thread Model (Ellis-Hill et al. 2008) which suggests that people construct their sense of self and well-being through several interrelated narrative threads. The interpretation was also influenced by Gergen and Gergen's (1983) model of narrative direction whereby movement towards or away from a valued goal represents either

progressive or regressive narratives, that can be interpreted as helpful or harmful respectively. Data were coded by CW and interpretations discussed in doctoral supervision with CB, CEH and NJ.

Rigour

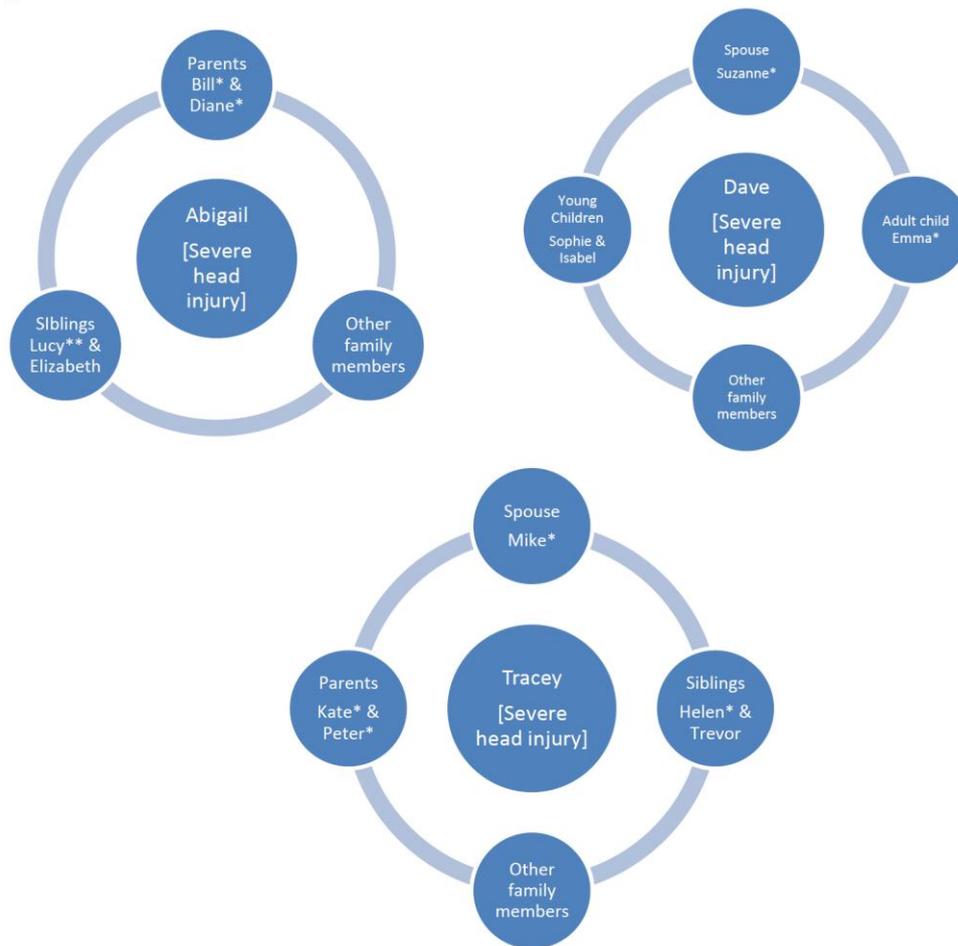
A reflexive diary was maintained throughout the research to assist in establishing an audit trail. In addition, an approach similar to negative case analysis was used whereby data were examined, for examples, that did not support interpretations (Creswell 2007).

One of the most robust ways to establish credibility is through prolonged engagement in the research setting (Streubert & Carpenter 2011). The longitudinal approach facilitated validation of data by enabling clarification of issues and testing emerging interpretations with participants. Therefore, member checking was not explicitly employed in this study. However, Riessman (1993) reminds us that stories do not have one interpretation and 'in the final analysis, the work is ours. We have to take responsibility for its truths' (p. 67). Final narratives were therefore considered a co-constructed experience between researcher and participant (Mishler 1995).

