

Individual and family experiences of loss after acquired brain injury: A multi-method investigation

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Abstract

After a person experiences an acquired brain injury (ABI), there can be grieving for what has been lost. Little is known about the loss felt by relatives of people with ABI. This study investigates concepts of loss among individuals with ABI and their families. Forty participants, recruited from a brain injury charity client pool, took part in a semi-structured interview. Of the participants, seventeen were in dyadic relationships (53% spouses, 41% parent/child and 6% sibling relationships). They also completed the Brain Injury Grief Inventory (BIGI; Coetzer, Vaughan, & Ruddle, 2011) as a quantitative measure of loss after ABI. Five main themes emerged from the interviews: loss of person; loss of relationships; loss of activity/ ability; loss of future; unclear loss. There were distinct differences qualitatively between individuals and relatives and only two dyads experienced similar loss, but there were no significant differences in loss as measured quantitatively by the BIGI. The differences between relatives' loss and individuals with ABIs' loss are discussed. This research suggests that it is important when supporting families to consider individual experiences, because even though the loss originates from the same injury, the loss as experienced may substantially differ among those affected by it.

Although rehabilitation advances for those who have sustained an acquired brain injury (ABI) have progressed significantly over the past thirty years (De Luca, Calabrò, & Bramanti, 2018), there is still much to learn about the psychosocial impact of such injuries, both on those who have the injury and their families. The growing evidence that ABI impacts the whole family rather than the individual has led to adoption of the term ‘head-injured family’ (Brooks, 1991) and a shift in focus from a patient perspective to a family one (Bushnik, Kreutzer, Marwitz, Sima, & Godwin, 2015). However, there is still much to learn about the differences in experiences between those with the ABI and those related to them.

For those who sustain an ABI, significant changes in identity and wellbeing can occur due to an altered sense of self. As described by Ownsworth (2014), the concept of self is complex. Our self refers to one’s enduring nature and spans a person’s past, present and future self. Our sense of self encompasses our identity, which is thought of as our understanding of how we think, feel and behave in the context of our social groups, and distinguishes us from others. After someone experiences an ABI, changes in how they think, feel and behave can disrupt their identity. Gracey et al. (2008) worked with a group of 30 individuals with ABI to investigate the construction of self and identity following changes brought on by their injury. Through the emergence of the theme ‘self in the world’, participants with ABI reported the loss of key activities that they once carried out that would have reinforced their usual pre-injury identity. The loss of meaningful activity was also reported by Turner, Ownsworth, Cornwell and Flemming (2009), whose study investigating experiences of transitioning from hospital to home highlighted the negative effect of lost activity for participants with ABI. The inability to carry out

previous activities, such as driving or sports, and the barriers to replacing these with comparable meaningful activities, can have a detrimental impact on quality of life and feelings of satisfaction with one's self after a brain injury. Indeed, the detrimental effect of impaired self-awareness on psychological wellbeing after traumatic brain injury has also been documented by Coetzer (2004), whereby individuals with ABI can face repeated failures through the process of attempting to engage with pre-injury activities.

There are some studies which focus more directly on the concept of loss of self after ABI. A qualitative investigation by Nochi (1998) of 10 participants who had all experienced a traumatic brain injury (TBI) identified a main theme of 'loss of self' which took various forms. Loss of self could be viewed as a loss of knowledge for who they once were, which was brought on by the cognitive impact of their injury. It also took the form of loss of self associated with comparing the pre-injury self with the less desired post-injury self. This comparison also created loss through the expectations the individual with ABI felt were laid on them by people in their surroundings and notions of who they were supposed to be in their social context. Carroll and Coetzer (2011) also found a pre/post injury comparison of self to be detrimental to individuals with ABIs' sense of identity and that the recognition of losses as a result of the injury led to greater negative feeling associated with their situation. This tendency to compare pre and post-injury self has not always enhanced feelings of loss though, as observed by Douglas (2013), and a detailed exploration of the differences between loss felt by individuals with ABI and the family around them has not, to date, been published.

However life has changed following ABI, the very fact it *has* changed can lead to a period of grieving for a former self and a prolonged period of ambiguous loss. As conceptualised by Boss (1999), ambiguous loss occurs when there is no resolution to a situation or normal focus for the loss (such as the death of a family member).

Ambiguous loss has been documented in other groups such as dementia (Dupuis, 2002) and military deployment (Huebner, Mancini, Wilcox, Grass, & Grass, 2007), but has only recently started receiving attention in brain injury literature.

Research with those experiencing the acute stage of ABI with loved ones in neurocritical care report the presence of ambiguous loss in cases where impairment was permanent, and at the point at which the likely impact of ABI is first realised (Kean 2010). In studies of marital relationships, ambiguous loss is frequently reported when a spouse must adjust to living with a partner who has been changed by their injury, and the familiar marital relationship has also been changed as a consequence (Godwin, Chappell, & Kreutzer, 2014). It is not uncommon for loved ones to describe their relative with a brain injury as a different person, where they have mourned the death of who they knew before, and had to come to terms with an altered relationship. As described by Godwin, Chappell, and Kreutzer (2014), married couples face a struggle to redefine their relationship in the absence of normal validations of relationship loss, such as death certificates or divorce decrees. Spouses can experience the loss of their partner without having these normative validations that aid acceptance when grieving. A detailed review of ambiguous loss theory in relation to traumatic brain injury (TBI) by Kreutzer, Mills and Marwitz (2016) highlighted how ambiguous loss is especially pertinent for family members, more so than the injury survivor themselves. Most recently, Holloway, Orr and Clark-Wilson (2019) asked

family members about their experiences of their loved ones' ABI and identified the theme of 'complicated grief', which described prevalent ambiguous loss among family members of individuals with ABI such as that described by Boss (1999).

