'Putting a new perspective on life': A qualitative grounded theory of posttraumatic growth following acquired brain injury

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Abstract

Purpose: An acquired brain injury is often described as a devastating experience and yet positive changes as a result of this event have been described. This study sought to understand the process of developing posttraumatic growth following ABI.

Method: Semi-structured interviews were conducted with 10 adults with acquired brain injury, recruited from three sites of a community day service for people with ABI. Grounded theory was used to explore the development of positive changes experienced as a result of the injury.

Results: PTG appeared to occur in a non-linear way as participants negotiated processes captured in the following themes: 'living with a life changing injury', 'trying to beat it and acceptance', 'identifying with a new you and others', and 'meaningful positive change'. Intra- and inter-personal comparisons emerged as important in accepting changes and reconnecting with pre-injury identity. This seemed to underpin accessing social and practical opportunities giving rise to connection with strengths and growth.

Conclusions: This study extends prior research into the process of adjustment and positive outcomes such as growth, although conclusions are limited to this specific sample and context. Further research and clinical practice development addressing acceptance and community engagement to develop positive change following ABI is required.

Keywords: Acceptance, brain injuries, emotional adjustment, post-traumatic growth, qualitative research, shared experiences

Introduction

An acquired brain injury (ABI) is defined as damage to the brain caused by events after a period of normal development. Sustaining an ABI is one of the most common causes of disability with long term implications for cognitive, emotional and physical abilities and relationships with family and friends [1]. Following ABI, the process of re-evaluating priorities and values in life may be associated with emotional distress during the early stages of community reintegration [2]. One of the challenges of adjustment following ABI is that the person is faced with a threat to their sense of self and of belonging to society [3]. A person will need to adapt to their new way of life, with changed cognitive abilities, possible increased dependency on others, loss of roles, and a need for accessing external support [2]. Over recent years research has begun to focus on the idea that a person's struggle with the new reality following ABI might result in positive psychological change [e.g., 1, 4] as they can start to view their experiences as a springboard for growth [5].

The concept of 'posttraumatic growth' (PTG) describes the phenomenon of positive psychological growth following a traumatic life event [6], with the suggestion that people can achieve a higher level of functioning than existed prior to the event. Critics of the concept of PTG question whether this represents genuine positive change, rather simply reflecting attempts to cope effectively [7]. However, proponents of the concept suggest that coping represents strategies to manage difficulties whilst PTG emerges through the person’s struggle and re-evaluation of who they are [8]. This positive psychological perspective highlights the need to explore both loss and potential for growth following ABI [9]. As such, the concept of PTG may be understood as different to resilience and coping, as these may exist without a person experiencing trauma [10]. Whilst, not everyone who experiences a traumatic event develops PTG studies have consistently demonstrated that people report similar aspects of positive change such as a greater appreciation of life, strengthened relationships, a belief that they are stronger because of their experience, changed priorities and deepening spiritual belief [11].

Previous research has described the development of PTG following ABI, highlighting the benefits and context of social support, activity and new relationships [1, 12, 10]. The consequences of ABI can fundamentally change a person's way of life and their sense of who they are, and this influences how they see themselves in the future [13, 14] and positive meaning can be derived through the reconstruction of sense of self following ABI [2]. Despite these changes to the sense of self following ABI, rehabilitation often focuses on how to support people to improve functional outcomes and reduce psychological distress, rather than on how trauma has changed their self-understanding [15]. Therefore, further understanding of how some people with brain injury develop PTG may provide insight into how people view themselves in positive ways as a result of their ABI, despite the impact often caused to their way of life.

People with ABI report PTG in a number of different areas such as improved life quality, enhanced personal satisfaction and increased spirituality [16]. A study involving interviews with 103 people suggested that positive psychological growth was found in half of the sample. It has been suggested that PTG takes time to develop and is often reported five or more years post injury [17], mirroring the long recovery process following ABI [18]. Despite this, one study which sampled people six months post discharge reported modest levels of PTG ranging between no change, a very small degree of change (spirituality), and a small to moderate degree of change (a greater appreciation of life) [5], suggesting that PTG can develop relatively soon following

ABI. Furthermore, the idea that a person has the ability to learn from surviving a serious trauma, which can shape their identity and lead to growth [12], appears to be an important concept for ABI where people's sense of identity and cognitive abilities are often shattered. Given this, it may therefore not be the length of time since injury that needs to be further understood, but the process of development.

As has been shown there is a lack of research and therefore clarity about the process by which PTG develops following ABI [5]. Therefore, the aim of this study was to understand the development of PTG by collating people's views and past reflections on how they experienced positive growth following their ABI. Clarifying in more detail the processes by which PTG develops following ABI could offer important insight into how rehabilitation services can enable people to achieve personally meaningful outcomes following ABI, despite ongoing limitations to functioning.

Methodology

Study design

This study was approached from a social constructionist perspective, i.e. that understandings of the world are actively constructed in co-ordination with other people [19]. Grounded Theory was used as a way of analysing multiple socially constructed realities whilst enabling the development of a model from the data [20]. This study followed the guidelines set out by Charmaz's social constructionist approach to grounded theory that is concerned with the psychological processes within a social setting, and the influencing factors that construct a particular phenomenon [21].

