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Townshend, J

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**The secondary impact of traumatic brain injury: An Interpretative Phenomenological
Analysis of the experiences of family and friends**

Jane Townshend¹ MSc, Dr Alyson Norman¹ PhD

1. School of Psychology, University of Plymouth, Plymouth, Devon, UK.

Corresponding Author: Dr Alyson Norman, A212A Portland Square, Drake Circus,
Plymouth, UK, PL4 8AA, tel: +44(0)1752 584844, email: Alyson.norman@plymouth.ac.uk

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Abstract

This study seeks to contribute to our understanding of the lived experiences of family members and friends of individuals with traumatic brain injury (TBI). The study employed an interpretative phenomenological approach, enabling family members and friends to identify and reflect upon the factors they themselves considered most significant about the impact of TBI on someone close to them, and how this experience has affected their own lives and their relationship with the [TBI survivor](#). Eleven participants, two males and nine females aged 22-79, were from the UK. Several strong and interconnected themes emerged from the interviews, clustering into four superordinate themes: ‘Continuity and discontinuity’; ‘Damage, loss and grief’; ‘Roles and responsibility’; and ‘Coping and not coping’. The study findings identify the importance of support and information provision for family members and friends of those with TBI to help them manage the long term impact of TBI.

Keywords: IPA, Traumatic brain injury, family

Introduction

In the UK between 2013-2014, there were 348,934 hospital admissions for acquired brain injury (10% increase since 2005-2006), showing an increase in the number of people sustaining a brain injury each year (Headway, 2014). Traumatic Brain Injury is the cause of long term disability for an estimated 500,000 people in the UK, affecting approximately one family in 300 (King & Tyerman, 2003). Symptoms of fatigue and irritability in particular have been found to affect TBI survivors across all levels of injury severity ([Belmont, et al., 2006](#); Juengst et al., 2013). While symptoms relating to mild head injury diminish and typically resolve within three months, those individuals sustaining moderate to severe or very severe injury are likely to experience neurological damage which contributes, directly or indirectly, to some level of longer-term or lifelong disability ([Lezak, 1985](#); Ponsford, 1995a). Research from different countries has consistently reported that the majority of post-discharge support for those with TBI is provided by family members (Kreutzer et al., 2009; O'Callaghan, McAllister & Wilson, 2011; Stebbins & Pakenham, 2001). For the predominantly young people acquiring TBI, this post-injury phase of disability may extend into several decades (Ylvisaker & Feeny, 2000). TBI as a chronic condition represents a serious challenge, therefore, to the individual who has sustained the injury; and, frequently, a significant burden of responsibility for those close to them (Allen, Linn, Gutierrez & Willer, 1994).

Characteristic symptoms following TBI such as flattened affect, loss of interest and motivation for activities, tiredness, irritability and disordered sleep patterns may, according to Eames and Wood (2003), represent a TBI-specific neurological syndrome arising from frontal lobe and limbic damage, rather than a psychological disorder per se. This suggests that neurological disruption rather than psychological predisposition may in many cases be key to the emergence of depression (Hibbard et al., 2004).

Gainotti (2003), while acknowledging the clear relationship between patterns of neuronal damage and the emergence of emotional disorders in TBI [survivors](#) points to psychosocial causes secondary to the injury as playing an important part in the development of post-TBI depression. His viewpoint is supported by studies indicating that measures of emotional distress and psychological 'intolerances' are not, unlike longer-term cognitive function, predicted by injury severity (Van Zomeren & Van den Burg, 1985). This suggests that while neurological damage plays a part in the genesis of emotional and psychological difficulties, the level to which they are expressed may be related to contextual factors (Pagaluyan et al, 2008; Van Zomeren & Van den Burg, 1985). Cognitive difficulties arising from organic damage (King & Tyerman, 2003) may feed into post-TBI depression: frustration at problems arising from poor concentration and loss of autobiographical memories, for example, can exacerbate characteristically depressive feelings of hopelessness, impotence and loss of self (Bessell, Watkins & Williams, 2008).