The notion of a grieving period for the person with the ABI was documented by Persinger (1993), whereby cognitive deficits as a consequence of the injury were described as barriers to the normal grieving cycle, and should be considered as integral to supporting someone through the adjustment process. However, a sufficient understanding of how loss is experienced and what factors are most important for individuals with ABI and family members is still to be developed. In particular, the similarities or differences between families affected by the same injury has not been established. When considering family interventions, it is important to understand how family members are responding to ABI, both individually and as a unit. Therefore, the current study addressed the following questions:

1. What feelings of loss are experienced by those who have had an ABI?
2. What feelings of loss are experienced by the relatives of those who have had an ABI?
3. Are there differences in experiences of loss among dyadic relationships, or is loss experienced in the same way in individuals with ABI and their relatives?

These questions were designed specifically to take a broad view of 'loss', rather than a focus on changes in any specific area, and to allow for natural and unprompted feelings of loss to arise from the interview respondents. A direct comparison between

dyads within families has been intentionally designed to investigate if feelings of loss are shared between those in the same family unit, or if they remain unique to the individual.

Method

Design

This manuscript has been prepared in accordance with the 32 items of the Consolidation Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury, & Craig, 2007). The research is primarily qualitative, with supporting quantitative data creating a multi-method design. The addition of quantitative data allows for a number of variables to be considered as factors which may or may not be important in determining how a person is experiencing loss. It also allows for general patterns among the data to emerge that may highlight differences or similarities based on the participant type. Combining methods in this way lends itself to a pragmatic epistemology which enables the researcher to utilise both inductive and deductive methods of inquiry. Using two forms of data collection also allows for the subjective experience of brain injury to be investigated through qualitative methods which are difficult to capture through quantitative means alone, whereas standardised quantitative measures help to build a wider picture of the brain injury population that can be compared across studies. Quantitative data allows us to examine how different variables interact with each other to explain a construct of interest (Tuli, 2010). This design was chosen due to the growing recognition that the use of multi-methods produces a rich and meaningful data set for investigating complex populations in health and social care research (O'Cathain, Murphy, & Nicholl, 2007).

The philosophical standpoint taken for the qualitative component of this research is that of a constructivist - interpretivist epistemology. A constructivist-interpretivist stance postulates that one's reality is viewed through his/her own personal lens which is created by past experiences, beliefs and biases. It is this belief that has led to the interviews being integral for the understanding of lived experiences post-injury (Tuli, 2010). No two brain injuries are the same so it is important to seek out individual perspectives on the impact they have. It is assumed that the perceived experience of that person is their reality. For example it is of equal interest to know how someone *feels* they have experienced a loss, as well as considering more objective measures of loss such as those of marital relationships or vocational status. Akin to a constructivist-interpretivist stance, data analysis is an interpretation made by the researcher through their own lens and is open to reinterpretation and questioning.

Data were collected as part of a wider study for the first author's doctoral research whereby an in-depth semi-structured interview was conducted, incorporating 12 open ended questions. The first part of the interview schedule regarded questions about coping strategies and how these related to the experience of ABI. The middle section of the interview asked about changes to family functioning after the injury, and the final stage of the interview asked about feelings of loss and adjustment. Qualitative data presented here pertains to aspects of that interview in which experiences of loss relating to ABI were discussed. These responses were mainly derived from the question "could you describe whether you have, or have not, experienced a sense of loss since the injury?" Follow up prompts were used to help participants expand on their responses as necessary. For example "what are the main areas of loss you have felt?" or "could you explain why you haven't felt loss?"

Quantitative measures were used to enable the investigation of loss between participants in relation to other variables such as gender and age. The Brain Injury Grief Inventory (BIGI) is a twenty item questionnaire developed by Coetzer, Vaughan, and Ruddle (2003) and comprises two scales: Loss and Adjustment. The eleven items which make up the Loss scale were calculated for each respondent as a quantitative measure of feelings of loss after ABI. This scale was developed for use with patients, so here a second version was revised to be read from a relative's perspective. For example 'I miss the things I cannot do since I had my injury', becomes 'I miss the things I cannot do since *they* had *their* injury'.

Demographic information was collected to be included in the analysis, comprising gender, age, age at time of injury, months since injury, employment status, level of education, injury cause, amount of services involved at time of study, and whether they lived with their corresponding relative or not. Ethical approval was granted by the research ethics committee at Anglia Ruskin University, Cambridge, and the study was conducted in accordance with the tenets of the Declaration of Helsinki.