Participants

As the study was exploring the process of PTG following ABI eligible participants were those who had sustained an ABI, were attending one of three sites of a community-based service (Headway) and self-reported experiencing positive changes since their ABI. Purposeful sampling was therefore utilized due to the specific characteristics of the target population, to ensure that the sample was able to effectively take part in the interviews and due to constraints relating to time and resources. Eligible participants were required to (a) have capacity to consent, (b) be over eighteen years old, (c) have acquired a brain injury after the age of 18 years old, (d) have sufficient language and communication abilities to participate in interviews and (e) identified themselves as experiencing positive changes following their ABI.

Ten participants (six men and four females) were recruited, of whom 6 sustained traumatic brain injury (four male and two female), one a haematoma (female), two a haemorrhage (both male) and one an abscess (female). No eligible participants were excluded from the study based on type or severity of ABI, this was because the study aimed to be as inclusive as possible to all those members attending one of the Headway sites. Of all the eligible participants no one refused to participate or dropped out. Injury severity and functioning were varied but all participants were living in the community. It was not possible to gain complete information on severity of injury due to length of time since injury and lack of access to medical records in this setting. The average age of participants was 49.9 years, ranging between 32 and 77 years. The average time since injury was 15.6 years, ranging from two to 58 years.

Participants were recruited from one of three Headway centres that provide community day services to people with an ABI. Headway is a UK- wide registered charity, which works to improve life after brain injury (www.headway.org.uk). The first author (I.L) held informal face-to-face information sessions at the three Headway centres, explaining the aims of the study, prior to staff at the centre obtaining consent for those interested to be contacted by the researcher (I.L.). If the person was deemed eligible to participate an accessible information sheet was given, and written informed consent obtained. All reported information has been anonymised and pseudonyms are used. Ethical approval was sought and gained from the Research Ethics Committee of the Faculty of Medicine and Health Sciences at the University of East Anglia.

Data Collection

Face-to-face audiotaped semi-structured interviews were carried out by I.L. in a private office at each of the three different Headway centres used for recruitment. The interviews ranged from 45 to 70 minutes. An interview schedule was used initially with questions such as ‘what was life like for you after your brain injury?’ how do you describe the person you are now/were before?’, ‘have there been any positive changes since your brain injury?’ and ‘from your point of view, what has contributed to these positive changes?’. Following the iterative process of grounded theory, the interview schedule was used as a guide. Each interview was transcribed and coded before another participant was interviewed. Therefore, the interview schedule evolved with each interview and analysis and the questions were refined according to the emerging findings. It was not possible to conduct more than one interview with each participant or to conduct member checking due to the nature of the sample and time pressures but results were disseminated back to the participants via informal face to face sessions by I.L. The iterative process of data collection, analysis, theoretical sampling and focused coding was continued until 'theoretical sufficiency' [22] was judged to be achieved. It was decided that ‘theoretical sufficiency’ but not saturation of the data was achieved as the themes that were emerging from the data were thought to be sufficient to increase the understanding into the process of PTG following ABI. It has been suggested that six to ten interviews are sufficient for ‘theoretical sufficiency’ [23]

Sensitivity to context

As the research was carried out from a social constructionist viewpoint, experiencing the context of Headway was a key component of the research. The first author (I.L) spent time prior to data collection in the participants' everyday surroundings at the Headway centres. This allowed otherwise unobtainable views of what was significant from the viewpoints and actions of the participants within their social milieu [22] and also allowed relationships to be established prior to interview. Following data analysis, the findings were fed back to service users of Headway including those who participated in the study. The findings were then interpreted by Headway members via an art project, resulting in them designing and making a sculpture to represent the themes that emerged from the data.

Reflexivity and Rigour

During the course of the study, numerous steps were taken to ensure reflexivity and transparency. A reflective journal was completed throughout the study. This is recognised as good practice [24] in order to think through emerging ideas and make any influences explicit.

Pre-existing conceptualisations that might influence 'theoretical sensitivity' were reflected upon. By not confusing an 'open mind with an empty head' [22, p. 176] the research could be approached with the pragmatic view that prior knowledge can be used to inform analysis but not direct it. To deepen and extend this reflective process and to ensure trustworthiness of the data and analysis, the authors also discussed the evolving analysis between themselves and within an ABI research group within the institution.

The Consolidated criteria for Reporting qualitative research (COREQ) was referenced during the writing up process to aid reporting important aspects of the research [25].

Analysis

A qualitative, constructionist, interpretive method was selected for data analysis as the study aimed to gain a rich account of individual and shared processes of developing PTG. Data collection and analysis followed grounded theory guidelines [21], ensuring that a constant comparative method was used by adopting simultaneous collection of data and analysis, as shown in Figure 1.

[insert figure1]

The analysis and procedure were reviewed by the second author (PF) on multiple occasions to ensure agreement was reached for all themes. The resulting model was discussed with both the second (P.F) and third author (F.G) throughout this process.