Findings

Between August–December 2009 nine non-injured family members were recruited (Figure 2). Recruiting three cases and a small number of participants facilitated an in-depth inquiry. Two other families were approached but did not meet the inclusion criteria.

Figure 2 Family cases recruited (see below)



Although data were not collected from the brain-injured person, it was confirmed from family accounts that all had severe injuries requiring sedation in intensive care and periods of posttraumatic amnesia of more than 24 hours. One person fell more than six meters, another was hit by a car and another crashed their own car. One year later, all injured persons had resumed most activities with some residual effects. This outcome would be described as 'good recovery' according to the Glasgow Outcome Scale (Jennett & Bond 1975).

The between case analysis revealed five interrelated narrative threads that illustrated the meaning attached to stories of head injury. Specifically these were: trauma, recovery, autobiographical, suffering and family.

Trauma narratives

Family members represented trauma by talking specifically about the events that they had witnessed. The reason trauma made such an impact on the analysis was for its ability to act as a catalyst for crisis and distress. Embedded in the accounts of such crisis was raw emotion and desperate attempts by family members to make sense of the events that were unfolding before them. Without exception, all family members experienced some level of fear, helplessness and/or horror:

Bill [T1] *'So.. .I don't know what you think, just didn't really, you don't imagine I suppose, not having seen her on the road.. .saw where her shoes were, or one of em in particular erm.. .your just sort of like, numb.. .[. .]... .you don't know what to make of it because you don't know what's happened apart from what you can see.. .the ambulance, you see lots of police, you see lots of stuff lying around.. .and you've got people telling you 'it was awful you know, this car come through, we heard revving, he did this he did that bonk!.. .':*

Helen [T1] *But in the intensive care.. .with the other families.. .and you watch other people disappear because.. .the person their look- ing after's.. .not made it.. .that's quite upsetting to watch.. .other families fall apart.. .and one of the things that really upset me.. .you can hear them telling the families in the next room.. .you can't actually hear them say it.. .but you can kind of hear through the wall the responses.. .that was just awful.. .*

Peter [T1] *And just that one word.. .vegetative state.. .and you thought.. .oh hell.. .and we looked at each other.. .and your heart sank without a doubt.. .you know.. .you think.. .have we done her any justice like.. .have we got her life saved to be a vegetable.. .and you think god.. .what have we done.. .you know have we.. .has technology condemned her to.. .something worse than hell for the future.. .have we done the wrong thing.. .*

Most of the trauma narratives were situated in the first interviews and represented the immediate impact of head injury. These narratives lacked the temporal features of a full narrative and seemed to exist in the 'incessant present' (Frank 1995, p.99). These fragments of narrative illustrate the origins of dismay, fear and horror families were exposed to.

Recovery narratives

Recovery narratives traced the chronological features of the injured person's attainment of physical health. As such, these were largely progressive in nature as the injured person moved towards the valued goal of return to their pre-injury state:

Peter [T2].. *.once she woke up and started talking.. .erm.. .she.. .she was.. .almost instantly back to.. .to her normal, normal self although she was obviously sort of.. .you know only just capable of talking and.. .just.. .you know.. .her manner and the way she's you know.. .talking and speak, speaking to people.. .it hasn't changed.. .it's just.. .it was wonderful to know.. .it was.. .it was our Tracey that was back and not.. .a half, a half something of a Tracey that was back...*

However, threatening this narrative of recovery was perception of change. In the recovery narratives, family members grappled with the understanding that people who sustain head injuries often change and in the narratives of good physical recovery, change was often ambiguous, hard to quantify or measure:

Lucy [T2] *my mum wanted me to cook Sunday lunch.. [..].. and said to me 'Lucy you need do lunch for about two'.. [..].. and Abigail comes down stairs and goes 'What's this.. you're cooking lunch for just you and Mum'.. [..].. 'well I'm gonna go out for lunch with my friends because you're having lunch, you're cooking a roast for just you and Mum'.. and I was like why do you think that.. [..].. 'I'm cooking it for everyone'.. 'because Mum said lunch for two'.. [laughs].. I was like not for the two of us.. for two o'clock!.. and she went 'oh yeah!' [laughs]..*