Participants

Participants were registered clients of Headway Cambridgeshire (HWC), a charity helping brain injury survivors and their families cope with the challenges of life after ABI. To be eligible to take part, individuals with ABI were required to be at least two years post-injury to allow for a normal course of grieving and adjustment to take place. One participant sustained their injury at the age of 16 years, whilst all other participants were over the age of 18 years at the time of acquisition. Individuals

with ABI needed to be considered to have capacity to understand and consent to the study, and be over the age of 18 years at test. For a relative to be eligible to take part, they needed to have a family connection, either familial or by marriage, to the individual with ABI and to have sufficiently been involved with that person both pre and post injury to be able to reflect on changes.

Approximately 38% of participants were met for the first time by the first author for the purposes of this research. All participants were aware that the first author was an employee of HWC and it was made clear that the research did not form part of their services or impact on the HWC support they received, but that the findings would be used to inform HWC services in the future.

Forty participants took part in the semi structured interview and 66 completed the BIGI. Demographic characteristics of the participants can be found in Table 1. Of the participants completing the semi-structured interviews, twenty-one had sustained an ABI and nineteen were relatives of someone who had sustained an ABI. From these participants, 17 dyadic pairs were present, that is, an individual with ABI had a family member also take part, thus reporting on the same injury experience. Of the participants completing the BIGI, 44 had sustained an ABI, 22 were relatives of someone who had sustained an ABI, and 21 were dyadic relationships of someone with an ABI and their corresponding relative. Among the relatives, 14 were spouses, six were parents, one was a sibling, and one was the son of an individual with ABI. The causes of injury were predominantly vascular events ($n = 19$), with the remainder covering traumatic brain injuries (11 road traffic accidents, 7 falls, 1 assault), tumours ($n = 3$), one case of hypoxia, one with infection and one with insulin hypoglycaemia.

Males made up 70% of the individuals with ABI sample and 32% of the relatives' sample. This imbalance of participant gender is consistent with the population, with ABI predominately affecting males (e.g., Colantonio, 2016; Munivenkatappa, Agrawal, Shukla, Kumaraswamy, & Devi, 2016). Of the 66 people who took part in the quantitative phase of the study, 32 did not complete the qualitative interview as well, mainly due to time and fatigue issues. Of the people invited to take part, no one refused, dropped out or asked for their data to be removed.

Procedure

Meetings for data collection took place either at HWC premises or at the participant's home. Volunteer sampling was encouraged via poster, leaflet and email invitations which were circulated to aid recruitment of participants. The first author also gave talks about the research to clients of HWC who attended services there. Other staff members used some purposive sampling by inviting clients who they felt would be suitable to take part using the inclusion criteria as a guide. Once interest was shown, participants were given a two week cooling off period to ensure they wanted to take part and to give time for questions or concerns about participation to be addressed. All participants who volunteered were found to meet inclusion criteria and took part, although two of these participants had to have scheduled appointments to wait for the two-year post injury threshold to be met. The first author conducted all the interviews and had been employed by HWC for ten years supporting individuals with ABI and their families as well as experience of conducting qualitative interviews at post-graduate level, making her well placed to provide the skilled communication and sensitivity needed when conducting these interviews.

Interviews were recorded on a Dictaphone then later transcribed verbatim using standard conventions with the primary author and interviewee present only. Participants were interviewed separately from their family members to allow people to be free from answering desirably about their experience due to a loved one being present. Data were mainly collected in two independent stages to manage fatigue and concentration and availability challenges. Participants could complete the quantitative and qualitative stages in any order, or within one interview if preferred. This meant that participants could subscribe to part of the research without having to commit to the full interview, and neither stage of the data collection was reliant on answers given from the preceding stage.

The interviewer did not annotate the transcripts with observations or keep field notes about the interviews to ensure later analysis remained centred around the raw interview data. Interviews typically lasted between 30 and 45 minutes and no repeat interviews were necessary due to sufficient and clear responses to the interview questions being obtained. If ambiguous answers were given these were dealt with in the interview with clarifying follow-up questions. Names were changed to protect the identities of the participants as well as those being discussed in the interviews and any defining characteristics were omitted during the transcription process. The BIGI was completed with the participant to ensure understanding and correct completion.

Analysis

Semi-structured interviews were analysed using Bryman's (2008) four stages of qualitative analysis, which uses a systematic framework to interpret the interview transcripts. The four stages of the coding process are described in Table 2 along with

the actions taken to adhere to this process. Data saturation was judged to have been reached when no new themes emerged. A selection of transcripts (3 individuals with ABI and 3 relatives) were independently coded by the second author and discussed with the first author to reach a consensus on main themes. First and second stage coding conducted on the transcripts was also checked by the second author for consistency. A sample of participants were invited to provide feedback on their coding to check the interpretation of their interviews. Those invited to partake in this stage were purposively chosen due to their ability to engage with the process of checking the coding, as well as the minimal chance of emotional distress arising from reading through their transcribed speech. These participants were given time to read through their transcripts and comment on the coding and interpretation via a one-to-one discussion. No changes to coding were required as a result of this process.

No software was used to code the qualitative data and a hand coding approach was adopted. SPSS software (IBM, 2016) was used to analyse quantitative data elicited from the BIGI questionnaire and demographic variables via a one-way analysis of variance (ANOVA) and Pearson r correlations respectively.