Several longitudinal studies have directly addressed the links between [survivor](#) outcomes and the psychological wellbeing of family caregivers, suggesting that those caring for someone with TBI may themselves be at increased risk of depression or other psychological disorders (Florian & Katz, 1991; Livingston, Brooks & Bond, 1985). A reasonably large body of work exists specifically addressing psychosocial outcomes; and many of these include data collected from family members, including perceptions of burden and psychological consequences for the carers themselves. Most often, however, these data are included as an indirect way of assessing the level of [distress in the individual with the injury](#) ([Kinsella, Packer & Oliver., 1991](#); O'Callaghan et al., 2011). While acknowledging the experience of family carers, therefore, such research remains focussed on understanding the ways in which TBI has impacted upon the [person with the brain injury](#). Studies which have included the experience of carers and families as a phenomenon in its own right usefully highlight the

level of burden and distress they may carry ([Allen et al., 1994](#); [Livingston et al., 1985](#); Norman, 2016; [Oddy, Humphrey & Uttley, 1978](#); [Oder et al., 1992](#); Wade et al., 2001;).

Most of the literature concerning family experience, however, quantifies this phenomenon in terms of incidence of psychological disorder or score on measures for perceived burden and distress. Such research presupposes which kinds of difficulty may be of importance to those involved. There is, to date, far less in the literature exploring the way in which those caring for people with TBI make sense of the experience for themselves ([Florian & Katz, 1991](#); Perlesz, Kinsella & Crowe, 1999).

There has been less attention still focussed on the impact for siblings, children and friends of a person with TBI, who do not act as primary caregiver but may nonetheless be profoundly affected by changes to the person with whom they share an emotional connection; and by disruption to the family or peer group dynamic (Perlesz et al., 1999). One of the rare examples, a grounded theory analysis by Duff (2006) extended the research to relatives beyond the family nucleus, including grandparents, siblings and in-law relations, for example. This study focussed on family impact at the acute stage. It therefore does not offer reflection on the behavioural and emotional sequelae of TBI discussed above as particularly problematic in the longer term. Moreover, although Duff addresses the issue of who can be thought of as constituting ‘family’ and concludes that the concept may extend well beyond the traditional limits of relationship by blood or marriage, the study did not include close friends of the [TBI survivor](#).

Enquiry into the wider impact of TBI may be valuable, as the outcome for both the TBI individual and their family has been shown to be affected by the way in which friends and the extended family respond to the injury. Bay, Blow and Yan (2012) reported that TBI [survivors](#) who “felt they did not have a valued fit and involvement with others” found it more difficult to self-regulate their emotions, and lost confidence within their remaining relationships (Bay

et al., 2012). TBI individuals who were supported by family in a way that improved perceived self-efficacy, on the other hand, have been shown to engage more fully with rehabilitation (Cicerone, Mott, Azulay & Friel, 2004), and reported lower subjective disability at a 12-14 year follow-up (McMillan, Teasdale & Stewart, 2012).

The current study has been conducted within the context of a biopsychosocial model of TBI outcomes (Yeates, Gracey, & McGrath, 2008), where the focus is not predominantly on the biomedical model of TBI, but on the wider social context of TBI, with specific reference to the experience of the social network surrounding TBI survivors. Traumatic brain injury is not conceived of as a cluster of symptoms affecting the individual, but as a phenomenon expressed within, affecting, and affected by the dynamic of the person's social context. This is important for interpreting the experiences of those with TBI and their family members which may not fit comfortably within a more biomedical model of TBI. The objective of this study was to explore the experiences of TBI for family members and friends. The research focused on understanding how family members and friends make sense of the event leading to TBI, their feelings surrounding the recovery process, and to gain a better understanding of changes in their relationships with the TBI survivors and the impact TBI has on their daily lives. The study seeks to contribute to our understanding of the ways in which the incident of TBI and its subsequent consequences are experienced by family members and friends, and how these experiences- are interconnected with one another and with the consequences for the person with TBI. To this end, the study employed a phenomenological approach, enabling family members and friends to identify and reflect upon the aspects of experience they themselves considered most significant about the impact of TBI on someone close to them, and how this experience has affected their own lives.