The interviews were analysed, firstly using line-by-line coding. Following this, focused coding was used to start to separate, sort and synthesize the data into codes that had analytical significance. From this there were 63 initial codes that were sorted and reduced to establish 15 theoretical categories, with the emerging four themes being formed in an iterative process. Theoretical sampling was introduced after interviewing seven participants, who except for one had all had their ABI 14 or more years prior to the study. Therefore, eligible participants identified by staff as being 14 years or less post ABI were sought. A further three participants (2 years, 5 years and 6 years post ABI) were thus recruited and interviewed.

Where necessary, participant quotations have been slightly edited to enhance readability and ensure anonymity.

Results

For the participants in this study the process of developing PTG following ABI emerged out of the initial struggle with the impact of their ABI and then coming to accept and identify with a new and different sense of themselves. This appeared to be a complex and dynamic process that varied between participants, but also shared some common features. The key processes identified are set out in Figure 2, below.

[Insert Figure 2]

Participants described themselves as actively engaged in processes considered in our analysis to iterate between four phases, illustrated by the four boxes in Figure 2 and the themes described below. The large arrows represent the fluid process by which a person may move back and forth between the themes, with the smaller arrows showing how the themes influence one another. The italic text refers to key words used or specific processes described by individuals as they negotiated the wider processes.

In summary, the grounded theory developed from our analysis suggests that acceptance emerged through a process of attempting to return to previous ways of doing things, and realising that this would not be possible when living with the impact of their ABI. At times these experiences seemed to prompt comparisons between their own pre and post-injury selves, and between themselves and others with an ABI. Where a degree of acceptance was achieved, where favourable comparisons occurred, or where continuity of identity was experienced, the possibility of identification with ‘a new you and with others’ arose. The participants all spoke about the importance of being with others for support, and for gaining confidence to try things, which itself seemed to contribute to ‘meaningful positive change’. Positive experiences of growth therefore appeared to emerge from multiple interacting intra- and inter-personal processes. Whilst capacity to ‘look at things anew’ or to have a ‘new perspective’ contributed to meaningful positive change, further positive experiences, and identification of personal strengths, seemed important to sustaining new, positive meanings. As such, the process of PTG appeared to be continuous, dependent on various interactions to be maintained, and therefore potentially waxing and waning over time. These four processes are outlined in the following section.

Living with a life changing injury

All participants spoke about how following their ABI their way of life had changed and that for many of them it was something they had never realised would happen to them. In living with the impact of a life changing injury such as ABI, the participants described the “effects of brain injury” as well as not having the “knowledge” of how to cope. This shock and realisation that their way of life had changed is described by Mary:

> You don’t realise that your whole life can just change, at the drop of a hat, and you don’t have the ability to do the things you used to do and we all take that for granted and we all take for granted daily activities you just get up every day and you don’t ever think that anything is going to happen to you, you don’t realise how lucky you were when you were fit and well’ (Mary; under average age; 6 years or less post ABI).

All the participants described that the change to the way of life resulted in confusion and difficult emotions in the months and/or years following their ABI, as explained by Elliot.

> I felt bewildered; I was struggling to come to terms with all the different feelings. I just felt pretty lonely pretty desperate (Elliot; above average age; 6 years or less post ABI).

The difficult emotions often came from not being able to do the things they had been able to do before their injury and having a different life to what they had before their ABI as described by Harriet:

> I had a bit of a breakdown, I used to cry a lot and I was angry, agitated, upset and frustrated because I couldn't do what I used to be able to do. So I didn't want to get out of bed. (Harriet; under average age 14 to 19 years post ABI).

However, this change was not only for things that the participants found they could not do anymore but their ABI also impacted on their relationships with others, as described by John:

> It messed my life up completely, from that point those roles [between his wife and him] have had to change. I suppose our social life has been destroyed to some extent because having a brain injury is allied to leprosy. (John; under average age group; 14 to 19 years post ABI).

The participants all described having a life changing injury which impacted on what they were able to do and their relationships with others. The ABI was described as a sudden change and something they had not been prepared for. The result of this change was that all the participants described experiencing difficult and confusing emotions that they were unsure how to manage. The implications of these negative emotional experiences are explored in the next theme.

Trying to 'beat it' and acceptance

In reflecting on how they accepted and adapted to their ABI, the participants described a process of initially trying to "get rid of it", but then coming to the realisation that "you can't" get rid of the ABI". Instead, they described trying to learn or accept help from others (as some participants described being angry) to "teach me how to deal with it". Part of this involved trying to go back to how they did things prior to their ABI, not at first realising that things needed to be done differently as described by Elliot:

> I tried to go back to work because I thought I was ready, but I was nowhere near and after a couple of months I was made redundant (Elliot; above average age; 6 years or less post ABI).

Other participants described adapting and accepting their ABI as a difficult process as described by Kathy who describes the dilemma for her wanting to go back to how she was but also knowing that things have changed:

> [Been difficult], the rationalised side of me knows that going back is not going to happen but the un-rationalised side of me wants to be back at work, enjoying my hobbies, my life is totally different to want it is now…. You do learn coping mechanisms to do things like reprogram your brain to do what you would automatically do and that's what I've learned. Because I am stubborn and very determined basically, I won't give in and that's always been me like this it is not going to beat me (Kathy; above average age; 6 years or less post ABI).