Results

Of the forty interviews, thirty-seven participants expressed a form of loss relating to the injury. Of these, thirty expressed a clear and identifiable loss that was present and enduring, whereas seven of the interviews did not express living with loss per se, but could identify losses resulting from the impact of the injury. The proportion of individuals with ABI and relatives reporting loss was nearly identical in

the participant groups (81% of individuals with ABI versus 83% of relatives). Two participants clearly stated no loss, with one relative clearly stating no loss.

Five main loss themes emerged from the semi-structured interview data: loss of person, loss of relationships, loss of activity/ability, loss of future and unclear loss. Results are presented by theme, including discussions of theme interpretations followed by considerations of dyadic representations.

Theme 1 – Loss of person.

“I was just left as this personality free blob”

This related to a loss of the person who ‘was’ before the injury. These participants expressed a disruption to their core sense of self. This could be profound, even when resulting changes could be interpreted positively. This was evident in eleven of the interviews and expressed more with relatives than individuals with ABI (7/16 relatives to 4/14 individuals with ABI). For the most part, these losses are ambiguous in nature as they transcend the changes in identity experienced after ABI, and relate more to the grieving for the psychological aspect of the person left in the physical body.

For individuals with ABI, loss for the person was persistent and profound. Initial changes in the sense of person were all-encompassing and affected wellbeing even as cognitive and physical challenges improved through rehabilitation. The feeling of not being as they were was evident and predominantly negative.

“A loss of ‘me’, and what I could do, and who I was...things were a bit skewed for a while. Knowing where my future was, where my direction was, knowing my plan....saying what made ‘me’, felt like it had gone, and I didn’t know who I was

anymore” “I miss who I used to be and I miss how I could just turn my hand to anything without really thinking about it, you know...I used to do that and I used to be that...and now it’s an effort to do anything really” – Diane, individual with ABI

For some relationships the observed change in the individual with ABI had left profound ambiguous loss, as Neil expresses about his daughter’s injury. His ambiguous loss is clearly evident in that he is experiencing a grief for the psychological loss of the daughter he had, even though she has not been lost physically, as described by Boss (1999):

“There is a family loss there. Even though we’ve got the same body, we’ve just got a different person that lives in it. We’ve lost a daughter and gained another one, even though it’s the same person.”

This was expressed by another parent, Rosa, along with the complexity of ambiguous loss in brain injury populations:

“Well the loss of Stuart that was, to the Stuart that is now. In a lot of serious illnesses you don’t lose the person, and as they get better they start losing the illness that they’ve got, but it just seems that with brain injury, if it’s affected the person who’s got it, they are different.”

Even though the loss of person was the most profoundly expressed of all the losses, people still showed an ability to see positives that have come from dealing with and withstanding this level of loss. Although there has been a change, there is acceptance of the new person and a co-existence of affection for their loved one with sadness for what has disappeared. Feelings of loss for the person were still being experienced, even when the new person was accepted and loved. This positive perspective was reported by both individuals with ABI and relatives.

John felt his perspective on life had been changed after his injury for the better and he had an improved work/life balance as a consequence. Even though he was happy with his post-injury self, he still felt a loss from the change:

“It’s a balancing act. Yes I do feel loss because I’m not the same person I was since I had my injury, but I do feel that I’m a better person....it’s positives and negatives but it’s a balancing act”

Liz experiences a clear loss for the changes to her husband after his injury, although she can accept and live with the husband she has now:

“And I think suddenly it hits you. You haven’t had time to grieve, because you have lost somebody. You have lost that person. And people used to say ‘oh you’ve got him back’, and I used to want to say ‘I have somebody that looks like him but it’s not the person that went out that morning’. I mean Jerry is very different now to what he was, but that doesn’t mean it’s a bad thing. ”

Some found confidence in the resilience gained from surviving their experience and could take strength from acknowledging that surviving the brain injury trauma added something unique to their lives:

“I had a brain injury and it affected me in lots of ways... I was just left as this personality free blob....I’m not saying I’m different or special than anybody else, but I feel these things happened and here I am. I did that” – Nikki, individual with ABI

“I wouldn’t change it. I wouldn’t go back and not have it happen again, for there were lots of positives that came out of it.” –Shirley, mother

A positive gratitude helped some live with their changed loved ones:

“They are different. I can’t say it’s a bad difference in Stuart, in fact some of it is quite nice how he is, but that is the bit, we’ve lost the Stuart we had forever now, but we love the Stuart we’ve got.” – Rosa, mother

These stories show how, even if people have adjusted well to the changes, either within themselves or in their loved one, there can still be loss present.

In addition to the above individual representations, there were nine interviews that formed part of a dyad, but only two dyads 'matched'. That is, only two individuals with ABI felt loss in a similar way to their relative. Relatives made up six of these interviews, with individuals with ABI expressing this loss in three interviews. It emerged that, out of nine dyadic relationships, only twice did a dyadic pairing feel the same loss of person. These dyads both expressed ambiguous loss, with a clear feeling of a different person living inside the same body post-injury.