Method

Participants

Eleven participants (two male), aged 22-79, were recruited as an opportunity sample.

Participants identified as family members or friends (2) of TBI survivors. Two participants were parents of a TBI survivor, three were siblings, one was a partner, 1 a child and 1 a niece (se Table 1). Data describing participant relationship to the person with TBI, gender and current age of participant, time since injury, cause of injury, and TBI individual's gender and age at injury can be seen in Table 1. No other demographic information was collected from participants

The study was advertised at UK south-west centres of the brain injury charity, Headway and through Plymouth University. Sampling was purposive: inclusion criteria were that participants identified themselves as being affected by the traumatic brain injury of a family member or friend; that they knew the person both before and after injury; and were 18 years or older at the time of interview. Pseudonyms were used rather than participants' real names. One participant (Grace, interview 4) took part in two separate interviews, discussing her experiences in relation to two different individuals with TBI. In this case, each interview was treated separately during analysis.

The sample size is consistent with the recommended scope for IPA studies which retains an idiographic mode of enquiry, where up to around 10 participants are recruited (Smith & Osborn, 2008).

Insert table 1 here

Data collection & Analysis

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Participants each took part in a semi-structured interview conducted by the first author lasting approximately 1 hour. The interview recordings were transcribed verbatim. Non-verbal utterances such as sighs or laughs were included in the transcription, and pauses were also noted. These details help to preserve indications of hesitancy and the emotional nuance of statements, and therefore assist the researcher in using the transcript as the basis for an analysis which is faithful to participants' ways of expressing themselves in interview.

The transcripts were analysed using Interpretative Phenomenological Analysis (IPA), based on the model described by Smith and Osborn (2008). IPA has an idiographic focus, seeking to represent in as rich depth as possible the participant's own view of their 'lived experience' in relation to the research area (Smith & Osborn). The subjective experience of participants was actively interpreted by the researcher, presenting a double hermeneutic. This involved the participant making sense of their world and the researcher making sense of how the participants made sense of their world (Smith, Flowers & Larkin, 2009).

The process of analysis was in keeping with principle of IPA and the process comprised of four stages: 1) reviewing the data in the first transcript and noting comments and emergent themes in the margins. Potential themes were noted in the left hand margin as commonalities within the transcripts became apparent. Themes were then rearranged on separate post-it notes as overlap emerged. A list was then compiled of issues relevant to the research questions and noting where in the transcript supporting evidence could be found; 2) reviewing subsequent transcripts in the same way, adding new issues to the list, or new evidence in support of those highlighted previously; 3) repeating the process for all transcripts; 4) clustering related issues into superordinate themes: 'Continuity and discontinuity'; 'Damage, loss and grief'; 'Roles and responsibility'; and 'Coping and not coping'.

While the principles of reliability and validity as applied to quantitative research are inappropriate in this context, it is important to note that qualitative studies have an equal responsibility to ensure trustworthiness and integrity of research methods and data presentation (Coyle, 2007). Smith (2004) identifies two broad criteria by which to assess reliability and validity in IPA research: internal coherence of the study; and appropriate presentation of evidence. These are delineated with reference to coherence, transparency and rigour (Coyle, 2007).

Coherence: The concept of coherence means ensuring the research process reflects the research question and objective and is in keeping with the epistemological underpinnings of IPA. The methodological approach used here is consistent with the aims and objectives of the study: to explore the impact of TBI upon those close to the TBI survivor as a family member or friend, as made sense of by the individuals themselves. The chosen approaches to data collection and analysis are complementary, underpinned by an assumption that words can translate experience into a meaningful account, accessible to others. Each stage of the enquiry focuses on the task of illuminating the participants' own 'lived experience', as made sense of through words.

