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ORIGINAL ARTICLE

A qualitative exploration of how individuals reconstruct their sense of self following acquired brain injury in comparison with spinal cord injury

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Abstract

Primary objective: The present study aimed to investigate the specific ways in which individuals reconstruct their sense of self following injury to the nervous system, by comparing individuals with acquired brain injury (ABI) and individuals with spinal cord injury (SCI), two groups that have experienced a sudden-onset injury with life-changing repercussions. *Research design*: Phenomenological qualitative research. *Methods and procedures*: Nine individuals with ABI and 10 individuals with SCI took part in an interview exploring the ways in which individuals reconstruct their sense of self following injury. Data were analysed using interpretative thematic analysis. *Main outcomes and results*: Findings showed similar themes identified within the interview data of the ABI and SCI groups. Both groups developed positive and negative self-narratives. Individuals employed strategies that facilitated the reconstruction of positive self-narratives. In addition, individuals described their sense of self as simultaneously continuous and changing. *Discussion*: Findings are discussed in relation to proposed models of self-reconstruction post-injury to the nervous system.

Keywords

Acquired brain injury, sense of self, spinal cord injury.

History

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Introduction

Biopsychosocial approaches to neurorehabilitation emphasize the complex interactions of biological, psychological and social influences on mood and behaviour when working with people with acquired brain injuries (ABI) [1] and spinal cord injuries (SCI) [2]. An individual's sense of self is at the heart of the biopsychosocial approach to neurorehabilitation, as it interacts with and is affected by the biological, psychological and social sequelae which result from acquiring an injury to the nervous system, such as an acquired brain injury (ABI) or a spinal cord injury (SCI) injury.

Throughout an individual's lifetime, most will suffer a life-crisis point, be it the death of a loved one, trauma or diagnosis of serious illness [3]. Following a life-crisis point, an individual is required to reconstruct their sense of self [3,4]. Sense of self develops as the individual makes sense of the world around them using their intact cognitive functions [5]. In contrast to individuals with SCI, individuals with ABI are in a unique position, in that following the trauma of sustaining a sudden-onset serious injury the subsequent reconstruction of their sense of self is compounded by ongoing cognitive, emotional, behavioural difficulties resulting from damage to the brain.

Comparing the self-narratives of individuals who have sustained an ABI and individuals who have sustained an SCI

The reconstruction of self following a sudden-onset life-changing injury, such as ABI or SCI, has been well documented in the literature [6–14]. Contrary to theory suggesting that self-narratives post-ABI would be affected by on-going cognitive, emotional and behavioural sequelae, a review of the literature exploring the self-narratives of both individuals with ABI and individuals with SCI showed several similar themes.

First, a discontinuity between an individual's sense of self pre- and post-injury is evident throughout the literature, which gives a clear rationale for investigating this process [6–16]. Second, the predominant notion of a 'loss' or 'shattered' sense of self following injury and its subsequent reconstruction was highlighted in the literature that explores the narratives of individuals with ABI and individuals with SCI [8,12,17,18]. 'Loss of self' refers to a sense of grief and longing for the self and life that once was and 'reconstruction of self' refers to the process of the individual rebuilding a new post-injury identity. Furthermore, the trajectory of the literature, in relation to both ABI and SCI, more recently progressed from notions of loss

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and reconstruction of self post-injury to an acknowledgement of a continuous sense of self (from pre- to post-injury). The aforementioned discontinuity of self was explained by emphasizing the multifaceted nature of self. Self was divided into aspects that remained the same, an 'inner' self or core essence, and aspects of self that had changed, an 'outer' self, indicative of changes in bodily functioning, relationships with others and links to society [8,17,18].

Subsequently, theorists criticized linear or multiple linear models of self-reconstruction following injury and postulated alternative representations for the way in which individuals reconstruct their sense of self following ABI and SCI. Yoshida [14] devised a model of identity-reconstruction following SCI that was shaped like a pendulum, contrasting with linear process models of loss and adjustment. Yoshida [14] described five identity categories through which the individual's sense of self swings: the former self, the supernormal identity, the disabled identity as total self, the disabled identity as an aspect of total self and the middle self. The pendulum swings back and forth between an identity which is based on the continuation of the former self and that which is defined by the disability. Yoshida [14] sees identity reconstruction as a continuously evolving, fluid, dual-directional process.

Similarly, Muenchberger et al. [11] proposed a non-linear model of self-reconstruction following ABI. They framed the experience of rebuilding self following ABI as contracting and expanding. Several factors were identified as contributing to an individual experiencing a diminished sense of self. For example, viewing one's life-course as suddenly halted or an over-emphasis on regaining functionality by the individual and significant others, adopting an 'illness script' or being defined by one's inabilities. An expanding sense of self was described as feeling as though one was given a second chance at life, focusing on short-term goals and a desire for stable outcomes in terms of employment and relationships, taking a positive meaning from their experience, re-evaluating priorities and weighting social norms of success as less important and inner successes as more important. According to Muenchberger et al. [11], reconstructing self following ABI is a process that does not develop straight from a period of contraction to a period of expansion. It is a dynamic process, which goes back and forth between contraction and expansion of self. A 'tentative balance' exists between the contracted and expanded selves as the individual rebuilds their sense of self continuously throughout the rest of their life. Notably, the pendulum model [14] and the model of expansion and contraction [11] are similar in that they emphasize movement between an individual's positive and negative self-narratives.