As reported, this theme was more frequently expressed among relatives, with almost half of all relative interviewees reporting a loss of person. The dominance of this theme in relatives suggests it is harder for an 'onlooker' to witness the changes in a person and respond positively to this, which may be harder to comprehend due to them not being experienced personally. In contrast, the changes in person for the one that has been 'changed' intrinsically by the injury are not felt as a loss as such. It may be that the focus for the individual with ABI is more on external reminders of their injury, such as reduced ability to play a favoured sport or a loss of independence, rather than an experience of emotional lability or personality changes.

It is also a consideration that this type of loss is not felt as strongly among individuals with ABI due to impaired insight into the way they have changed after their injury. Individuals with ABI may simply have reduced awareness of the way they have changed as a person and therefore this type of loss is felt more profoundly for relatives as a result.

Theme 2 – Loss of relationships.

“I’m not close to anybody anymore. Well I don’t feel as if I am.”

Losses occurred from changes to groups of relationships, such as social connections or friendship groups, or from more acute changes within specific family relationships. This theme was expressed by ten out of thirty interviewees reporting loss, and it was more present for individuals with ABI than relatives (6/14 individuals with ABI to 4/16 relatives). Losses were evident if relationships were felt to have been lost as a result of the injury, or to have changed from how they used to be.

The losses of friendships led to negative feelings about people and a harbouring of resentment. The loss of friendships was expressed as a feeling of being let down or abandoned at a vulnerable time. This was only reported in individuals with ABI’s interviews:

“I mean the one time you needed, I needed them to be there, but they weren’t. Yeah that still, that still upsets me to this day.” – Nikki, individual with ABI

“I think along the way I have lost friends because they don’t understand what I am still going through.” – Emma, individual with ABI

For some, the loss of friendship referred to the quality of their friendships, with a feeling there was a changed ability to connect on a deeper level:

“Sometimes when I’m out for a drink and people deliberately come up to me, and that’s nice. But the fact that I’m treated as a, someone that had a stroke, they don’t hang around me. So yeah, that’s a loss.” – Anthony, individual with ABI

“I’m not close to anybody anymore. Well I don’t feel as if I am.” – Barry, individual with ABI

For relatives the experience of relationship loss tended to relate to more intimate relationships and family connections which had changed rather than disappeared. Something about the way the relationships worked had been changed due to the injury. Although changes in the person could be interpreted positively in the previous theme, changes in the relationship were considered negative, largely down to an imbalance of responsibilities and loss of partnership that was once enjoyed. There is an increase in burden on the relative as a consequence of the ABI, and this is felt to be one-sided in the relationship. This type of loss was only described by spouses:

“You’ve got all the disadvantages of living on your own, and you’ve got all the disadvantages of being married if you like, but none of the advantages either way it seems.” - Jeff, husband

“It’s a kind of loss of someone needs to be on the ball all the time and it would be nice just to think actually, I could just kind of not deal with this and someone would deal with it....so it’s almost loss of, I just feel more responsible, I can’t be as carefree as I used to be.” Katy, wife

“It’s a bit more like we’re friends in a way...you know it feels like we both need more time out from each other.” - Hazel, wife

Of the ten interviews in this theme, six were from one half of a dyadic relationship, but none were felt on both sides of those relationships. No dyads reported a similar relationship loss, revealing how subjective this theme is. Just because one person in a relationship is feeling a change, it does not mean it is affecting the other party in the same way. This suggests changes in relationships are

individually centred, even though there are two people in the relationship being discussed. When considering families as units, one member may be living a strained experience that is not felt by others due to how they see their relationships have been changed within the family as a result of the injury. Individuals with ABI mainly experienced friendship losses, which could have a wider impact as a loss of social integration or wider support networks, putting additional pressure on the family to counteract these deficits. They spoke predominately about the reactions of their friends and peers, and less about changes in their romantic or familial relationships. In contrast, spouses of individuals with ABI, in particular, were predominantly concerned with the changes in their romantic relationship, which had led to an increased burden and sense of imbalance in what had previously been a more equal partnership pre-injury.

Theme 3 – Loss of activity / ability.

“I used to play rugby, I could run a marathon, yet I can’t run now, I can hardly walk”

This theme describes the feeling of a loss of a skill or activity that was once enjoyed or revered. The loss occurs due to the consequences brought on from the lack of skill or activity. For example, driving creates loss as it is felt as a loss of freedom and independence. Loss of skills equate to people experiencing a loss of confidence, competence and/or identity.

This theme was described in nine of the interviews and predominantly an issue for individuals with ABI rather than relatives (7/14 individuals with ABI to 2/16 relatives). Individuals with ABI described this loss from a very personal perspective,

whereas the loss of activity for relatives was about things enjoyed together with their loved one.

Physical changes that inhibit the ability to carry out previously enjoyed leisure activities can be a stark reminder of the effects of ABI. Jerry reflected on specific activities that he used to enjoy before his injury, with a clear feeling of then and now:

“I used to play rugby, I could run a marathon, yet I can’t run now, I can hardly walk.”