Transparency: Transparency refers to an openness surrounding the research process. The methods used in conducting this research have been clearly detailed in the account above in accordance with principles of transparency. Transparency regarding the relationship between the raw data of the interviews and the researcher's interpretation is achieved through presenting sufficient primary evidence from the interviews within the results and discussion section below. The juxtaposition of interview excerpts with the researcher's interpretations of the same allows the reader to critically appraise the researcher's conclusions.

Rigour: This refers to attempts to ensure that the findings from IPA studies are reproducible. Interpretative Phenomenological Analysis acknowledges the researcher as an active instrument in the process of analysis, as well as in the interaction which produces the interview data (Smith & Osborn, 2008). The first author practiced reflexivity, referring back to the interview transcript in order to verify that interpretation was faithful to the meanings the participant expressed. Methods of rigour include member checking where participants are asked to review the analysis and provide feedback on the accuracy of the interpretation. This was carried out in this study, with all but one participant agreeing to view their own analysis. Participants provided positive feedback on the analysis process. Additionally, a method of triangulation was employed, where the second author independently analysed a subset of the transcripts and cross-reference the analysis with the first author's.

Results and Discussion

In the following text the use of ellipsis (...) refers to pauses in text or further speech between quotes. IE = interviewee; IR = interviewer. Where text is not ascribed, it represents the interviewee's words

Theme 1: Continuity and discontinuity: making sense of post-injury identity

A strong part of the 'making of meaning' participants were engaged in during interview concerned finding ways in which to explain 'who the person with brain injury is', in context of that person's pre-injury life and identity. Participants talked at length about the changes that occurred within the TBI survivor and reflected on the difficulty of managing that or incorporating that new identity into their own view of the individual. A traumatic event itself causes rupture in the person's life narrative; and for those individuals with moderate to severe injuries, the period of coma, post-traumatic amnesia (PTA) and inpatient care brings 'normal' life temporarily to a halt. As it becomes clear that the person will survive their injuries, there

may be an expectation that the trauma has represented a hiatus, and that the person returning from hospital is ‘the same’ as the one known before injury.

I guess... other than the wheelchair you wouldn't necessarily know that too much had happened to him (Int 3; 216-221)

The problem of continuous and discontinuous identity emerged in the present study as a striving by participants towards understanding and accepting an individual who seems both familiar, and in some ways a shifted and off-centre version of their former self. This process was highlighted by participants as fundamental in maintaining the relationship with the TBI survivor.

“he was always incredibly mischievous and quite flirtatious before the accident...it was like that heightening of that particular personality trait had been the thing that we weren't able to deal with... (Int 1; 956-972).

Applying a metaphor of dismantling and mismatching reassembly to John's physical and psychological being allowed Laura (interview 2) to make sense of the disconcerting experience of encountering someone who “was John but [...] not quite John” (Int 2, 107-108).

While physical injuries and PTA at the acute stage can be disturbing, disrupting the individual's identity and the meaning of relationships as perceived by those around them, the rapid pace of recovery often observed during the first few months following injury may complicate the process of accepting less immediately apparent but longer-term changes in a person with TBI. Laura describes the difficulties associated of understanding her friend post-injury and trying to incorporate his new identity into her new world view of him:

“I think also being a grown up, a grown man – I mean what was he? Twenty-seven, twenty-eight, a grown man, and suddenly having to become like, it was almost like he was a child-man, which was quite upsetting, I mean I found it disturbing because I, I, well when we were younger we'd both been attracted to each other..(Int 2; 581-590)

While describing certain changes as attributable to the effects of brain injury, Peter talks about these changes in terms of an extension to, or heightening of behaviour (attention-seeking), which was already a part of Meg's pre-injury personality. Peter expressed frustration with Meg's difficulties throughout the interview and perceived their origin as ambiguous. This ambiguity made it difficult for Peter to understand Meg post-injury and reformulate his relationship with her.

