RESEARCH ARTICLE

Social cure and social curse: Social identity resources and adjustment to acquired brain injury

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Conflict of Interest Statement
The authors have no conflict of interests to declare.

Ethical Statement
The study received full ethical approval from University of Limerick ethics committee and ABI Ireland research ethics committee.

Transparency Statement
The raw materials and data of our study are not publicly available, as the authors did not seek permission for these qualitative data to be accessible to the public at the time of data collection. This was done due to both the sensitive nature of the data collection situation, and because the detailed accounts of how participants sustained and survived their injury would almost certainly result in the identification of participants in a country as small as Ireland. This would have resulted in potentially sensitive information about social surroundings, (mental) health status and other personal information being revealed. All data, however, has been archived on a secure server at University of Limerick by the corresponding author.

Abstract

There is increasing evidence that identification with social groups can protect and enhance health, establishing a kind of 'social cure'. However, for those affected by chronic or disabling conditions such as acquired brain injury (ABI), their identity may also represent a burden, a form of 'social curse'. The present study explored the identity benefits and burdens available to 15 participants living with ABI using semi-structured interviews. The qualitative data was then analysed systematically using thematic analysis. The findings highlight social identity changes as central to the experience of brain injury. Participants reported changes in their social networks and social group memberships after injury. Identity loss and reduced social support were described as disabling. Engagement in meaningful group activity with others affected by ABI and access to affected peers enabled new group-based resources such as social support. In this way, group activity can be seen as a form of identity enactment that can drive social cure effects. Similarly, adaptation to life after injury was demonstrably linked to social identity processes pointing to the importance of a social cure approach to rehabilitation.

Keywords: social identity, social cure, social curse, acquired brain injury, rehabilitation, social support

Since the 1970s, social psychologists have been interested in how people derive a sense of self from their social group memberships, attributes referred to as social identities (Tajfel, 1982). However, it has only been in the past decade that we have gained substantial knowledge about the important role of social groups and associated social identities in determining health. This phenomenon, increasingly referred to as 'the social cure', has been shown to be driven by a sense of belonging and social connectedness (Greenaway, Cruwys, Haslam, & Jetten, 2016), the quantity of group memberships (Sani, Madhok, Norbury, Dugard, & Wakefield, 2015) and the availability of reciprocal social support as a consequence of these group memberships (Haslam, O'Brien, Jetten, Vormedal, & Penna, 2005; Walsh, Muldoon, Gallagher, & Fortune, 2015). These factors can be referred to collectively as social identity resources. Belonging to and identifying with social groups is associated with positive outcomes in a range of health contexts—for example, in determining healthy ageing (Haslam, Cruwys, & Haslam,

2014), recovery from addiction (Best et al., 2016), heart surgery (Haslam et al., 2005), and positive adjustment to acquired brain injury (Haslam et al., 2008; Walsh et al., 2015). It is this latter context, acquired brain injury (ABI) that is the focus of the present study.

Acquired brain injury (ABI), caused by accident, assault, stroke, tumour, disease, hypoxia, anoxia, viral infection or brain surgery, can occur to any individual, at any point in their life. ABI is a significant public health concern, being one of the most common neurological disorders (Howes, Benton, & Edwards, 2005). The estimated incidence of ABI is 1 per 500 of population globally with occurrence likely in children (under 4) and young adults (under 30) meaning that, worldwide, there are a very many people living with an ABI. The consequence of ABI differs from person to person but can include physical effects, cognitive effects, behavioural effects, communication difficulties, and interpersonal skills (Elbaum & Benson, 2007). In an effort to understand how individuals are affected by ABI, the literature has referred to identity loss (Broks, 2003; Nochi, 1998) and an altered sense of personal identity (Ownsworth, 2014) after ABI. For instance, Nochi's (1998) work emphasises the loss of self and self-knowledge where individuals fail to remember their own personal characteristics—those self-categories which define individuals as unique (e.g. talkative, hard-working). These findings also demonstrate how individuals struggle with their own inability to conduct day-to-day activities and how their relationships are altered in the aftermath of brain injury. While these findings are insightful and important, we propose that both social identities and identity resources (e.g. social support, feeling socially connected) that are accessed via social groups may also be changed or interrupted by ABI. While we expect that identifying with social groups may confer benefits to individuals after ABI (a form of social cure), we also consider an alternative hypothesis that examines the extent that being categorised as 'having an ABI' (and therefore belonging to the group of people affected by ABI) may also result in some negative consequences (a form of social curse: Kellezi & Reicher, 2012). Our study is the first to consider, using a qualitative approach, the social or collective dimension of identity change for those affected by ABI. The present study breaks new ground by considering changes in social identities, the social categories linked to the self (e.g. female, football fan) after ABI.

Social Identities as a Social Cure and a Social Curse?