Differences between the narratives of individuals with ABI and individuals with SCI

While the similarity of the themes identified within the literature exploring the narratives of individuals with ABI and individuals with SCI is pronounced, differences were also identified. For example, sub-themes associated with a loss of memory functioning and resulting effect on an individual's self-narrative were identified within the self-narratives of individuals with ABI [9,12], clearly indicating the impact of impaired cognitive functioning on the ways in which an individual rebuilds their sense of self. However, the majority of the differences reported by individuals with ABI and individuals with SCI were not as evidently linked to the cognitive sequelae associated with damage to the brain. For example, Sparkes and Smith [15] found that individuals with SCI experienced loss in comparison to their pre-injured self that centred around lost social circles dependent on a sport or activity that the individual could no longer take part in. This theme was not identified in the narratives of individuals with ABI. However, Sparkes and Smith [15] sampled individuals who had sustained their injury in sports accidents and a comparable study with individuals who sustained ABI through playing sports has not been completed. Thus, it cannot be extrapolated that individuals with ABI do not experience a loss of self in relation to social circles which were dependent on a sport or activity that the individual could no longer take part in. Furthermore, individuals with ABI described engaging in meaningful activity as positively influencing the reconstruction of their sense of self, resulting in a feeling of improved capacity and ability [9,19]. This subtheme was not present in the research exploring the narratives of individuals with SCI. However, it has been identified that engaging in a meaningful occupation is beneficial for individuals with SCI in rebuilding their sense of self [20], despite omission from the research exploring the self-narratives of individuals post-SCI.

Diverse interview protocols and sampling techniques may account for the discrepancies between the self-narratives of individuals with ABI and individuals with SCI. However, differences in injury-related sequelae such as the impaired cognitive functioning experienced by participants with ABI may also account for the discrepancies, necessitating a direct comparison of the narratives of individuals with ABI and the narratives of individuals with SCI.

It is evident that there are similarities in the narratives of individuals with ABI and individuals with SCI. Angel et al. [21] compare the findings from their case study research of a woman with SCI to previous research with stroke victims and report similarities in their experiences of struggle throughout the rehabilitation process. Theoretically, it is suggested that on-going cognitive, emotional and behavioural sequelae resulting from brain damage should have a compounding effect on the ways in which an individual reconstructs their sense of self in the world. Furthermore, it would be expected that this effect would be evident when examining the self-narratives of individuals with ABI in comparison to the self-narrative of individuals with SCI. However, a review of the literature suggests that this is not the case. Thus, a direct comparison of the self-narratives of individuals with ABI and individuals with SCI is warranted to ascertain if the experience of acquiring a sudden-onset life-long injury affects the ways in which an individual reconstructs their sense of self post-injury, more so than the compounding impact of the type of injury sustained.

Rationale for the present study

Current theory and research supports the idea that sustaining a sudden-onset injury, such as an ABI or acquired SCI, affects

the ways in which individuals reconstruct their sense of self [3,4,11,14]. ABI and acquired SCI are similar in that both are injuries to the central nervous system with sudden onset. Both individuals with ABI and individuals with SCI have a normal life expectancy and the consequences of incurring the injury can have dramatic effects on the ways in which individuals live their lives, particularly in social, psychological and occupational areas. Both ABI and SCI are most likely to occur to men who are aged between 15–30 years, a time when social and occupational arenas of life are most salient [22,23].

Sustaining an ABI differs from sustaining a SCI in that damage to the brain can result in cognitive impairments. Sense of self develops as the individual makes sense of the world around them using their intact cognitive functions [5]. Thus, it is expected that sustaining an injury that impairs cognitive functioning will have a confounding effect on the ways in which an individual reconstructs their sense of self. Through exploring and comparing the narratives of individuals with ABI and the narratives of individuals with SCI, the present study will investigate the ways in which individuals with ABI and individuals with SCI rebuild their sense of self following injury. The present study will directly explore the similarities and differences between the self-narratives of individuals with ABI and individuals with SCI, identifying the processes of self-reconstruction unique to each type of injury.

Sampling procedure

In the present study, candidates with ABI were purposefully sampled by experts in the field of neurorehabilitation. The experts included two senior clinical psychologists and two rehabilitation medical consultants. Inclusion and exclusion criteria for suitable candidates taking part in the study were predetermined. Suitable candidates with ABI were required to be a minimum of 2 years post-injury and aged between 18–65 years. Individuals were excluded from the study if they suffered severe cognitive or communication difficulties rendering them unable to take part in the interview. Furthermore, individuals were excluded from the study if they had a history of psychiatric illness that would have had an effect on their sense of self, for example personality disorder or schizophrenia.

Candidates with SCI were also purposefully sampled by experts in the field of neurorehabilitation. A convenience sample of individuals, who volunteered to take part in the study in response to a flyer distributed with the Spinal Injuries Ireland quarterly magazine, was also used. Suitable candidates with SCI were required to be a minimum of 2 years post-injury and aged between the ages of 18–65 years. Individuals were excluded from the study if they had a history of psychiatric illness that would have had an effect on their sense of self, for example personality disorder or schizophrenia.

Participants

Ten individuals with ABI were interviewed for the study. The interview data from one participant was excluded as he sustained his injury at 1 year of age and, thus, had minimal experience of life before acquiring his injury. Thus, the data from 9 individuals with ABI were analysed (see Table I). Ten individuals with SCI took part in the study. The data from all 10 participants were analysed (see Table II).

Interview approach

The current study adopted a phenomenological life-story approach to explore the ways in which individuals reconstruct their sense of self following ABI and SCI, similar to that used by Muenchberger et al. [11]. Participants are asked to think of their life as though it were a book divided into chapters. Individuals were then requested to describe how they saw themselves at each life stage. Significant life events marked the transitions from one life chapter to the next. Individuals were asked to describe the impact of the significant life event on the ways in which they saw themselves. Interpretative thematic analysis was used to determine the themes presenting in the interviews of individuals with ABI and individuals with SCI. Inter-rater reliability was used to maximize bias-free coding.

Results

The aim of the present study was to investigate the ways in which individuals reconstruct their sense of self following an acquired injury such as acquired brain injury or traumatic spinal cord injury. Moreover, the aim was to examine which injury related self-narratives are specific to individuals with ABI and which injury-related self-narratives are specific to individuals with SCI.