“...her sense of timing is absolutely awful...She's [sigh] Whether it's genuine or whether it's, it's as I explained to you [...]she has rather, um used the head injury as a way of getting attention.” (Int 5, 91-102).

The observation by participants that traumatic brain injury may exacerbate existing behaviours and personality traits, or disinhibit latent ones, recurred across each of the eleven interviews, and points to the difficulty there can be for those around the TBI survivor as they seek to distinguish the 'real', or pre-injury self from behaviours attributable to the brain injury:

“[...]there were a lot of things that I'd perhaps assumed were to do with the accident, and now looking back I'm not sure that they were, I think that they were just actually part of Paul's personality that were.. accentuated by the accident. So he, he's always been a very angry person from what I can make out, very angry and very frustrated with the world”. (Int 4; 814-824).

Theme 2: Damage, loss and grief

The theme of continuity and discontinuity discussed above outlines the ways in which participants made sense of the impact of change in a family member or friend, and incorporated this into their representation of that person as they talked. The theme of damage, loss and grief encompasses emotional reactions which were evident in the interviews as the participants discussed such changes. The participants' accounts included reflections on

perceived loss within the life of the TBI survivor; loss of the interviewee's own former or hoped-for relationship to the TBI survivor; and, frequently, damage to other relationships within the family or social network, caused indirectly by the injury. One participant, Anne (Interview 1), visualised the impact of injury as spreading like "ripples in the pond", a single event affecting many lives (Interview 1; 447).

"I mean, most sons of forty-two you can have, um [sigh] a normal conversation with, but you can't really with him. He's, he's very...wrapped up with his own little world ..., and not really aware of other people's way of looking at things". (Int 1, 844-847).

As well as loss of 'normal', reciprocal relationship between the participant and the person with TBI, the damaging effect of injury on other relationships, particularly those within the family, emerged within the data.

"[I] felt that I'd lost, I'd really lost, I honestly felt like I'd lost my Mum, and there's this other woman here who's my mother, but she's not like my old mother and... she seemed to have lost a lot of her strengths, and that was quite difficult, because I didn't have that person there any more to rely on, and my Dad was focussed on my Mum, naturally..." (Int 6; 449-459).

Loss was talked about in terms of its longevity as well as spread, with participants describing the ongoing and sometimes multiplying difficulties faced by the person with TBI and those close to them. Implicit in this picture of chronic or recurrent loss is the experience of a complicated grieving process, as highlighted by Hannah in interview 6 when she talks of her mother "still grieving losing the son that she knew". Repeated stages of unrealised hope for improvement may be experienced as further, incremental losses adding to the grief set in motion by the initial traumatic damage. Grace (interview 4) describes the ambivalence with

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which she and her mother regarded Paul's injuries after it became clear he was likely to survive. In context of his former self-destructive lifestyle, the post-injury recovery phase seemed to offer the potential for positive change and a new start:

in those early few months after the accident, it was – we actually had this really ridiculous hope that this might actually be..the thing that changed his life, in some ways for the better.. So although.. everyone else was telling us this was gonna be effectively a death sentence for him, because of what he'd been like before we actually thought that he might stand a chance of turning himself around.(Int 4; 603-615)

The impact of complex grief was highlighted by participants, often with ambivalence surrounding the survival of the person with the TBI:

“He wakes up in the morning and he, he feels like he has nothing to live for. Because everything that he had to live for was taken away the moment he had his accident..I still genuinely believe that it would have been the best thing for him and for everyone around him if he'd died in that accident. Cos he hasn't truly lived a day since he came out of hospital and neither have we as a family.”
(Int 4; 2098-2118).

Theme 3: Roles and responsibility: behaviour towards the TBI survivor

The interviews represent different relationships in terms of the levels of practical responsibility taken on by participants in relation to the brain injured individual. Only three interviewees (Grace, interview 4; hannah , interview 8; Ben, interview 9; Mandy, interview 10) describes themselves as formally responsible, acting as advocates or carers. In spite of this, the theme of responsibility emerged across all eleven interviews. Responsibility was related to the concept of roles, and the experience of role changes brought about by the injury: in particular, the loss of what might be thought of as normal adult capabilities in the person with TBI.