Kathy who was 2 years post injury in the quote above expresses her view of struggling with what has changed, not wanting to let it 'beat' her. Perhaps this initial experience is important in the process of acceptance and ultimately for the development of PTG; as through the struggle people often then re-evaluate their experiences. In the next quote John (14-19 years post ABI) described this process for him in coming to accept and adjust to the changes to his way of life following his ABI by re-evaluating what he has lost to what he can develop:

> For years, I thought I could beat it, and then you start to learn it isn't something you can beat, it's always there. You are always remembering, trying to hope that you were the person before the accident. It helps when people are accepting more, and more importantly, me accepting it more. It's

> like you are locked inside this room, you become a prisoner and in the beginning you are banging on the door asking someone to let you out. You finally discover you can't get out of there. So you start to think I've got to live in here, so you start to move the furniture around so in a more acceptable position, you get those bits [pointing to objects in the room] and make a little cooker, you start to use the wall as a calendar the whole thing starts to change. I have to make the best of this, let's work on this from here. (John; under average age group; 14 to 19 years post ABI)

In addition, participants reflected on the importance of learning new things and how this might make them feel stronger, for example Harriett described:

> Learn to relive my life, I've had to learn and that's made me stronger to be more independent. Can't do all you used to be able to do so you have to learn to be stronger and cope with that disability that you've got (Harriet; under average age; 14-19 years post ABI)

The idea of struggling was described by all the participants and learning and adjusting to these changes over time led to acceptance of both the impact of their ABI but also the person they are now, as described by Mary:

> [in the beginning] I struggled, I used to bump into things and I had to learn how things had to go in the home. I can't pin point acceptance as such I think time itself and adjusting to the new you. Being active and not on your own that has helped with my acceptance as well (Mary; under average age; 6 years or less post ABI)

Over time and through the experiencing of the impact and difficulties associated with ABI the participants described learning to accept that the changes to their life as a result of their ABI will not go away, instead this process led to re-evaluating how they view themselves and that despite loss participants started to view positive things as a result of their ABI, as described by Pete:

> It's like hitting the re-set button I literally had to rebuild. If you've got a brain injury for heaven sake look at it as an opportunity. There is a lot of negativity, there is a lot of things wrong, there are a lot of things you don't recover from, there

> are a lot of things you can't do anymore but at the same time I've found in my experience there are an awful lot of things you can do, that you can look at anew and you can turn aspects of your brain injury into a positive thing.' (Pete; under average age; 14-19 years post ABI)

These last quotes indicate a possible process where moving back and forth attempting things, re-evaluating and learning may have been important for acceptance. Participants also reflected on the importance of being with people who have had the shared experience of ABI, often in more positive ways, which is described in the next theme.

Identifying with a new you and others

The participants described the importance of being with others who understood and shared their experiences; words like "compatriots", in the "same boat" were used to describe other members of Headway. Being with others who understand was described as helping with acceptance as described by Wayne:

> Headway has helped me a lot with my having a bit of a chip on my shoulder and helping in my life. I've always wanted to do things and I've never at the time realised that I couldn't actually do it, and Headway has been a good anchor to try and explain it. The activities I do and even socialising with the people at Headway help because everyone else is in the same boat and it's like a family situation - you've got more understanding (Wayne; under average age; 14-19 years post ABI).

Being with others was also described as an opportunity to learn to cope with changes, and also to do things they had enjoyed before, helping them to reconnect with themselves, as described by Colin:

> I think mainly just being interested in things. I was still fascinated by reading and to try and cope with what I'd been left with. (Colin; above average age; 20-60 years post ABI)

Being with others also allowed the participants to compare themselves to others and then reflect on how things have changed for them following their ABI, as described by Mary:

> When I first came to Headway I was very embarrassed that I might answer a question with a silly answer, that never happened – not one person ever giggled or laughed. For me, being amongst other people that have a little bit of understanding of what struggles you have, for me it's a huge comfort - I feel relaxed in the environment. In the early years, I used to compare [to how I was before the ABI] but over the years I don't make that comparison. I shouldn't grumble because the people with physical difficulties [at Headway] don't moan they're not miserable they kind of have to get on with it and I admire them for that. A lot of people go through grieving for the old you but it takes times to accept the new you (Mary; under average age; 6 years or less post ABI)

Furthermore, John describes how comparing himself to others and reflecting on what he still had allowed him to notice things he could feel grateful for:

> I look around and see people worse off than I am and that's another thing Headway has shown me. I am very lucky I still have the same wife, I mean lots of compatriots here, their marriages have been destroyed by the brain injury (John; under average age group; 14 to 19 years post ABI).

Participants also spoke about how being with others in a similar situation to them helped them reflect on their life prior to their injury allowing new perspectives on themselves and life following their ABI. Nate describes how being around others at Headway helped him to think about the people he knew prior to his ABI and how that has also changed how he describes himself in a more positive way.