All 19 individuals identified acquiring their injury as a critical incident in their life-stories. For the purpose of the present study, the experience of sustaining a sudden-onset injury refers to the experience of sustaining the injury and the subsequent recovery and rehabilitation process. The experience of the injury did not end and was still being lived by all participants at the time of the interview. A plethora of self-narratives in relation to acquiring a sudden-onset injury was identified from the interview data of individuals with ABI and individuals with SCI. Self-narratives were identified as being either positive or negative. Individuals described positive and negative self-narratives that seemed to have been reconstructed parallel to each other. In some cases negative self-narratives were closely followed by positive self-narratives, indicating that the negative self-narrative had been reformulated or reconstructed in light of a positive self-narrative. Quotes by individuals with ABI are in curved parentheses {} and quotes by individuals with SCI are in square parentheses [].

Positive self-narratives in relation to acquiring an injury

Both individuals with ABI and individuals with SCI reconstructed positive self-narratives in relation to the experience of acquiring an injury. The positive self-narratives in relation to the experience of acquiring an injury were categorized into two sub-themes: Positive self-attributes that developed from the experience and factors that promoted the reconstruction of positive self-narratives (see Figure 1).

Positive self-attributes that developed from the experience

The majority of individuals with ABI and all of the individuals with SCI reconstructed narratives of the experience as having contributed something positive to their sense of self. Individuals described newly developed skills as a consequence

of the experience, {'In some ways you think your accident actually helps you do things because it does make you think other ways around, you know. I found that anyway'}. Furthermore, one individual with SCI described how having a disability granted him a social vantage point providing him with greater insights into the workings of other people.

['Then again there's all the strategies that you can use with people and I think being disabled, because you are different, you do tend to see a lot more in people. You can see, notice a lot of the way things, people, the way they act. About whether say they are defensive or whether they are comfortable with you or uncomfortable'.]

Both individuals with ABI and individuals with SCI described how acquiring an injury had afforded them positive self-attributes. Individuals described the experience of having a brain injury and subsequent process or recovery and rehabilitation as making them stronger, {'I think I am a stronger person'}.

Individuals with ABI and individuals with SCI explained how the experience has had a calming effect on their personality, ['I guess I'm more sensible now. I take it more easy. I'm more sensible']. And,

{Yeah probably would change me a bit like. I wouldn't go, be as mad or just doing spur of the moment things or anything. Just nice and just cruising along. I'd be alright like, I just wouldn't be going wild or anything.}

One individual with SCI perceived that he had 'slowed down' as a result of the experience. He felt this was a positive consequence,

[I don't get as stressed out about things as I used to. In ways I'm more relaxed in the head. When I'm left to my own, to my own devices I'm more relaxed. If I go for a walk in the woods every now and again by choice, not by choice for my.... I can't go very fast so I take in more what's happening around me.]

Furthermore, one individual with ABI felt that the experience had made him was more at ease with himself, {'I would say that characteristically speaking I was, I am more peaceful maybe. I don't know if that makes sense. Just more at ease with myself'}.

Both individuals with ABI and individuals with SCI described the experience as making them more open-minded, ['How would I say I'm different is like my mind is, my mind is so open now like. Before I might have this, that and that pigeonholed into categories or whatever']. They also described a heightened awareness of the difficulties other people confront in their lives. One individual with SCI described the sudden acquisition of this knowledge,

[Because I knew very little about wheelchairs. I would have had everybody's sympathy for a person in that situation, but no precise knowledge whatsoever, so I see a distinct break in my life at that point, where I was just trundling through life, regardless and then bang, hit a wall and a very sudden change. And since then I have a very different consciousness of the situation that people are in.]

In addition, several individuals with SCI identified the experience of acquiring an injury as facilitating an increased appreciation of existing relationships,

[I'm very conscious of the difference from before and after, in my friends. Family less, but my friends, definitely. And not in a negative way either. I would say that there is a very distinct difference in the way.... Because I've many friends from before who continued to be my friends and they are probably closer friends now. They've gone through this experience with us.]

It was identified within the interview data of individuals with ABI and individuals with SCI that individuals reconstructed the experience of the injury as facilitating a re-evaluation of life priorities. Individuals reconstructed self-narratives that reflected this re-evaluation and the resulting positive self-attributes,

[I would be just more, I'd be more positive now. Before you can take negatives and for minor things. Whereas now I do take a more positive outlook and rather than complaining about trivial things.]

One individual with SCI described the experience as instilling in him a deeper appreciation for people,

[But all in all I think it has made me a little bit more appreciative of life, a bit more appreciative of people. You know what I mean. You appreciate more what people do for you, say then I did before.]

Following a re-evaluation of life priorities, one individual with ABI constructed a self-narrative that was characterized by a search for a meaningful relationship,

{I find different things attractive in women now than I did before. And also, I suppose I'm more into the whole talking and how are you? You know. Whereas before this it was just, right, kiss and go to bed.}

One individual with SCI perceived his injury as facilitating an activity that he found meaningful, ['I'm doing a bit of writing. That's, that's something I've always wanted to do but may well never have got around to doing, if I hadn't had the accident'].

Following on from the theme of re-evaluating life-priorities, it was identified within the ABI group interview data that individuals reconstructed narratives of the past to highlight the positive contribution of the experience of the injury on their sense of self. Two individuals with ABI described their pre-injury lives as characterized by drugs and crime. They perceived acquiring the injury as having a positive effect on their lives, {'Me and my dad and my family we all totally agree like, that if I hadn't a got the, the ABI was a blessing in disguise. In only one word, I think I'd be like my best mate, OD, dead'}. And a second individual with ABI

said, {'Now I might have been now, before that crash now I'd tell you I was like. You know what I mean. And I still would be if that crash hadn't a happened like. I'd be say locked up now I'd say'}.