Diane [T3] *I've said to her before you know.. do you think this is what you were like before or.. or is this something, 'oh yes[!]' she says, it was probably what I was like beforehand'.. er.. [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-.. and er.. the bay.. the beach we'd gone to was really calm.. and you had to walk a long way out.. [laughs].. she thought she might wash away.. so she stayed nearby which was nice.. I suppose*

Suzanne [T3] *that's when we sort of find that.. under stress he doesn't cope as.. as well as before.. because he's sort of, sort of a calm person and.. he would just deal with it you know really well.. I think now he just gets really vocal and.. sometimes you know 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 you know.. he never used to do before..*

Where present this discourse of change was powerful and seemed to devalue recovery achieved. Therefore, family members found it difficult to engage in these conversations without also emphasizing the remarkable recovery that had taken place.

Autobiographical narratives

Autobiographical narratives explored the family member's sense of self. Through the re-telling of their story family members showed how the experience of illness from a non-patient perspective was a critical life event. Family members embarked on a journey to make sense of what they were exposed to. Normal life was suspended as they became submerged in a new life that called for a renegotiation of roles and responsibilities. For one family member, the importance of this life event was emphasized through the friends he had made during his wife's hospitalization:

Mike [T3].. *that's a question I always ask myself.. whether I'd go through it again.. the outcome's been so good and we've made such good.. friends.. or me I, in particular have made a few really close friends.. [..].. we'll keep in contact for the rest of our life- .. you know there was.. several people out of that.. out of that relative's room.. that.. I wouldn't ever want to lose as friends and I'd never of met unless it happened.. and.. some of them weren't so lucky and their.. partners or.. sons or daughters didn't.. make it.. but we keep in contact.. and it's almost like a secret club if you like.. if you don't know the secret knock you can't come in..*

The experience of illness from a non-patient perspective demands revision of certain taken for granted attributes of character. The consequence of this was a form of biographical

revision as the experience of head injury left an imprint on the lives of the non-injured members. However, the narrative effect often went unnoticed or unappreciated by the injured person because they were not actively present due to coma, sedation or confusion.

Suffering narratives

Narratives of suffering represented a longer term accumulation of subjective loss and change. As the sharp edges of trauma dulled over time there remained a presence of pain and distress manifesting in some family members' accounts. This pain and distress were less immediate, more gradual and the effects endured:

Suzanne [T3] It has changed.. .the whole family.. .well I feel I had my life before and after I've got an existence.. .I exist.. .[laughs].. .well I can't say that the children er.. .but there was my life before.. .and now I'm just sort of.. .surviving.. .but I'm not.. .I don't feel I can be happy hundred per cent as I was before.. .[. .].. .but as a family.. . [exhale].. .yeah we feel.. .what's the word.. .harmed I suppose, it's scarred.. .mmm.. .that's something that.. .you know.. .we'll remember always.. .it's changed, changed everyone.. .especially [our daughter].. .you know it just, you know she.. .cries.. .and I don't know.. .she only little, poor thing.. .it's not fair.. .yeah very scarred...

Kate [T2] Now we're this side looking back.. .it was the dark side really wasn't it.. .you just don't want to go back there do you.. .I mean it's just.. .[pause].. .I mean we did wonder.. .whether we done the right thing.. .you know if she'd done the right thing in surviving.. .if she's going to be brain damaged for the rest of her life.. .[. .].. .if she did survive with serious brain damage.. .I mean it was too late to turn the machine off.. .but.. .[pause].. .but erm.. . [5 sec pause].. .no.. .[5 sec pause].. .but I wouldn't want to go back there anyway.. .[pause].. .

Although not present in all family members' accounts, it was important to understand how the accumulation of subjective loss, pain and distress led to enduring suffering over time. A feature of much of the suffering was 'living through' and as such these stories were very much of the moment. Suffering frequently included the hallmarks of a regressive narrative as family members moved away from positive representations of the future and reduced their capacity to look forward, preferring to locate themselves and their narrative, in the difficult present.