> Some people I grew up with, they've just turned out right ruffians and they haven't got a care in the world. The people who come here [at Headway] they probably take the mick out of them for how they are but I'm not like that because I know

> I’ve been through it. That’s why I care about people more. (Nate; under average age; 14-19 years post ABI)

Being around others in a similar situation, being encouraged and having new opportunities allowed the participants to develop their abilities and confidence, as described by Helen:

> It’s amazing I found different talents that I didn’t think I had and things that I thought I wasn’t good at before. People praise you [at Headway] and that is important as people outside degrade you a lot (Helen; under average age; 6 years or less post ABI)

Participants also spoke about viewing how they are with people differently and that this has been a positive experience for Pete:

> One thing that has changed in me - because I do try and make people smile, I try and make them laugh - and that's one thing I like about myself since my accident. Now don't get me wrong, for quite a long time I was very reserved, if I was in a new situation it was very difficult, but one of the things that's happened here at Headway is that its allowed me to flourish in a way that I hadn't done before and its allowed me to do things that I couldn't do (Pete; under average age; 14-19 years post ABI).

The process of developing a new view of themselves seems to develop over time from acceptance and being able to be around others with a similar experience. This process did not appear to occur in isolation to the difficulties that they experienced following their ABI but rather through a process of engaging with challenges and reflecting on specific experiences or difficulties. In this way new things were discovered about themselves which helped contribute to a more positive view of themselves. This development of viewing positive changes as a result of the ABI is further elaborated in the next theme.

Experiencing Meaningful positive change

Describing positive change as a result of their experience of having an ABI, participants spoke of “flourishing”, “new talents”, and having a “life after brain injury”. Despite participants moving back and forth between the initial phases of having to manage the impact of their ABI and coming to terms with the changes, the participants all described viewing things in a different and more positive way as a result of their ABI, for example viewing the experience as an “opportunity”. Participants often reflected on how they were prior to their ABI and how they have changed as a result of this event, even if many years before, as described by Colin:

> I've learnt to tolerate a lot of things that I wouldn't have tolerated before, other people. I used to - just before the accident I was flying high and I was very full of it. Tolerance has increased because of the head injury. I recognise my own failings more than I use to. (Colin; above average age; 20-60 years post ABI).

Some participants also expressed that they feel their life would have benefited if they knew what they know now before their ABI. As such, the non-linear process of PTG is not only about accepting, learning and viewing themselves in a new way but is also rooted in reflections on the person they were prior to their injury as described by Elliot:

> I was a different person to what I am now. I really think I’ve found a more important and new meaning [to life]. I felt very blasé prior to this happening and I wish I knew ten years ago what I know now because my life could have been so much more different (Elliot; above average age; 6 years or less post ABI).

Some participants also described how their experience following their ABI had brought them closer to some people and had in fact allowed for new relationships to develop. This was despite John earlier describing he had lost his social network following his ABI. Here John describes developing a relationship that existed before his injury but since then has changed for the better:

> I've become a lot closer to my sister than I ever was before - things became more bonded from speaking once a year to everyday, not straight from brain injury, it's something that has sort of grown (John; under average age; 14-19 years post ABI).

Participants also spoke about enjoying the same things but in a different way, that their experience of an ABI has also changed their perspective on things. As described by Kathy:

> I would have enjoyed the sun but not in the same way [before injury], I was sitting the other morning and thinking, isn't this wonderful isn't this good to be sitting here and watching the sun rise, realising there's a purpose to it. I think prior to the head injury you kind of think life just ticks away and you lose the concept of what really life is about. The simple things like the sun coming up, stupid simple things, being able to do things now, being able to move on and read again and enjoying a book, seeing things come on and move on and not stand still. There is a life after brain injury, you have to put a new perspective on life (Kathy; above average age; 6 years or less post ABI).

Even with this view of positive changes as a result of their ABI and being able to have a life following it, the participants described the continued back and forth process of reflecting on what they couldn’t do, what they needed to learn and how this can lead to feeling more fortunate, as described by Mary:

> There is no magic cure to bring your old self back. I'm not saying it's easy and I'm not saying I 100% accept it but I feel that I am better. I just feel fortunate to be able to do what I can do now I'm making the best of what I can do. I used to bump into things and be clumsy and my husband had to learn because everything has got to stay in the same place, so it's been a learning curve for my husband. I feel I'm lucky because we've got a different life now but we still do have a lifestyle and I’m taking advantage of the things I can (Mary; under average age; 6 years or less post ABI).

Despite the positive changes the participants described, they also shared that the negative aspects of their ABI still remain; rather it is how they have come to accept and view themselves and others that has changed, as described by Pete:

> Life is too short, there's never enough chocolate and never enough sex and there's so little time. What I mean is if you've got a brain injury for heaven's sake look at it as an opportunity. There is negativity about brain injury not just for the person but for the people around them, and a lot of things wrong… There are a lot of things you don't recover from, there are a lot of things you can't do anymore but at the same time I've found in my experience there are an awful lot of things you can do. A lot of things that you can look at anew and you can actually turn some aspects of the brain injury into a positive thing, you know, which I have done successfully and I think everybody has these little triumphs (Pete, under average age; 14-19 years post ABI).

These four themes reflect that learning to live with and accept ABI was a fluid process of attempting to do things they had done prior to their ABI and then realising things had changed. Over time participants described that being with others who understood and who they could compare themselves too as well as doing things they enjoyed helped them to view themselves differently and re-evaluate their experiences. In addition, being able to identify with people who had a similar experience also helped influence acceptance as well as how they lived with their ‘life changing injury’. For the participants moving back and forth between these phases over time led to developing PTG and this in turn influenced how they viewed themselves, others and the person they are following their ABI.