Another individual with ABI described his life pre-injury as characterized by a hectic work schedule. He also perceived acquiring his injury as having a positive influence on his life, {'Kind of glad now maybe that things did happen the way they did because I don't know if I could overly do it for good, or forever. I don't know what kind of effect it would have had on me'}.

Both individuals with ABI and individuals with SCI said that they felt proud of the ways in which they overcame challenges presented by the experience, ['I felt I had to overcome obstacles but I think I did. And I think I did very well with all of them']. In addition, one individual commented {'I think I coped relative well with what happened you know'}. One individual with ABI described a sense of pride in having the ability to persevere,

> {Now there was times like, awh getting too much, I'll have to give up, you know. But you didn't. You kept going and eventually you just come out the otherside, you know. And so I'm a lot, it's done a lot for my recovery you know. And, and I'd say I actually feel proud now because I come out after the injury.}

This individual acknowledges that at times recovering from brain injury was very challenging; however, he persevered and was proud of what he achieved in his recovery.

Strategies that promoted positive self-reconstructions

Both individuals with ABI and individuals with SCI employed strategies that promoted positive self-reconstructions following the experience of acquiring an injury. The strategies identified were 'placing oneself strategically in relation to others', and 'engaging in a meaningful activity'. 'Placing oneself strategically in relation to others' refers to thought-constructs used to promote positive self-narratives, whereas 'engaging in a meaningful activity' refers to engaging strategically with the external world to promote positive self-narratives. Furthermore, an associated theme of positive outside influences was identified from the interview data. Although these factors were not agented by the participants themselves, they were considered as having a positive influence on self-reconstruction.

Both individuals with ABI and individuals with SCI placed themselves strategically in relation to others as a means of promoting positive self-reconstruction. Both individuals with ABI and individuals with SCI saw themselves as successful in comparison to others, {'And next of all, 2 years later you get the job, what the hell, when everyone else is struggling to make ends meet, and there's me getting a job'}. Furthermore, one individual with SCI compares himself to his siblings,

> [If I remember rightly I was thinking in the hospital that if this had happened to my brothers that they wouldn't be able to cope. So, well you know, I felt that was the way I wrestled that. That I was able to cope better than they could.]

Similarly, individuals with ABI and individuals with SCI saw other people's situations as worse than their own, ['As badly off as I am, there's always somebody else worse off than me']. Strategic comparisons were facilitated by exposure to new people, {'It wasn't until I went to college and I start meeting people. And I think that just gave me a good kick up the arse. There are worse people out there then you'}. One individual with ABI compared his level of physical functioning with another person's level of functioning,

> {I know I'm bad, but there's a guy over the road in a wheelchair, same age as me and he'll never walk again ever. At least I'm walking even. It doesn't matter how bad it is, at least I can walk. He won't. He can't.}

One individual with SCI compared his type of injury favourably to other types of injury, ['But again over the years I got to say look, there's people going around with strokes and cancers worse than me']. Another individual with SCI compared the age at which he acquired his injury favourably to the age other people acquire their injuries,

> [There are certainly people who are worse off than I was. I mean there are kids there whose lives were just beginning who would never walk again. They are going to be in a wheelchair. Well you can't help feeling better off than that. For a start I've lived 50 years before I had the accident. And they hadn't. And I ended up getting back more than they are ever going to get back. And yet a lot of those were really positive guys.]

This individual compared the length of his pre-injured existence to that of others, seeing 50 years as a favourable length of time. He further remarks on the positive attitude of these younger individuals with SCI.

The positive influence of re-engaging in a meaningful activity was prevalent within the interview data of both individuals with ABI and individuals with SCI. Re-engaging in a meaningful activity was identified as a strategy, which facilitated individuals to reconstruct positive self-narratives,

> [And in terms of self-esteem it was right down, right down, I can tell you. For the last year. But now since I've come back to work it's obviously much better. You have a sense of who you are.]

This individual with SCI described how returning to work facilitated a positive self-narrative, one which was self-defining. One individual with ABI described how re-engaging in a meaningful activity provided him with a self-purpose,

> {Well I do volunteer work you know. I've done that for the last two and a half years. And that, that whole thing, you know, the feeling of being useful again you know. A great moral booster you know.}

Table I. Participants with ABI background information.

Code	Pseudonym	Background information
ABI-1	DAVID	David was a 59-year-old man who sustained an ABI in a road traffic accident 9 years ago. David was in full-time employment at the time of his injury and did not return to work post-injury. He was retired at time of testing. David was attending an art course run by his local community centre. He lived at home with his wife and three children and was in receipt of a community rehabilitation service.
ABI-2	CARL	Carl was a 46-year-old man who sustained anoxic damage to the brain secondary to a heart attack 5 years ago. Carl sustained a second ABI in an assault 2 years later. Carl was in full-time employment at the time of his injury and had returned to work after his first injury. However Carl did not return to work following his second ABI. Carl was not in a relationship at the time of either of his injures nor at the time of testing. Carl lived alone and was attending day services and was in receipt of a community rehabilitation service.
ABI-3	EATHAN	Eathan was a 44-year-old man who sustained an ABI after contracting meningitis $5^1/_2$ years ago. Eathan was in full-time employment at the time of his injury. He did not return to work post-injury and was retired at the time of testing. Eathan was not in a relationship at the time of his injury nor at the time of testing. He resided full-time in an ABI rehabilitation residential service and was attending an assisted vocational college.
ABI-4	GREG	Greg was a 62-year-old man who suffered a stroke 5 years previously. Greg was in full-time employment at the time of the injury and was unemployed at time of testing. Greg was divorced before sustaining his injury and at time of testing. He resided full-time in an ABI rehabilitation residential service and was attending day services.
ABI-5	HARRY	Harry was a 29-year-old man who sustained an ABI in a road traffic accident 4 years ago. Harry was in full-time employment at the time of his injury and was employed part-time at the time of testing in a different field of work. Harry was not in a relationship at the time of his injury nor at time of testing. Harry lived alone and availed of a community rehabilitation service.
ABI-6	IAN	Ian was a 56-year-old man who sustained an ABI resulting from an industrial accident 9 years ago. Ian was in full-time employment at the time of his injury and did not return to work post-injury. Ian was married at the time of his injury. At time of testing Ian was living with his wife and engaged in voluntary employment part-time. Ian availed of a community rehabilitation service.
ABI-7	JOHN	John was a 28-year-old man who sustained an ABI in a road traffic accident $3^1/_2$ years ago. John was in full-time employment at the time of his injury and did not return to work post-injury. John was not in a relationship at the time of his injury nor at the time of testing. At the time of testing John lived with his father and was attending an assisted vocational college. John availed of a community rehabilitation service.
ABI-8	BARBARA	Barbara was a 59-year-old woman who suffered a burst aneurysm 5 years previously. Barbara was a homemaker at the time of her injury and at time of testing. Barbara reported that her responsibilities in the household had been reduced since acquiring her injury. Barbara was married at the time of her injury and at the time of testing. Barbara lived with her husband and availed of a community rehabilitation service.
ABI-9	KEVIN	Kevin was a 28-year-old man who suffered a stroke $2^1/_2$ years ago. Kevin was in full-time employment at the time of his injury and had not returned to work post-injury. At time of testing Kevin had recently completed a 3-month college course. Kevin was not in a relationship at the time of his accident nor at the time of testing. Kevin lived at home with his parents and was not availing of any rehabilitation service.