For others it was more of a general feeling of independence that had been lost due to a change in ability after their injury. It is not just the activity or ability that has been lost, but the wider lifestyle and identity impact that loss brings:

“I’ve lost my freedom. I can’t just get in the car and go off when I want to.” – Carl, individual with ABI

“It’s a bit self-centred, but it’s about things I’ve lost that I can no longer do. I can’t get in the car and drive for two hours and listen to music.” – Pete, individual with ABI

“Of course I feel loss. Not only do I not walk anymore, or even stand up, but my eyesight is rubbish. When it comes to reading things I can’t read unless it’s really big text.” – Liam, individual with ABI

For relatives, the loss was more about changes to their lifestyle due to not being able to take part in regularly enjoyed activities together as before. The changes in their loved one has meant wider changes in the family lifestyle:

“We can’t just go out anywhere. Whereas before we used to get in the car and go out for the day somewhere. That we really can’t do now...we can perhaps do a bit more with support for me, but the life we had is gone.” - Margaret, wife

"I suppose we've lost some things. We used to go to the football matches regularly." -
Duncan, father

There was one dyadic match for this theme, although the type of activity lost was not the same. For the father in the dyad, the loss was attending football matches together, whereas for the son in the dyad the loss was for the ability to drive. Four other members of dyads were present in this theme; three individuals with ABI and one relative, but none were dyadic pairs. It seems logical that this theme is presented as more individual because an ability or activity lost is often a personal one, although when expressing relationship changes, it would perhaps be understandable if there were more shared activities that were no longer attainable due to the effects of the injury.

Theme 4 – Loss of future.

"You think 'what if'"

This theme related to a loss of what could have been and a feeling of unfulfilled potential. Of the six reports of this loss, it was predominantly represented by relatives, with only one individual with ABI experiencing this type of loss (5/14 relatives to 1/16 individuals with ABI).

For the individual with ABI experiencing this loss, it was clear the injury was seen to have held them back in many areas of life, and created a feeling of wondering, such as how things might have been different if the ABI had not occurred:

"Well I look at them [friends] and their lives, where they are in their lives, well now they've got partners, marriage, children, careers. I mean my mate he lives in New York, and here I am, still stuck in Blighty.....I think if I hadn't had my brain

haemorrhage I would probably be a little bit more sorted in my career...because the thing that really held me back, it's like having the reins on the kids so they don't run away" – Calvin, individual with ABI

Calvin's mother, Faye, also felt this loss for her son's future:

"Yeah it is a terrible loss. You think 'what if? What if he hadn't have had that? What would he be? What would he be like?' He's never going to fulfil what he could have been,"

Mainly, relatives reported a loss of future plans and a change in the lifestyle that was meant to be for them as a couple:

"It's a loss of things we could have done when the children had grown up, that we can't do. It's not gonna happen now, you know, then you see other people and...we can't do that." – Barry, husband

"It's a loss of what we'd planned together and just things not being how they were meant to be really." – Katy, wife

"It's regretting some of the possibilities, or the opportunities, that you might not now be able to take....it's about maybe things we were planning to do actually, it's not really gonna be achievable....anymore. So it's a loss of potential rather than looking back at something perfect beforehand." – Alice, wife

As reported above, there was only one dyadic match for this category, with a son and mother both expressing very similar feelings for a loss of future and potential as a result of the ABI. Three more dyads were present for this theme, but only the relatives in the dyads felt this type of loss, with their corresponding individual with ABI not expressing the same feelings. As with loss of person it could be that the individual with ABI can either accept these changes more readily, or has a changed priority to the present rather than harbouring a future plan that can no longer be

fulfilled. For the relative, who maybe has not had the same level of support to cope with a changed future, and can be viewing the effects of the ABI in a wider context due to greater insight, this loss is more prevalent.

Theme five – Unclear loss

In addition to the thirty interviews which defined at least one way in which loss was being felt, there were seven interviewees that found it hard to express their experience as loss. The inclusion of these interviews is important to understanding how people may experience brain injury in terms other than loss, which may be equally as relevant as those expressing a clear definition of loss after ABI.

This theme appeared in seven interviews (5/14 individuals with ABI and 2/16 relatives). Unclear loss was present when the person did not connect with the concept of 'loss', but there was still a negative expression of the effects of the injury, and a longing for before the injury occurred.

For example, Max felt his injury had affected his sense of time and relation to before and after in terms of his injury timeline. As a result, he did not connect with 'loss' because he did not hold a time of being in mind to recognise it:

“So no I don't have a sense of loss, but I do have a sense of not doing what I was that then gets applied to other things without me really knowing why...I could be specific about some 'thing' that I might attribute to the accident and my feelings around it. That might be anger, that might be sadness, that might be happiness, it might be bitterness. It's more normally bitterness and anger that will lead to sadness. But I don't know what loss was. Again, you'd have to put that on a particular timeline and I don't have that, so it's confusing.”

From the relative's perspective, the concept of loss was not always recognised if there was an acceptance for how things had changed:

"Occasionally yeah, 'cause our relationship is different now, so I think there is some sort of, I don't know if it's a feeling of loss or if it's just that you think well this is how it is. " – Mandy, wife

Debbie describes how the positives have helped to outweigh the negatives in terms of her husband's injury effects. There is a loss there, but it is not a lived loss within the relationship:

"Not really. I know it sounds mean to say but I've had more of Philip since he had his injury than before because most of the time before he was a workaholic so he was there all the time, so although it wasn't a nice thing to happen, I've got more of him than I'd had before....well we used to like holidays, and you miss those because they were quite adventurous type things, which you would have done then."