Discussion

The findings from this study echo previous conceptualizations of PTG as the result of a struggle with events which represent a significant challenge to the person and their ways of understanding the world and their place within it [26]. In this study, the development of PTG was conceptualised as a dynamic process. Participants initially described a phase of ‘living with a life changing injury’ as outlined in the first theme. The second theme, ‘trying to beat it and acceptance’, captured the process of moving between attempts to accept and adjust to the loss and changes as a result of their ABI and attempts at returning to how things were prior to their injury. Acceptance seemed to be a key process for how they viewed their ABI and it has been previously suggested that learning to accept oneself and developing pride in one's achievements were important steps in viewing oneself in a positive way [6]. Furthermore, for the participants another important aspect was the dynamic process of comparing themselves to how they were before their ABI, or making comparisons to others with an ABI. This phase was described in the ‘identifying with a new you and others’ theme. Through these phases, the participants described how they were able to appreciate things differently and how they viewed themselves to have grown in positive ways as a result of their ABI, as described in the ‘experiencing meaningful positive change’ theme. This phase also then influenced how the participants viewed their experience of ‘living with a life changing injury’ as depicted in the model.

In addition, being with others in a supportive and encouraging environment where they could share experiences with others was thought to facilitate the process of developing PTG. Indeed, the participants reflected on the importance of attending Headway and resonates with research that suggests that people often come to know who they are, partly by knowing who they are as group members [27]. Previous research has suggested that cognitive ability, communication and other sequelae of the injury can lead to disruption to social opportunities, facing negative judgments and resulting in exclusion from groups [28]. These negative instances post-injury are experienced as a threat to self and may lead to attempts to cope via avoidance and, withdrawal from social and activity contexts [2]. The participants in this study described the benefits of being able to talk with others who understood them and the importance of not feeling embarrassed or judged by others and it has been suggested that people may positively redefine themselves in a dynamic and multi-faceted process by forming new priorities and interests (e.g. joining support groups) which can restore self-esteem and enhance satisfaction with life [28].

It may also be important to consider how acceptance appeared to play a key role not only in attending Headway and being with others with an ABI but also in the development of PTG. Further understanding acceptance such as through the ideas of the 'Y-shaped model' [29] which proposed that coming to awareness, and understanding, and resolving discrepancies with the self before and self now, involves the process of adaptation and leads to reintegration into society. In particular, this relates to the conceptualisation of the process of change and the reduction of self-discrepancy for the psychological (meaning, identity, understanding, expectations) and the social (roles, activities, contexts, relationships), which can occur through engagement in activities [2]. Being able to engage with others has been suggested to support the re-creation of a narrative, which is essential in giving a person's life a sense of meaning and purpose [30]. The findings form this study suggest that comparison between themselves and others with an ABI was also important in helping to develop positive change and it may be that not only comparing themselves to how they were prior to their ABI but also comparing to others with an ABI supported understanding as well as re-evaluating their experiences. It has been suggested that PTG should not be viewed as 'one piece of the complex puzzle, but rather as the fundamental frame that holds the entire puzzle together' [31, p. 65]. Therefore, the importance of opportunities for people to narrate their experiences and story of recovery after ABI into a coherent and meaningful narrative account could be part of the process for PTG to emerge.

Clinical implications and recommendations

This study has clinical relevance for those working with people who have experienced an ABI. The results from these participants reflections described a non-linear and dynamic process for developing PTG. Therefore, clinicians may need to consider the timeliness and readiness of the person with ABI when formulating and planning interventions which may support a person along this process. Understanding where a person is in viewing the impact of their ABI, how they identify with themselves following this event and how they view others with an ABI may be important questions when planning interventions. As well as normalising both the initial reaction to the impact of an ABI and highlighting the benefit and opportunities that groups such as Headway may offer.

When working with people with an ABI it may be important to provide understanding, compassion and acknowledgment and strategies to initially manage the difficult emotions before focusing on developing acceptance. Developing acceptance appeared to emerge following a process of wanting to go back to how things were and as such clinical interventions could focus on how to support people to weigh up the pros and cons of attempting to do what they had done before, as this realisation was an important phase in acceptance of their ABI. Focusing on developing skills and strategies as well as doing things that they enjoy whilst being able to be with others in a supportive space is also likely to be important. Processes such as these have been described in identity oriented and socially contextualised approaches to rehabilitation [2, 29]. It may also be important to view interventions as needing to be multi-faceted as acceptance and growth was not just about learning coping skills to help adapt, but rather a complex mix of socially contextualised process involving engaging with challenges, sense-making, acceptance of differences and investment in new perspectives or strengths.