Family narratives

Family narratives explored the evolution of the family unit. As such family members aligned their narratives to represent their family in the past, how they were functioning in the present and what they predicted the lasting effects on the family would be:

Emma [T1].. .I was just joking saying actually 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].. .where we've all been kind of.. .grouped together, I guess, he wasn't actually really a part of that. That's a bit odd really isn't it? You'd think that he'd wake up and you'd feel really close to him or something, well no.. .he was just under sedation and then being a weirdo [...] so.. .yeah! [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 gone on!.. .laughs].. .

Diane [T3].. *.the police were wanting Abby to write.. .a statement about how she felt.. .about the accident and.. .Abby.. .couldn't put it into words really.. .she's like 'well I don't know how I feel.. .I don't remember it'.. .and I said 'well I can write it[!]' it's like schu- ch, schuch, schuch.. .[mimicking writing].. .essay done here you go.. .[laughs].. .and she's like 'oh'.. .I said yeah because.. .it's com- pletely changed.. .everything.. .how it was.. .your future.. .every- thing how we were looking forward to.. .life.. .on.. .you know.. .as life was going to be a completely different world to what it is now.. .and we just had to kind of like.. .all of a sudden go.. .it's like a bump [slaps hands].. .stop.. .and then it's like.. .this pond of ripples*

Head injury brought taken for granted relationships back into focus. Opportunities were realized for new relation- ships to be forged in all families, but equally some relation- ships deteriorated. There was a sense that to feel closer was underpinned by mutual respect, empathy and understand- ing. These enhanced relationships were often interpreted by family members as the primary way that positive meaning could be taken from the experience.

Discussion

The analysis revealed five interrelated narratives that emphasized that the first year postinjury was a turbulent time of constant renegotiation. Riessman (2008) suggests that stories emerge from ruptures in our everyday lives. Trauma narratives served to represent these ruptures and bring to mind the devastation left in their path. 'Broken' narratives such as these find some alignment with the chaos narratives identified by Frank (1995). Stories of this kind are considered chaotic in nature because of the absence of narrative order. Storytellers are thought to lack the meta- phorical distance to facilitate self-reflection and the process of sense-making. Being unable to make sense of such events causes us to question the taken-for-granted aspects of our lives. At this point, there can be deep despair or immense opportunity for change.

Many of the autobiographical narratives demonstrated features that Bury (2001) labelled 'moral narratives' where 'people are more able to identify more clearly their own personal values and sense of self-hood' (p. 277). As such, the theory of posttraumatic growth (Tedeschi & Calhoun 1996) is useful when considering the broad benefits that sometimes accompany the process of meaning making. Tedeschi and Calhoun (1996) identified three categories that were all present in the data: 'changes in self-perception, changes in interpersonal relationships and a changed philosophy of life' (p. 456). These features of a narrative can bring about a sense of benefit and purpose to traumatic events and illness.

Recovery narratives grappled with the understanding that people who sustain head injuries often change. Change is well established in lay and professional discourse about head injury and a feature of seminal literature (Lezak 1978, 1986, 1988). However, examining narratives

reveals the complex processes involved in the judgement of pre-and post injury change. Change is neither a one-dimensional outcome nor is it an endpoint in the recovery journey, a stage to be reached and then accepted and adjusted to. The findings of this study revealed that for at least a year after injury family members vacillated between aspects of the brain-injured person that stayed the same and aspects that were enhanced, subdued and sometimes changed. Acknowledging and engaging with these co-existing perceptions may be a useful way of working with families post injury.

In this research, suffering narratives contained some of the features of the kind of chaos narrative that dislocates the future from the present (Frank 1995). However, the interpretation also resonated with the fracturing and enduring story lines that Brown and Addington-Hall (2008) identified in the stories of patients with motor neurone disease: The enduring storyline tells us about quiet suffering [...]. Enduring was a way to live through an unwelcome and difficult situation (p. 204). The fracturing narrative tells of loss, breakdown of self, fear of the future, denial of reality and living in a surreal notion of time (p. 205).