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“You’re his friends, it’s your job to be there to support him, and it doesn’t matter what you say, you, you know, it’s just the fact that he knows you’re there that’s the issue”. (Int 3; 422-426).

Recalling her childhood, Grace (Interview 4) described a strong connection between herself and Paul, and it is this in part which seems to drive her compulsive sense of responsibility towards him. At the same time, responsibility is experienced as a burden, associated with feelings of frustration, powerlessness and resentment originating in her experience both as a child and as an adult taking on the role of supporting her brother. Grace recalls that in the early years following the accident,

“I felt like that that was, that was my role, because of the experiences that I had had, and um, having been through the process with [brother] I was acutely aware of how easy it is for your friends, the friends of somebody with a brain injury to just disappear after an, an accident.” (Int 3; 160-170).

As well as talking about the responsibilities of those around the person with traumatic brain injury, the theme of the TBI individual’s own responsibility also emerged. As already discussed in the section on continuity and change, understanding the extent to which a person with invisible disabilities can be considered responsible is fraught with difficulty.

“I felt like I was the only one who was offering up that kind of [emotional] support [...] It was me that was taking him out socially, it was me who was there for him when he was at his lowest.[...] To be perfectly honest there were times I hated him for it. You, you know I understood that he hadn’t forced me to be in that situation... but my own sense of responsibility was not going to allow me to let him do it on his own. But there were times when I hated him for it, cos I felt he was destroying my life along with his own.” (Int 4; 936-7; 949-964).

The frustration expressed in these interviews highlights a perception that the person is in some way responsible for their own level of disability.

Theme 4: Coping and not coping

Something which has emerged throughout the analysis is a picture of the multiple levels at which participants process their experience of being close to someone with a TBI. The themes emerging as important within the participants' accounts, and which have been explored so far relate to cognitive reappraisal of the TBI survivor's identity and the relationship they share with that person; emotional processing of loss and change; and the practical and psychological meanings of responsibility and burden. These themes all connect with and converge upon the problem of coping. The participants, in responding to the question of TBI's impact on their own lives, describe the strategies used by themselves and others as they coped with this experience through its different stages.

This discussion focuses on evaluation of what can be broadly termed 'positive' and 'negative' coping strategies described by participants, and on the experience and implications of not coping. Anne's account (interview 1) reveals her means of coping with the chaos and stress of the early days after Rob's injury as a task of 'being practical' and 'keeping things normal' for the rest of the family. Anne herself describes this balancing act as "a bit stressful to say the least" (Int 1; 459), and the usefulness of this approach seems uncertain. Grace's recollection of her experience at 12 of being at the receiving end of such a strategy suggests that imposed avoidance of the reality of the situation may heighten rather than quell anxieties:

IR So you were saying about how you remember being – you saw him thrashing around and then being ushered out. What was your response to that? Did you want to leave or did you feel like..

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IE No. Not at all. I remember being quite angry that they weren't..letting me know what was going on (Int 4; 158-166)

Denial was **identified** to be an unhelpful strategy, associated with greater continuing distress, while acceptance was linked to a reduction in perceived burden for family members.

“It does get easier to cope with, as time goes on. I won't say it gets better as such, though it does to some extent, but you learn to cope with it better.” (int 1; 1008-1012).

The theme of ‘not coping’ which emerged from the interviews is associated with the experiences of feeling emotionally overwhelmed; holding unresolved guilt in relation to what happened; being unable to make sense of altered relationship; and feeling ill-equipped to deal with the needs of the **TBI survivor**.

“I walked out of the house at eighteen and was going to University but was living in a shared house [rather than home] because I was like,.. I wasn't going to put up with this anymore, that was it. Parents couldn't understand, but it gave me a bit of a breather from the home because there was so much emotion going on there all the time, over everything.” (Int 6; 576-585).