These expressions of unclear loss show how some participants are living with changes due to the ABI, but that in some cases the ability to appreciate the positives that have come with these changes can mediate the negative effect of the change itself. Also, it may be that these participants have reached a level of adjustment to their situation which means they can acknowledge losses, but that they are not felt in the same way as someone who is still coming to terms with accepting the consequences of the injury.

Not every person felt a type of loss from their experience. In fact, three of the participants (two individuals with ABI, one relative) did not report any feelings of loss from their experience, and could actually identify positives as a result of the changes they have faced:

“I don’t know I just feel the same, although there was some difficulties. But it wasn’t like I couldn’t carry on...well I guess my family, well they did, they must have supported me so well that I just felt like I could get on with it. And it’s not like I was really that bad....If anything it’s made it better, because I actually try with stuff. I’m constantly trying. Before I was like, I didn’t really care.” – Harry, individual with ABI

“In some ways I’ve experienced a gain...I appreciate what I’ve got.” – Gordon, individual with ABI

“I personally don’t feel I’ve experienced a loss. Maybe at the time I did, in some strange way but I don’t feel I’ve lost anything. Yeah okay he’s not, he’s got a brain injury now that he didn’t before, that’s his loss not mine. Yeah, I don’t feel any, I personally don’t feel any, that I have loss....We’re just so grateful we’ve still got him. We’re just so proud of how he’s doing.” – Patricia, mother

When these participants were asked what helped them feel the way they did, they all expressed a feeling of ‘it could be worse’ and showed a positive perspective on how much they could do despite the injury. A feeling of having made a good recovery, when at the outset things were much bleaker, was a contributing factor to feeling no loss as a consequence of the injury. Also, these three participants were no longer active clients involved in HWC services, therefore the feeling of not needing professional support anymore may provide a sense of normality and achievement which in turn mitigates any feeling of loss that may have once been present but is no longer identifiable.

Quantitative data

There were no statistically significant correlations between demographic variables (age at participation, age at time of injury, months since injury, number of services involved, level of education) and BIGI loss score either for individuals with

ABI or relatives ($p > .05$ in all cases). One-way analysis of variance (ANOVA) also revealed no significant effects of type of injury, employment status, whether living with a relative or not, gender or marital status on BIGI loss scores in either participant group ($p > .05$ in all cases).

To investigate differences between individuals with ABI's and relatives' BIGI loss scores, an ANOVA was conducted with participant type as the factor (relative or individual with ABI) and BIGI loss scores as the dependent variable. Levene's test for equality of variances was violated, therefore the Welch F -ratio is reported. There was no significant difference between the means, $F(1, 63.927) = 2.477, p = .120$.

These findings show that, in this sample, there is no statistically meaningful difference between how strongly individuals with ABI feel loss when compared to relatives of people that have sustained an ABI. Furthermore, demographic variables such as gender, age and employment status did not predict strength in feelings of loss for either group. The length of time that had passed since the injury occurred, as well as the type of injury, did not significantly impact on severity of experienced loss. These results suggest that time may not be a key determinant in the reduction of loss, and the cause of the injury may not be of importance to how the person involved subsequently feels in this respect.

Discussion

In this research we investigated experiences of loss after ABI, and considered how these might differ between those who have incurred the ABI and those who are related to them. The occurrence of the five main themes of loss show how the person at the centre, i.e. the person with the brain injury, can be affected in similar yet

separable ways to someone who is related to an individual with ABI. The use of dyadic analysis showed that loss is experienced from a single perspective, independent of how other people's experiences of loss, yet also dependent on how the brain injury has affected an individual.

The theme of 'loss of person' related to changes in the personality or the identity of the person with the ABI, either experienced personally or as an observer. Ambiguous loss was present in this theme, with the loss for the person being present without the physical loss of that person. This observation indicates that ambiguous loss can begin at the acute stage of brain injury rehabilitation, as described by Kean (2010), but can also remain a profound focus of loss even years after the injury occurred, for both individuals with ABI and those related to them, as also reported by Holloway, Orr and Clark-Wilson (2019).

The theme 'loss of relationships' describes the way relationships are altered by the experience of ABI. Predominately for relatives, there is a shift in the equality of the relationship and a feeling of additional responsibility as a result. For individuals with ABI, this feels more evident among friendships, with a feeling of not having the same quantity or quality of social networks as before the ABI. The reasons for this difference in relationship focus were not clear. One possible explanation is that the relatives protect the individual with ABI from their feelings of negative relationship changes, and they are therefore not as apparent to the individual with ABI. Furthermore, as many individuals with ABI reported no longer taking part in the same vocational or recreational activities due to the effects of their injury, friendship groups may have more naturally declined for them, leaving a greater loss for the person with

the ABI than for the relative. Given our observation that changes in relationships underpin a strong sense of loss for those affected, we encourage further research in this area.