A useful way of thinking about this life change following ABI is in terms of social identity change. The *Social Identity Model of Identity Change* (SIMIC) highlights particular social group processes that predict successful life transitions (Haslam et al., 2008; Jetten, Haslam, Iyer, &

Haslam, 2009). In general terms, the approach argues that, although social change is unsettling or even traumatic, change that results in social identity gain, a new group-based identity, will tend to have positive consequences while change that results in social identity loss will tend to have negative consequences (Jetten et al., 2009). Internalised social identities can influence well-being and health by providing social and psychological resources that help group members cope with adversity. Therefore, in the present qualitative analysis, in line with the social cure literature (Jetten, Haslam, & Haslam, 2012), we expect that participants will describe some benefits derived from their sense of belonging to social groups after ABI.

On the other hand, Kellezi and Reicher (2012) invoked the concept of the 'social curse' to describe how social identities can negatively affect health and well-being. They found that where membership of a group was undermined, perceived social support from fellow group members was lower, which in turn led to poorer well-being. Similarly, Stevenson, McNamara, and Muldoon (2014) demonstrated that even where health and social care service users and providers shared the same goals, the absence of shared identification between the parties acted as a social curse because it corroded relations between these two groups. This had a negative effect on users and providers alike, ultimately discouraging service engagement and the perceived quality of the health and social care provision. Therefore, in the context of the many changes associated with ABI, the potential for social identity change to negatively affect adjustment is also considered here.

Perhaps because of these potentially conflicting effects, evidence would now appear to suggest that navigation of life change is made easier by having multiple social identities (Jetten et al., 2015). The greater the number of important group memberships a person has to draw on, the more psychological resources they can recruit when attempting to deal with change (Steffens, Cruwys, Haslam, Jetten, & Haslam, 2016). These multiple and varied social identities facilitate a subjective sense of belonging, trust (Jetten et al., 2015), and a desire to give and receive help from fellow in-group members (Levine, Prosser, Evans, & Reicher, 2005). Old or maintained social identities that remain intact after life change provide a sense of continuity (Haslam et al., 2008). Prior multiple group memberships can again be protective. Previous positive group experiences can also increase people's willingness to participate in new groups (Cruwys et al., 2014; Haslam, Cruwys, Haslam, Dingle, & Chang, 2016). In one study of stroke patients, those who belonged to more social groups before their stroke experienced better adjustment afterwards (Haslam et al., 2008). This was due to the increased likelihood that those who had suffered a stroke were able to maintain at least some of their pre-stroke group memberships and thereby maintain a sense of identity continuity.

Clearly, though, people are not always able to achieve this sense of continuity, not least because life changes require people to lose or let go of old identities. For example, loss of valued occupational group memberships is often reported after experiencing a traumatic brain injury (Walsh, Fortune, Gallagher, & Muldoon, 2014). Similarly, in the first year following ABI, impairments can mean those affected lose their pre-morbid social group (Walsh, Muldoon, Fortune, & Gallagher, 2017). On the other hand, the loss of social identities in post-injury life is only one part of social identity change. A new identity linked to brain injury and/or disability can also permeate life after ABI. SIMIC points to the importance of a second pathway that involves developing new group memberships following a life change as a basis for self-redefinition—the social identity gain pathway. One recent study indicates that ABI survivors can acquire new group memberships post-injury (e.g. men's shed, friendships at residential housing, social, craft or art groups organized by community rehabilitation organizations), and that belonging to these multiple groups is associated with enhanced self-regulation skills and reduced depression levels (Kinsella, Muldoon, Fortune, & Haslam, 2018). In the current analysis, drawing from the SIMIC model, we therefore consider the extent to which these pathways are evident in participants' experience of living with ABI.

In addition to exploring the role of group membership, we also consider the value of active engagement with social groups after ABI. For new groups to be meaningful there must be opportunities for enactment (Dixon, Levine, Reicher, & Durrheim, 2012). However, work and family responsibilities can be dramatically altered and those affected by ABI can be reliant on others to initiate or manage the logistics of their social interactions. In the aftermath of ABI, maintained identities are often limited to those shared between families and close friends (Nicholson et al., 2012). A recent study by Walsh et al. (2015) suggests an important link between strong group memberships such as family identities and enactment of new identities in those affected by ABI. Social identities that were associated with a strong sense of belonging offered important social identity resources which facilitated engagement with acquired identities. Interestingly, having the ability to engage with new acquired identities was what appeared to have a direct effect on well-being for this ABI sample (Walsh et al., 2015).

For those affected by ABI, new group memberships opportunities might include participation in rehabilitation activities, support groups, and work or training programmes. Gracey et al. (2008) demonstrated that post-injury, ABI survivors make sense of themselves through participation in social activities. In a similar vein, Douglas (2013) reported that when ABI survivors engaged in meaningful social activity this engagement supported social identity construction with knock-on effects for individual affective well-being. These opportunities may be particularly valuable to those affected by ABI due to physical, cognitive and social changes after brain injury which can result in reduced opportunities to actively engage with pre-injury identities. Importantly, however, the ability to engage with these new identities and access identity resources may be contingent on maintained identity resources.