Social support, in addition to information and knowledge, was a significant positive theme emerging within the context of ‘coping and not coping’. Lack of perceived social support was associated with feelings of frustration and loneliness, and identified as a major problem for the TBI individual as well as for others in the friendship group.

“I think about...maybe just talking to each other about it. I think that's the key thing [..] Um, I think the ones in our friendship group that did talk about it are the ones that probably coped best with it, and the ones that didn't that suffered

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more and dropped out, quicker...Um, so yeah – talking to each other is a really important thing.” (Int 3;1260-1273).

“[My sister] knows a bit about brain injury so she understands [...] so she’s quite good, she’s someone to talk to about it, ‘cause she understands as well...but, like, my friends, they know the situation but not really well ‘cause it’s quite complicated...so yeah, I don’t talk to them about it that much. But it can be quite difficult, ‘cause if I have plans with them and then I get a ‘phone call and it sounds like he needs me to go up there, then I’ll go up and see him, and have to change my plans with my friends, and they don’t always get that”. (Int 7; 612-629).

“As soon as I go home we’ll have a big, long chat about it [interviewee and mother] and I think it helps her to get it all off her chest [...] I guess it’s just helpful when you know it’s not just you going through it.” (Int 7; 794-802).

“I haven’t got support for myself because I can...I’ve got good friends...I like my work, I got things that can take me away from it” (Int 11; 287-291).

The significance of the emergent themes ‘knowledge and information’ and ‘social support’ in relation to the wider experience of coping are therefore also discussed.

“There needs to be...brain injury should come with a manual...a list of people who can help you, here are a list of support services...” (int 8; 515-522).

The significance of social support to the participants’ own coping, as well as theme, discussed in the previous section, of taking responsibility to provide appropriate support to the TBI survivor, suggests that the participants in this sample acknowledge coping as something which occurs through talking and active engagement, as well as through understanding. This finding supports the idea discussed in the introduction and borne out by previous studies, that adjustment to a situation like the one which is the focus for this study is something that happens between people, within the social circle, and not in isolation.

Discussion

This study has identified themes which may help to explain some of the difficulties of practical, psychological and emotional adjustment experienced by individuals close to a person with traumatic brain injury. In particular, the experiences of loss and grief, and the problems of adjusting to changes perceived within the TBI survivor, as well as to roles and responsibilities taken on by the individual and others in the social or family group, have been highlighted by this research. The participants' accounts also talk about the kinds of relationship, coping methods and resources which have helped them adjust to a greater or lesser extent. The research has introduced new information helpful to understanding the broader impact of TBI by including the experiences of friends as well as family members.

The expressed need to feel better equipped to deal with the emotional and behavioural changes following TBI emerged particularly strongly in the two interviews conducted with friends of a TBI individual. Given the small sample size and the fact that the data here represents an idiographic picture of experience, this may be attributable to chance, and is an observation which should be interpreted with caution. However, this highlights a potential need for information to be provided to the wider social network surrounding those with TBI, and not just immediate family members.

The themes identified in this study represent previous literature surrounding the experience of TBI more generally. The theme of discontinuity and continuity of the TBI survivor in highlighted by Lezak (1985) who observes that the familiar appearance and mannerisms of the person may make it difficult for those close to the TBI survivor to appreciate that often profound changes have taken place at less immediately obvious levels.

Research by Bright (1996) has outlined the prolonged and disrupted grieving experienced by family members after a loved one experiences chronic disability, with families experiencing a

sense of grief for a person they have lost, whilst remaining interactions with the person who is still present. This impact seems to be heightened following TBI where there are significant personality changes that make it difficult for family and friends to maintain their previous relationships with the TBI survivor. This is likely to be associated with the experience of guilt in those who feel responsible for the wellbeing of a person with TBI as identified by Duff (2006), which highlights a circular connection between burden, resentment and guilt.