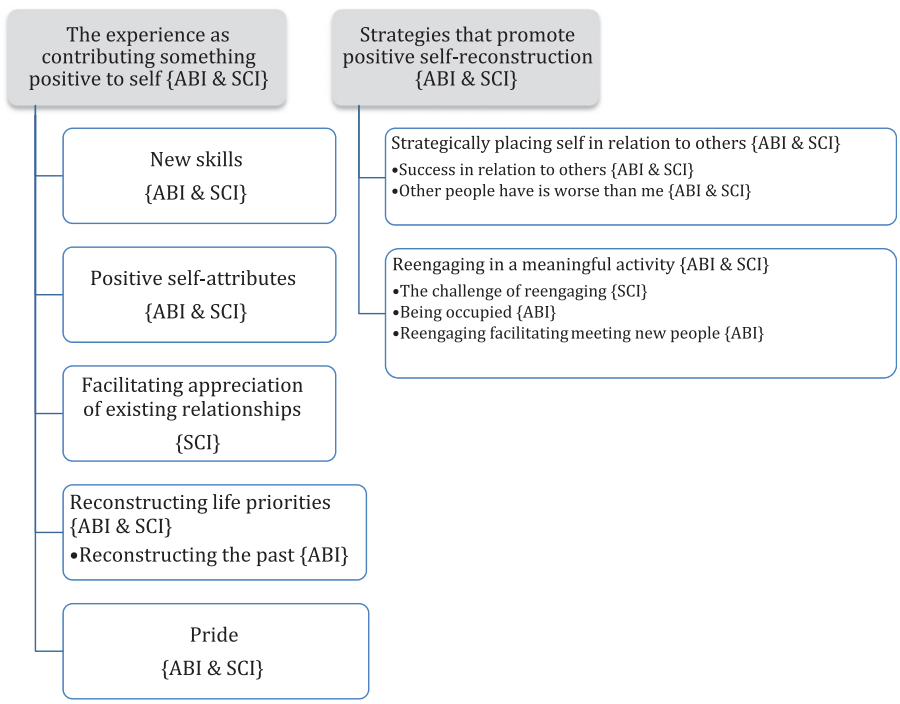

Figure 1. The experience as contributing something positive to sense of self and strategies that promote positive self-reconstruction.

Table II. Participants with SCI background information.

Code	Pseudonym	Background Information
SCI-1	ADAM	Adam was a 47-year-old man who suffered a C4/C5 SCI from a fall at work 5 years ago. Adam's injury rendered him quadriplegic. Adam was employed full-time at the time of his injury. He did not return to work post-injury. Adam was not in a relationship at the time of his injury nor at the time of testing. Adam lived alone and received community services.
SCI-2	BILLY	Billy was a 41-year-old man who suffered an incomplete L4/L5 SCI from a fall 5 years ago. Billy could walk with the aid of a walking stick. Billy was in full-time employment at the time of his injury. He did not return to work post-injury. Billy was not in a relationship at the time of the injury, but had married and divorced since his injury. Billy lived alone and was not availing of any services.
SCI-3	CIARAN	Ciaran was a 54-year-old man who suffered a T10/T11 incomplete SCI after an operation to correct a ruptured disk 14 years previously. Ciaran was a wheelchair user with full upper body mobility. Ciaran was in full-time employment at the time of his injury and at the time of testing, although he had changed profession to accommodate his reduced mobility. Ciaran lived at home with his wife and three children. He did not avail of any services.
SCI-4	DAN	Dan was a 57-year-old man who sustained a SCI at multiple injury points both complete and incomplete in a road traffic accident 45 years ago. Dan was a wheelchair user with full upper-body mobility. Dan was in full time education at the time of his injury and was retired after a long working career at the time of the interview. Dan lived at home with his wife at time of interview. He did not avail of any services.
SCI-5	EDGAR	Edgar was a 48-year-old man who sustained a C5/C6 incomplete SCI from a fall at work 10 years ago. Edgar walked with the aid of a cane. Edgar was in full-time employment at the time of the injury and did not return to work post-injury. Edgar was married at the time of the injury and lived at home with his wife and two children at the time of the interview. He did not avail of any services.
SCI-6	FRANK	Frank was a 56-year-old man who sustained a complete C4/C5 from a road traffic accident 38 years ago. Frank was a wheelchair user and also suffered impaired use of his hands. Frank was in full-time employment at the time of his injury and was employed part-time at the time of the interview. Frank was not in a relationship at the time of his injury but had subsequently married. Frank lived at home with his wife and did not avail of services on a regular basis but did avail of occasional respite services.
SCI-7	GRAHAM	Graham was a 58-year-old man who sustained a T3/T4 incomplete SCI 7 years ago as a consequence of a cyst on his spine and subsequent operations. Graham was in full-time employment at the time of his injury and returned to work after having the operation. However, further complications and subsequent operations reduced Graham's level of mobility. At the time of the interview Graham was unemployed. Graham was a wheelchair user and retained full upper body movement. Graham was not in a relationship at the time of his injury nor at the time of the interview. Graham lived alone and was not availing of services.
SCI-8	IVAN	Ivan was a 64-year-old man who sustained an incomplete C3/C4 SCI 13 years ago from a sports injury. Ivan walks with a cane. Ivan was in full-time employment at the time of his injury. He did not return to work after sustaining his injury. Ivan was retired at the time of the interview. Ivan was married at the time of the injury and at the time of the interview. Ivan lived at home with his wife and did not avail of any services.
SCI-9	JEREMY	Jeremy was a 46-year-old man who sustained a L4/L5 incomplete SCI from a road traffic accident 27 years ago. Jeremy walks without assistance and uses splints. Jeremy was a student at the time of the injury and was in full-time employment at the time of the interview. Jeremy was not in a relationship at the time of the injury nor at the time of the interview. Jeremy lived at home and did not avail of any services.
SCI-10	LAURA	Laura was a 54-year-old female who sustained an incomplete C2/C3 SCI from a spinal tumour 2 years previously. Laura walks with a cane. Laura was in full time employment at the time of her operation and has returned to full-time employment in the same job since her injury. Laura was divorced at the time of her operation and at the time of her interview. Laura lives at home with her son and does not avail of any services.