Although trauma narratives were identified in all family members' accounts, narratives of suffering were reserved for the few. The effect of not sharing these narratives was further isolation and separation. Charmaz (1999) identified that in people with long-term illness stories of suffering represented 'loss of control, loss of certainty and loss of an anticipated future' (p. 366). Although not suffering from illness themselves, non-injured family members displayed many of these features. The findings of this study also suggest that the long-term effects of hypothetical narratives that represent 'what could have been' were often afforded as much status as 'what actually happened'.

Family narratives find some resonance with family systems theory that states changes occurring to one person necessitate changes in others (Maitz & Sachs 1995, Walker & Akister 2004). These changes represent the ebb and flow of the family system that draws in during crisis (as family members come together to deal with the presenting situation) and moves out again once crisis has resolved. Common models of family adaptation post-head injury include Lezak (1986), Kosciulek et al. (1993), Degeneffe (2001) and Powell (2004). Models often include stages of denial and unrealistic expectations as features of the early experience, developing into anxiety, guilt and despair with a final phase of sorrow and mourning with the subsequent need for role reorganization (Verhaeghe et al. 2005). However, these models tend to reflect adjustment as a process that is reactive to head injury in isolation. While it is essential that we understand these reactions, it is also a constraining view to think that the only process involved is in response to the injured person and their needs.

At the beginning of this paper, a 'ripple effect' was used as a metaphor for understanding the family in the context of head injury. Consistent with this suggestion, family members recruited to this study had to find a way of living with the effects of head injury and re-stabilize the family system postinjury. This process of re-stabilizing has been referred to as returning to equilibrium (Verhaeghe et al. 2005, Wongvatunyu & Porter 2005, 2008a,b). The ripple effect assumes the family is stable pre-injury and is displaced by the head injury to a family member. Given the findings of this research, we might need to think of this metaphor in a slightly different way. A new metaphor, rain on water, suggests the family is a dynamic ever-changing system with ripples created by all family members moving in both similar

and divergent directions. The image of rain on water may therefore be a more useful representation of the family system responding to head injury (Figure 3).

Figure 3 Images of a drop of rain –ripples on water



Limitations

This was an in-depth case study that sought to understand the lives of a selective sample and therefore may not be generalizable. This selective sample meant there were family members who did not participate, how their stories might have contributed to answering the research question is unknown. Finally, despite this study having a longitudinal design one year is still a relatively short period of time. Therefore, this study does not tell us about the continuing process of adaptation and change over a more extended period.

Conclusion

Although the aim of this study was not to generalize the findings to a larger population there are lessons to be learnt that may inform similar situations. Although the experience of head injury will always remain with the injured person the story also belongs to the non-injured members who occupy the narrative especially in the early phases of recovery.

Recommendations from this study are: first that healthcare practitioners should understand why non-injured members become so embedded in the experience of a relative's head injury; second, healthcare practitioners may be able to support recovery of the whole family by not invalidating or disregarding people's stories and the lasting effects of their experiences; third family members need help to understand that they too are changing as a result of their experiences. Therefore, it would support family members if their story were heard and valued, both in its own right and as part of the patient's journey through recovery. Finally, injured and non-injured family members' stories may be the same or different. Where stories are different, there may be an opportunity to help families share their stories to support the whole family to come to terms with the effects. Alternatively it may help family members to identify narratives that can never be shared and be assisted to find ways to reconnect their narratives in the future.

This study has shown the importance of listening to people's stories and understanding their journeys irrespective of the injured person's outcome. This study provides an opportunity to significantly shift the focus of future research and practice by raising the profile of narratives and by supporting practitioners to consider narratives in everyday clinical practice. In doing so, care provision for the support needs of the whole family may be more effective.

Acknowledgements

The families who gave their time to participate in this study, the acute hospital trust where participants were recruited, Christine Harkin the Clinical Nurse Practitioner for Neuro-trauma, The Wellcome Trust and Headway. PJH is supported by a NIHR Research Professorship and the NIHR Cambridge BRC.

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