Niemeier and Burnett (2001) investigated the lack of a conceptual framework in which to understand the grief reactions of survivors in rehabilitation. The observations they make – that bereavement interventions for survivors experiencing losses of this kind must take into account the individual presentation of each case, and need also acknowledge the particular meaning of trauma – may apply equally well to the family who grieve for a person living with TBI.

Finally, the association of acceptance with better coping in those close to a person with brain injury is something supported by previous research. Wade et al (2001) note that because of the unpredictable course of TBI outcomes in the longer term, ‘active’ coping may not in these cases be a viable strategy, depending as it does upon changing variables intrinsic to the situation.

Limitations

Perhaps as a function of greater willingness to talk about this subject further into the adjustment period, the present study was able to recruit only participants whose family member or friend had sustained the injury ten or more years ago. While the time since injury allowed participants to reflect on changes to their experience in relation to both the acute and chronic stages of injury, the possibility that retrospective accounts may not represent the

current, lived experience of a person adjusting to earlier stages of coping could be regarded as a further limitation. Future research could use longitudinal or cross-sectional studies to chart the experience as it changes over time, and identify the points at which different kinds of support and information are most needed.

Implications & Benefits

This study highlighted a dearth of information and support services for those close to TBI survivors. This echoes previous research by Sinnakaruppan and Williams (2001) which concluded that the need for better access to information is the single factor most often identified by carers themselves as a means to better coping. It is also perhaps significant that it is the friends rather than family members of the person with TBI who have, in this sample, lost contact with the person in question; although again, the significance of this should be viewed with caution. Grace, in comparing her ability to cope with the behaviours of her brother and her friend respectively (interviews 3 and 4) suggests that the decision to tolerate difficult behaviours in a family member may be due simply to the greater sense of duty a person may naturally feel towards family, compared to a friend of relatively recent standing. It seems likely that friends, in comparison with family members, may need a greater level of input in order to encourage them to continue supporting the TBI survivor. Proactively targeting information towards friends as well as family of the TBI survivor could help to prevent erosion of the wider support network on which the family as well as the TBI person rely psychologically. The inclusion of this group of individuals, and family members who were not necessarily direct carers for the TBI survivors provides insight into the wider information and support needs of those surrounding TBI survivors.

The study aimed to gain a better understanding of the experiences of family members and friends of TBI survivors. This research has highlighted that those surrounding TBI survivors struggle to adjust to the changes in identity experienced by those with brain injury and that this is associated with a prolonged grief reaction which is subsequently associated with a sense of guilt and resentment. The study has highlighted a need for greater information and support services to be targeted specifically at those who make up the wider social network surrounding TBI survivors.

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Table 1: Participant information

| Participant | Participant's current age | Participant gender | Relationship to TBI individual | Cause of injury | Time since injury | TBI individual's age at injury | TBI individual's gender |
|--------------------|----------------------------------|---------------------------|---------------------------------------|------------------------|--------------------------|---------------------------------------|--------------------------------|
| 1 | 69 | Female | Mother | Car accident | 20 years | 22 | male |
| 2 | 50 | Female | Friend | Motorbike accident | 10 years | 23 | male |
| 3 | 32 | Female | Friend | Car accident | 18 years | 16 | male |
| 4 | 32 | Female | Sister | Car accident | 20 years | 22 | male |
| 5 | 55 | Male | Brother | Assault | 15 years | 35 | female |
| 6 | 26 | Female | Daughter | Workplace injury | 11 years | 52 | female |
| 7 | 22 | female | Niece | Fall | 8 years | 41 | male |
| 8 | 30 | Female | Sister | Motorbike Accident | 3 years | 25 | male |
| 9 | 79 | Male | Daughter | Stroke | 3 years | 50 | female |
| 10 | 68 | female | Husband | Workplace Injury | 20 years | 50 | male |
| 11 | 62 | Female | Grandmother | Fall | 2 years | 14 | male |