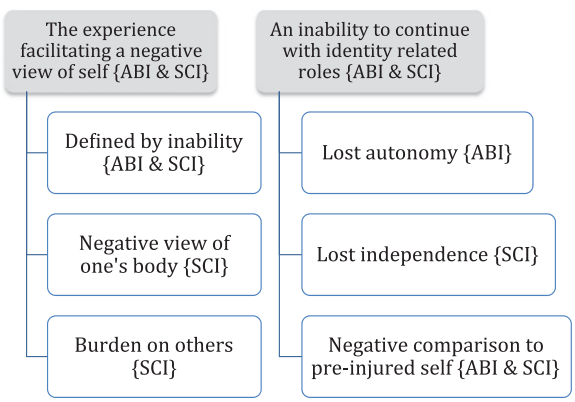

Figure 2. Negative injury-related self-narrative.

Individuals with SCI described the process of re-engaging in a meaningful activity as challenging,

> [There was an invitation put out over the email, would somebody do the flowers? So I offered to do the flowers. And boy oh boy it was a huge challenge. But it was lovely. But I really enjoyed it. I went down to the markets myself. Drove down. And got the flowers and I did them at home. Obviously my son had put them into the car for me. But that was a great achievement I felt. It was a personal achievement.]

One individual with SCI was unable to return to his pre-injury profession as a consequence of his reduced mobility. Thus, it was necessary for him to retrain in a new profession, ['And you know, bravely I got out there. Because I was

[construction industry professional] before and I can't be now, I've changed and retrained to be something else.

For one individual with ABI the positive aspect of re-engaging in a meaningful activity was being occupied outside of his house,

> {And so I end up with [voluntary organization] and it's gone on from there you know. So, but that has been great help you know. And keeping me busy because before that it was nearly at home all the time, you know. Very rarely went out you know. And its, that's got me out more you know. Everything just seems to have got better since then you know.}

In this comment the significance of re-engaging in a meaningful activity is evident, as the participant perceives it to have had a positive influence on all other aspects of his life. One individual with ABI described how engaging in a meaningful activity facilitated meeting new people which fostered positive affective states.

> {That made me feel a lot better you know. And I was meeting new people, meeting new people all the time there. You know interviewing people and stuff and that. Listening to their problems as well, so that makes you, you know you feel good cause your helping people.}

Finally, one individual with SCI spoke of the merits of focusing on things that are external to one's own thoughts,

> [I think it's important not to allow something like this to make you look too much inside. And there are… just because having been in the rehab [rehabilitation facility], I've seen a lot of other people in a similar, no one's exactly the same, but in similar situations. And the people that don't make it are the one's that retreat inside themselves. So I think it is important to sort of be aware of the world around you, the other people around you. It's a healthier sort of attitude.]

This individual remarks that negative consequences can occur for individuals who neglect to engage with the external world.

Negative self-narratives in relation to acquiring an injury

Individuals described instances whereby the experience of the injury affected their reconstruction of self-narratives in a negative fashion (see Figure 2). It is important to note that within the interview data negative self-narratives were often closely followed by positive self-narratives indicating that the negative self-narratives had been reconstructed or reformulated in light of the positive self-narratives. However, in some cases negative self-constructions did persist.

The experience facilitated a negative view of self

Individuals described the injury as facilitating a negative view of self. Both individuals with ABI and individuals with SCI described self-narratives that were defined by the injury or their functional impairments,

> [Because I would say I have experience of being a [professional's] son regardless of what the family was like. People think very middle class, very privileged. To all of a sudden overnight becoming somebody whose main identity thing is disability. There's a massive shift and before when you were somewhere and something, oh you know what does your dad do? You know because you are that age. But then all of a sudden it was like oh like your walking funny or you have crutches, oh what happened to you? And like if I was using the wheelchair it definitely was like what happened to you. And that was the only story that was available to you in relation to your life.]

An individual with ABI described himself as {'Somebody with no memory, that's, that's it, the nicest way of putting it'}.