The theme ‘loss of activity/ability’ most commonly occurred for individuals with ABI and related closely to lost skills or activities due to the impact of the injury. For individuals with ABI, the loss of an ability had wider reaching implications on their identity and sense of worth. The activity or ability per se was not the loss, but the feeling of somehow not being as capable or independent as they once were. For relatives the focus was on things that could no longer be enjoyed together with their loved one because of the effects of their ABI. This translated into changes to their lifestyle, with less spontaneity allowed for activities together now the ABI effects had to be considered. This loss of ability and activity had more of an impact on ABI individuals, with relatives feeling they could accommodate the changes to their lifestyle more readily because they were not the main focus of day-to-day life. As the individuals with ABIs’ loss was so personal, it may have been felt more deeply, whereas the loss for the relatives was more peripheral in comparison to other challenges they have had to accommodate. Although lost activity after ABI has previously been reported in the literature (Gracey et al., 2008; Turner, Ownsworth, Cornwell & Fleming, 2009), the inclusion of dyadic analysis indicates that the activities lost are personal and felt on an individual level, even when they were activities shared with family members. Just because one person feels the loss of a once shared activity does not necessarily mean this is still an area of importance for the other.

The theme 'loss of future' was much more of a concern for relatives than individuals with ABI. Relatives reflected on aspirations that their loved one would no longer fulfil and they held this loss much more evidently than individuals with ABI. Spouses particularly felt that their own future, as well as that of their loved ones, had been changed due to the injury, and plans made together would no longer come to fruition. For these people, there was no preoccupation with the past and how life was before the injury, but a loss of the future planned together and the experiences that would now not be possible. One explanation for the imbalance in feelings of this type of loss could be due to individuals with ABI focusing more on the day-to-day challenges that ABI brings, rather than looking too far ahead, whilst relatives are more able to consider how the plans for their futures together have been altered, as they are not personally experiencing the ABI effects.

Another reason why some individuals with ABI do not experience as much loss of future could relate to the cognitive effects of brain injury and how this can impact on the ability to have foresight and think about things which have not yet happened. Imagining a future that could have been may simply not be a skill so readily available to individuals with ABI due to the complex executive processes involved. Evidence for the role of the frontal lobes in enabling a future perspective (e.g., Fellows and Farah, 2005) raises the likelihood that many individuals with ABI tend to live more in the moment as a consequence of frontal lobe damage. Future research is encouraged to explore the impact of executive (dys)function on feelings of loss for the future.

The final theme of 'unclear loss' demonstrated how some people expressed a loss of ability, relationship or activity, yet would not describe it as 'loss'. For some, this appeared to be due to an ability to see positives over the negatives, which meant changes could be identified but not harboured after. For others, it could be that they have reached a stage of acceptance and adjusted to the changes which have taken place and may have in earlier stages resulted in a state of loss. This could have implications for the way interventions are offered to families after ABI, as they may not present with a need for support due to a disconnect with the terminology being used. It should be considered that the emotional sequelae of ABI can be confusing and unclear for those involved, and traditional terms of loss and adjustment may not resonate with everyone.

A unique aspect of this research is the inclusion of dyadic relationships. To the authors' knowledge, experiences of loss have not previously been presented together from two perspectives for comparison. The primary finding from analysing dyadic relationships is that even though the two people concerned are from the same family, they often reported different experiences of loss. For example, one person in the relationship can be feeling profound loss and expressing this negatively, whilst the other person does not necessarily consider such a feeling of loss in the same way. This observation suggests that that even though Brooks' (1991) concept of the head-injured family has been useful at highlighting the wider impact of ABI, it does not necessarily follow that family members are experiencing a similar type of loss as those who have had the injury, and vice versa. It may be that individuals with ABI experience is shaped by their rehabilitation journey, where focus is likely to have been on

functional outcomes and personal goals, rather than protecting, strengthening or rebuilding family relationships.

Participants in thirty of forty interviews expressed at least one of the loss themes, but few incorporated more than one theme. The maximum number of themes present was two, with this occurring in only seven of the total forty interviews. This finding suggests that when loss is present, it is focused and prominent in the person's mind and could possibly overshadow any other less significant areas of loss that may, or may not, be present. Future research could use the themes that have emerged from these interviews to investigate if multiple loss themes are commonly present amongst those affected by ABI. It could be that the breadth of loss themes has been under reported due to the self-generating nature of the interview method. If people are given suggested prompts about different types of loss, they may more readily subscribe to multiple loss themes rather than just the one that feels most pertinent at the time.

When considering standard quantitative measures, the meaning and/or severity of loss does not seem to be affected by the type of injury, or how long ago the injury occurred. Instead, the loss seems to be more connected with a person's perspective and expectations of life after ABI. Knowledge that the passage of time alone may not be sufficient to heal loss experienced by families affected by ABI could prove crucial for rehabilitation and clinical management decisions. To the extent that the normative grieving cycle associated with the physical loss of a family member (i.e., through bereavement) does not apply, more targeted interventions to support the grieving process among those affected by ABI may be required.

In summary, individuals with ABI and those who are close to them may not be affected by the injury in the same way. The injury often has wide reaching implications, but the individuals with ABIs' experience and feelings of loss do not transfer to relatives just because they are related to each other. The experience of loss is highly subjective and not necessarily related to functional losses as a result of the ABI. For relatives the experience of loss is two-fold: a personal loss for themselves as well as losses for their loved one. The focus for individuals with ABI is more on personal loss. With rehabilitation interventions currently centred on the person who has acquired the injury, we hope the present findings provide a motivation for addressing the complex dynamics of loss from the wider family perspective.

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