Previous research suggests that identification with others can provide a positive means to redefine the self after ABI [32]. This study suggests that feedback from others who have shared experiences may provide a positive environment where people are able to attempt new things. The benefits of being with others who have shared experiences following ABI may need to be considered when working within this setting and how best this can be facilitated within a safe trusting and cooperative environment, as suggested by the holistic rehabilitation approach [33]. Furthermore, the idea of 'social neuropsychology' [34], which can promote personal identities and increased social participation as a desired outcome, may be an important factor when considering a person's progress following ABI. The participants reflected that comparison to others was important in the process of PTG. They described that comparisons between how they were pre and post their ABI as well as comparing themselves to others who also had an ABI helped re-evaluate their experience. Some participants described being able to understand more the impact of their ABI and feeling ‘grateful’ for what they were still able to do through this comparison with others. Further research into how comparison can promote acceptance and PTG would be needed.

Thus, the clinical implications of this study are that it may be important to consider the timeliness of interventions (in relation to an individual's adaptation process), normalise, support and allow people to experience and make sense of the consequences of their ABI, as well as fostering a supportive environment where they can try new things and find new ways of doing things. In addition to meeting others with a similar experience and focusing on a person's strengths, interests and offer encouragement as well as acknowledging what has changed.

Limitations of the study and future directions

The social constructionist orientation of the research, in which the results are seen as co-constructed in a specific context, means that the findings cannot be interpreted as objective or generalizable, in the statistical sense, to other populations. The relatively small sample size also limited the analysis such that it was only possible to reach theoretical sufficiency, rather than saturation. A prospective study of the evolution of PTG over time would have enhanced the rigour of the findings. However, this would have required a large initial sample in order to include sufficient participants who do experience PTG. Therefore, prospective analysis was outside the resources and scope of the current study, which focused on participants who'd identified as having positive or growth experiences reflecting back on how these experiences came about. There was also a high degree of variation between the participants in terms of time since injury which might challenge interpretation of the findings and limit generalisability. However, diversity of participant characteristics is required in grounded theory in order to drive theoretical development, therefore the differences between the three centres in terms of space, geographical location and staffing and participant characteristics including number of years post-injury could also been seen as a strength. When considering the findings of this study, it is also important to consider the social milieu of Headway. The participants were all passionate advocates of Headway and this may have emphasised the role and importance of social support, although it is also possible that the social support gained drove their sense of connection and commitment to the organisation. Despite this, the participants all spoke about the emotional struggle following ABI and this was conceptualised to be an important aspect in the process of PTG.

Future areas of interest would be the role that social relationships and belonging to a group have in the development of PTG, as well as exploring the concept of a recovery narrative following ABI. The role of comparisons to others is an interesting idea in PTG - whilst the literature suggests that social relationships and re-connecting with community and people following trauma, are important, the idea of comparing oneself to others has not been widely addressed. Given the prominence of personal and social comparisons in models of post-ABI adaptation and adjustment [29, 30, 35] further research is needed to explore the role such comparisons may play in the process of PTG.

Conclusions

The current study sought to understand the development of PTG in a detailed way through retrospective interviews with a small sample of people with ABI. The findings indicated that PTG emerged from a process of adjustment similar to that described in the brain injury literature, through personal and social comparisons and reflections on continuity and disruption of identity. It appears that iterative and evolving cycles of social connection, engaging in and reflecting on challenges, and acceptance helped with identification of strengths and new positive meanings, allowing a new perspective on life and a view that, although changed, there is life after ABI. Research into emotional adaptation following ABI, and rehabilitation practice, should turn to focus on the conditions under which adjustment tips towards positive experiences such as growth.

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Declaration of interest statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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References

1. Powell T, Gilson R, Collic C. TBI 13 years on: Factors associated with post-traumatic growth. Disabil & Rehabil. 2012;34:1461-1467. doi:10.3109/09638288.2011.644384
2. Gracey F, Ownsworth T. The experience of self in the world: The personal and social contexts of identity change after brain injury. In J Jetten, C Haslam, SA Haslam. The social cure: Identity, health and well-being. US:Psychol Press. 2012:273-295.
3. Conneeley AL. Quality of life and traumatic brain injury: A one-year longitudinal qualitative study. Br J of Occup Ther. 2003;66:440-446. doi:10.1177/030802260306601002
4. Collicutt McGrath J, Linley PA. Post-traumatic growth in acquired brain injury: A preliminary small-scale study. Brain Inj. 2006;20:767-773. doi:10.1080/02699050600664566
5. Silva J, Ownsworth T, Shields C, et al. Enhanced appreciation of life following acquired brain injury: Posttraumatic growth at 6 months post discharge. Brain Impair. 2011;12:93-104. doi:10.1375/brim.12.2.93
6. Calhoun LG, Tedeschi RG. Early posttraumatic interventions: Facilitating possibilities for growth. In JM Violanti, P Douglas, C Dunning (Eds). Posttraumatic stress intervention: Challenges, issues, and perspectives. Springfield, IL, US:Charles C Thomas Publisher;2000:135-152.
7. McMillen JC, Cook CL. The positive by products of spinal cord injury and their correlates. Rehabil Psychol. 2003;48:77-85. doi:10.1037/0090-5550.48.2.77
8. Triplett KN, Tedeschi RG, Camm A, et al. Posttraumatic growth, meaning

in life, and life satisfaction in response to trauma. Psychol Trauma: Theory, Res, Pract & Policy. 2011;4:400-410. doi:10.1037/a0024204