One individual with SCI held a negative view of his body,

> [I used to have some, some sort of abstract idea. One way I would see myself being chopped in two. And I would see my upper body as being stuck on a body, a lower body which was dead and that's what you might say is a rather negative way. But it is a logical assumption of, perhaps a T12 complete paraplegic. Part of me is totally alive, the other part is perhaps living on the cardiovascular system of the other part and so on. But that's a rather negative view.]

Furthermore, individuals with SCI described negative self-constructions whereby they viewed themselves a burden on others. One individual described feeling as though he was a burden on his wife,

> [You are always sort of, you feel in the way a lot of the time too. You know and, you know even when you are out with [his wife]. And you know that when you are out with [his wife], occasions when you are around her, she doesn't, it doesn't bother her. But you know you're kind of a bit of a nuisance you know what I mean.]

The above quotes illustrate the negative self-narratives individuals constructed which were facilitated by the injury.

Negative self-narratives resulting from an inability to continue with identity-related roles

Both individuals with ABI and individuals with SCI described negative self-constructions attributed to an inability to continue with identity-related roles,

> [And not only the ability not only to do my job, because I focused an awful lot on studying and working in my job and getting on. And I'm the first [specialist health professional] in Ireland. This post was created about a year, just a year before my injury. Just a year before I got the news. And having worked so far, and all the study and suddenly then to be taking it away, to be taken away.]

And another person with ABI said,

> {I'd say I felt useless really you know. My wife took over doing everything then, you know. Like banking and everything you know. And yeah pretty pretty useless you know. Probably to the point of self-harm in them days. There was two incidents where you could say was bordering on that you know.}

In this comment it is evident that the individual suffered depressive symptoms attributed to the change in household roles, which had a negative effect on the way that he saw himself.

Also encompassed within the theme of negative self-reconstructions resulting from an inability to continue with identity related roles is individuals' perceptions of lost autonomy or lost independence. Loss of autonomy and loss of independence referred to individuals feeling as though there are self-spaces they can no longer occupy. Loss of autonomy was described in the narratives of individuals with ABI only, whereas loss of independence was described in the narratives of individuals with SCI only. Negative self-constructions in relation to a loss of autonomy occurred in the interview data of individuals with ABI,

> {It's different when you are living here, you have to tell them, tell the people who are responsible for you where you are going and what time you are coming back at and that type of thing. It's probably, it's a bit difficult for me you know. I'm 39 years of age I mean. And my life has to move on as well, rather than being stopped.}

This individual associated his loss of autonomy with feeling as though his life has been discontinued.

Negative self-constructions in relation to a loss of independence or dignity occurred in the interview data of individuals with SCI only, ['I had to have two people to assist me to the shower and having been such an independent person it was horrific to have this happen']. The loss of independence for this individual was in contrast to a previously held view of herself. Furthermore, individuals with SCI described a loss of dignity, which accompanied loss of independence,

> [I mean having the catheter and being in a wheelchair, it was just dreadful to me, because here I was like, the person who always dressed well, never had to depend, never had to depend on anybody for anything. And to have personal care done was just dreadful, dreadful.]

The above quotes illustrate the negative self-narratives, which resulted from an inability to continue with identity-related roles.

Both individuals with ABI and individuals with SCI reconstructed self-narratives that constituted a negative view of their current self in comparison to that of their pre-injured self,

> {Because I get embarrassed. I get annoyed. Embarrassed because of the way I am, as opposed to the way I used to be. And a lot of the men I see on the jobs were the men under me when I was well. Do you know, I was telling them what to do, you know. Now I'm going around with a stick or with a limp and paralysed arm.}

The above quote illustrates the sense of embarrassment and frustration this individual with ABI feels when he compares himself now to his pre-injured self.

The dynamic influence of positive and negative self-narratives

Negative self-narratives were often closely followed by positive self-narratives, highlighting an influential relationship between the two. This occurred in both the narratives of individuals with ABI and individuals with SCI.

> {I had violent headaches. And my vi... my vision used to be disturbed. I had no energy. I truly had no energy and I went to skin and bone. And now apart from the energy levels, I'm great. And I know how to look after myself. To a degree.}

This individual with ABI describes a time when she was plagued with physical challenges; however, she quickly follows this description with a positive self-narrative, suggesting that the reconstruction of the negative self-narrative which is situated in the past has been influenced by her current more positive self-narrative. For one individual with SCI a bad experience attending a vocational training college facilitated a negative self-narrative.

> [And the staff treated the people like awful. It was... so I suppose I started to see that difference in equality or whatever it is, like you know. Ehm and I... but even thinking about it, because I was so quiet, I didn't complain, I just left. Now looking at it now, if I was treated like that now... it wouldn't basically... I wouldn't put up with it like. But at that time I just left.]

Again this negative self-narrative is quickly followed by a positive self-narrative suggesting that the negative self-narrative, situated in the past, has been reconstructed in light of a current more positive self-narrative.

Paradox of self

As previously described individuals with ABI and individuals with SCI experienced their sense of self as changed in light of the experience of the injury. Paradoxically, it was identified from the interview data from individuals with ABI and individuals with SCI that they experienced their sense of self as simultaneously continuous.

It was identified in the interview data of individuals with ABI and individuals with SCI that individuals experienced their sense of self as continuous despite experiencing many changes, ['I'm the same person, but just different experiences. And I have multiple identities to draw from']. This individual with SCI draws a distinction between person and identities. He uses 'person' to refer to his continuous sense of self and

identities to refer to the changeable aspects of self. In addition, an individual with SCI uses the idea of a 'fundamental persona' to explain the idea of a continuous sense of self,

> [Well I don't know if I've changed that much. I don't know that I've changed fundamentally at all. I mean your fundamental sort of persona is set pretty early on. I'm not saying that it can't change. Saying that it could change in one. But I don't think it has changed me that much, not really as the person I am.]

It is evident from the above quote that this individual experiences a fundamental continuous sense of self.

Discussion

The present study set out to explore the narratives of individuals with ABI and individuals with SCI to identify ways in which individuals reconstruct their sense of self post-injury. In addition, the present study compared the self-narratives of individuals with ABI and individuals with SCI, identifying aspects of self-reconstruction specific to each type of injury experience.

Overall, the present study identified similar themes within the narratives of individuals with ABI and individuals with SCI. This suggests that the experience of acquiring a sudden-onset life-changing injury affects the ways in which an individual reconstructs their sense of self, more so than the type of injury sustained. Previous research has alluded to the similarity of experience of rehabilitation for individuals with ABI and individuals with SCI [21], yet neglected to directly compare these experiences. Contrary to theoretical understandings highlighting the cognitive underpinnings of self, the present research indicates that the experience of acquiring a sudden-onset life-changing injury and subsequent rehabilitation process influenced individuals' post-injury self-narratives more so than the presence of cognitive impairment.

In keeping with previous research [6,9,17,24] individuals with ABI and individuals with SCI identified positive post-injury self-narratives. Furthermore, several equivalent themes were determined between the two groups. For example, individuals described the experience of acquiring an injury as contributing something positive to their sense of self, such as new skills, new self-attributes or a new perspective that facilitated a re-evaluation of life-priorities. In addition, similar strategies for promoting positive self-narratives were identified in both groups, such as 'strategically placing oneself in relation to other people' and 're-engaging in an activity' that was meaningful for the participant. Equivalent themes were also identified within the negative injury-related self-narratives of individuals with ABI and individuals with SCI, whereby individuals described ways in which the experience of acquiring an injury facilitated a negative view of self and an inability to continue with identity related roles, in line with prior research [8,12,15].

Subordinate themes that differed between the two groups were also identified; however, only one that was considered as resulting from the difference in cognitive functioning between the two groups. Evident within the narratives of individuals with ABI only was a feeling of lost autonomy. Impaired cognitive functioning can affect an individual's ability to make decisions, thus individuals with ABI are often made wards of the court in financial and legal matters. Thus, a feeling of lost autonomy described by individuals with ABI is not surprising [25]. Conversely individuals with SCI do not face cognitive impairments and, therefore, do not have increased difficulties with decision-making. Hence, the theme of lost autonomy did not appear in the narratives of individuals with SCI.

The present study found that individuals experienced their self-reconstruction as paradoxically simultaneously changing and continuous. This is in keeping with several more recent studies investigating the experiences of self following injury for individuals with ABI [7,8,26] and individuals with SCI [17]. These findings provide support for theories, which postulate the existence of multiple selves or multiple self-narratives [27,28] and have strong implications for psychological interventions in rehabilitation settings. Individuals experience certain aspects of their sense of self as unchanged and in fact found great value and meaning in maintaining pre-injury self-narratives. However, individuals also found that aspects of their self had changed as a consequence of the injury, with some changes reconstructed in a positive fashion and some changes reconstructed in a negative fashion.

In addition, findings of the present study are more in keeping with the non-linear models of self-reconstruction following sudden-onset life-changing injury such as ABI or SCI [11,14] that highlight fluid interactions between self-narratives. It was evident from both the data of individuals with ABI and individuals with SCI that negative self-narratives situated in the past were often closely followed by current positive self-narratives, suggesting that one may be influencing the other and vice versa. This supports the models of self-reconstruction post-injury proposed by Muenchberger et al. [11] and Yoshida [14]. Muenchberger et al. [11] emphasize the dynamic nature of both positive (expanded) and negative (contracted) self-perceptions in individuals with ABI. Furthermore, Yoshida [14] highlights the dynamic nature of identity reconstruction following SCI describing the interaction between a 'disabled' and 'non-disabled' sense of self, one of which is viewed in a positive light and one of which is viewed negatively.

Limitations

The present study employed a qualitative research methodology, therefore was conducted on small sample sizes and over one or two occasions, thus the results cannot be generalized to a wider population or presumed stable over time. In addition, the researchers perspective cannot be excluded from the analysis, jeopardizing research validity. However, inter-rater reliability was used in the present study to maximize bias-free coding.

The ABI sample in the present study had a diverse range of brain injury aetiology and brain injury location. It was beyond the scope of the present study to extrapolate neuropsychological understandings from the present findings and caution is advised when generalizing these findings to other ABI populations. Furthermore, due to a lack of confidence in information on lesion location in the ABI sample, the present

research was unable to consider the implication of anosognosia. The SCI sample in the current study also had a diverse range of injury types and locations, thus caution must be exerted when extrapolating the findings to other SCI populations.

Only two individuals in the present ABI sample were not availing of any services. Thus, the majority of individuals were involved in on-going rehabilitation, which may have impacted their sense of self. Often brain injury rehabilitation programmes assist individuals to achieve specific life goals, such as social integration and vocational attainment. This may have biased the sample towards engaging in a meaningful activity as a strategy for promoting positive self-narratives. However, the majority of individuals with SCI in the present sample were not actively engaged in rehabilitation services and only 22.2% of the sample was in full-time employment, yet engaging in a meaningful activity was identified as a factor that promoted positive self-reconstruction.

Conclusion

The data from 9 individuals with ABI and 10 individuals with SCI were investigated in relation to the experience of acquiring an injury such as an ABI or SCI. Overall, the present study identified similar themes within the narratives of individuals with ABI and individuals with SCI, suggesting that the experience of acquiring a sudden-onset life-changing injury affects the ways in which an individual reconstructs their sense of self, more so than the type of injury sustained. Paradoxically individuals described their sense of self as both changing and simultaneously continuous. Both positive and negative self-narratives were reconstructed in relation to the experience of acquiring a sudden-onset lifelong injury and a dynamic interaction between positive and negative self-narratives was evident.

Declaration of interest

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