9. Tedeschi RG, Calhoun LG, Groleau JM. Clinical applications of posttraumatic growth. In Joseph S (Eds) Positive Psychology in Practice: Promoting Human Flourishing in Work, Health, Education, and Everyday Life. New Jersey: John Wiley & Sons. 2015;503-518.
10. Levine SZ, Laufer A, Stein E, et al. Examining the relationship between resilience and posttraumatic growth. J of Trauma Stress. 2009;22:282-286. doi:10.1002/jts.20409
11. Tedeschi RG, Calhoun LG. The posttraumatic growth inventory: Measuring the positive legacy of trauma. J of Trauma Stress. 1996:9:455-471. doi:10.1007/BF02103658
12. Linley PA, Joseph S. Positive change following trauma and adversity: A review. J of Trauma Stress. 2004;17:11-21. doi:10.1023/B:JOTS.0000014671.27856.7e
13. Evans JJ. Positive psychology and brain injury rehabilitation. Brain Impair. 2011;12:117-127. doi:10.1375/brim.12.2.117
14. Ownsworth T. Self-identity after brain injury. London: Psychol Press;2014.
15. Ownsworth T, Haslam C. Impact of rehabilitation on self-concept following traumatic brain injury: An exploratory systematic review of intervention methodology and efficacy. Neuropsychol Rehabil. 2016;26:1-35. doi:10.1080/09602011.2014.977924
16. McGrath JC. Posttraumatic growth and spirituality after brain injury. Brain Impair. 2011;12:82-92. doi:10.1375/brim.12.2.82
17. Powell T, Ekin-Wood A, Collin C. Post-traumatic growth after head injury:

A long-term follow up. Brain Injury. 2007;21:31-38. doi:10.1080/02699050601106245

18. McGrath J. Beyond restoration to transformation: Positive outcomes in the rehabilitation of acquired brain injury. Clin Rehabil. 2004;18:767-775. doi:10.1191/0269215504cr802oa
19. Burr V. Social constructionism. London: Routledge Oxford;2003.
20. Fassinger RE. Paradigms, Praxis, Problems, and Promise: Grounded theory in counselling psychology research. J of Couns Psychol. 2005;52:156-166. doi:10.1037/0022-0167.52.2.156
21. Charmaz K. Constructing grounded theory: Introducing qualitative methods. London: SAGE;2014.
22. Dey I. Grounded categories. In A Bryant, K Charmaz (Eds). The SAGE handbook of grounded theory. London: SAGE Publications Ltd;2010:167-190.
23. Braun V & Clark V. Successful qualitative research: A practical guide for beginners. London: SAGE Publications Ltd;2013.
24. Yardley L. Dilemmas in qualitative health research. Psychol & Health. 2000;15:215-228. doi:10.1080/08870440008400302
25. Tong A, Sainsbury P & Craig J. Consoldated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19:349-357. doi:10.1093/intqhc/mzm042
26. Tedeschi RG, Calhoun LG. Posttraumatic growth: Conceptual foundations and empirical evidence. Psychol Inq. 2004;15:1-18. doi:10.1207/s15327965pli1501_01

27. Turner JC, Oakes PJ. The significance of the social identity concept for social psychology with reference to individualism, interactionism and social influence. Br J of Soc Psychol. 1986;25:237-252. doi:10.1111/j.2044-8309.1986.tb00732.x
28. Douglas JM. Conceptualizing self and maintaining social connection following severe traumatic brain injury. 2013;27:60-74. doi:10.3109/02699052.2012.722254
29. Gracey F, Evans JJ, Malley D. Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. Neuropscyhol Rehabil. 2009;19:867-890. doi: 10.1080/09602010903027763
30. Nochi M. Reconstructing self-narratives in coping with traumatic brain injury. Soc Sci & Med. 2005;51:1795-1804. doi:10.1016/S0277-9536(00)00111-8
31. Pals JL, McAdams DP. The transformed self: A narrative understanding of posttraumatic growth. Psychol Inq. 2004;15:65-69.
32. Jones JM, Williams WH, Jetten J, et al. The role of psychological symptoms and social group memberships in the development of post-traumatic stress after traumatic injury. Br J of Health Psychol. 2012;17:798-811. doi:10.1111/j.2044-8287.2012.02074.x
33. Ben-Yishay Y. Post-acute neuropsychological rehabilitation. In AL Christensen, BP Uzzell (Eds). International handbook of neuropsychological rehabilitation. New York: Kluwer Academic/Plenum Publishers;2000:127-135.
34. Haslam C, Holme A, Haslam SA, et al. Maintaining group memberships: Social identity continuity predicts well-being after stroke. Neuropsychol

Rehabil. 2008;18:671-691. doi:10.1080/09602010701643449

35. Martin R, Levack W.M.M, & Sinnott K.A. Life goals and social identity in people with severe acquired brain injury: An interpretative phenomenological analysis. Disabil & Rehabil. 2015;37:1234-1241. doi:10.3109/09638288.2014.961653

Figure Captions

Figure 1. Flow chart of the recruitment, interviewing and analysis process following the grounded theory method

Figure 2. Diagrammatic figure displaying the themes from the study and key words used by participants. The arrows display the process by which a person moves between the themes