The Current Study

Whilst there has been some research on personal identity, the present research extends and complements existing quantitative work using a social identity approach (Douglas, 2013; Haslam et al., 2008; Jones et al., 2011; Walsh et al., 2015) to consider the impact of ABI on social identity. Given the identity disruption associated with ABI, social identity change cancan be central to adjustment and management of ABI (Walsh et al., 2014). This research differs from previous work in that it considers how social identity resources (e.g. social support, sense of belonging) may be interrupted by an ABI. Here we specifically look at how social identity *changes* may impact on those affected by acquired brain injury. Our exploration of this topic is twofold: first in the positive or 'curing' aspects of group identities and associated resources, *and* second in the negative or 'cursing' aspects of identification. Unlike the largely quantitative studies within the social cure tradition (e.g. Dingle, Stark, Cruwys, & Best, 2015), we adopt a qualitative approach for this new enquiry. This qualitative approach allows us to attend to positive and negative identity dynamics as well as to their subjective meaning to those affected by ABI. We are explicitly interested in whether there is evidence of altered social identities and changes in associated social identity resources after ABI, and how these changes might contribute to rehabilitation and adjustment post-injury. Therefore, the present study asks new questions about the role of changed group memberships and social identities in determining health, particularly following major life transitions.

Method

Approach to Data Collection

A qualitative approach, specifically a theoretically informed thematic analysis, was chosen here in order to explore in an open-ended way how participants experience and live with ABI. Our epistemological stance was informed by the social identity approach which argues that identities are socially constructed in everyday interactions that are shaped and constrained by social systems, institutions and macrosocial structures. Equally our analysis was informed by our theoretical interest in social identity change and so we oriented to this in our analysis at both the semantic level and beyond. It is not our intention to provide a comparative analysis indeed that is beyond the scope

Table 1. Participant characteristics

P#	Gender	Age	Marital status	Living	Area	Mobility	Nature of injury	Time since injury (years)
1	Male	39	Single	Supported community care	Urban	Wheelchair user	TBI: assault	8
2	Female	52	Separated	Supported community care	Urban	Some mobility	TBI: fall at home	4
3	Male	28	Single	Living at home	Urban	Some mobility	TBI: RTA	9
4	Male	26	Single	Living independently	Urban	Some mobility	TBI: RTA	7
5	Male	42	Married	Living at home	Rural	Fully mobile	Stroke	15
6	Male	50	Married	Living at home	Rural	Fully mobile	TBI: RTA	10
7	Female	38	Unmarried	Supported community living	Rural	Fully mobile	Brain haemorrhage	14
8	Male	35	Unmarried	Living at home	Rural	Fully mobile	TBI: RTA	7
9	Male	40	Unmarried	Supported community living	Urban	Wheelchair user	TBI: sporting accident	14
10	Male	38	Married	Living at home	Urban	Mobile	Stroke	6
11	Male	60	Married	Living at home	Urban	Wheelchair user	TBI: RTA	12
12	Female	51	Widowed	Living at home	Rural	Mobile	TBI: assault	12
13	Male	50	Separated	Living at home	Rural	Mobile	Medical injury	6
14	Female	53	Married	Living at home	Rural	Some mobility	Stroke	18
15	Female	27	Single	Supported community living	Rural	Some mobility	TBI: RTA	5

Note: RTA: road traffic accident; TBI: traumatic brain injury.

of qualitative research; however, our sampling strategy was purposeful and we worked with a national brain injury rehabilitation service provider to access this sample. Participants were recruited through the NGO, ABI Ireland, as well as through social media to ensure we had individuals who had engaged with rehabilitation services (such as ABI Ireland) and others who had not. We sought to interview a diverse group including men and women, older and young people, as well as those living and working in urban and rural locations. We included those with different types of acquired brain injury, and those with different types of care provision including those who have had access to rehabilitation activities and those who had not (see Table 1 for a more complete description of the sample).

Ethical Protocol

The study received full ethical approval from University of Limerick ethics committee and ABI Ireland research ethics committee. Given potential comprehension difficulties in this group, the team were particularly careful about gaining consent. As such, agreement to participate was sought and checked at multiple stages. In the case of participants who were recruited through ABI Ireland, information about the study and preliminary expression of interest in participation were completed prior to any contact with the research team. For those who responded to public recruitment efforts, information was offered in soft copy and by phone subsequent to the expression of interest. Once an expression of interest was received a briefing sheet was given to the potential participant. For those with carers, their carer was also furnished with an information sheet. One week after this expression of interest, participants were contacted by a member of the research team and asked if they were willing to participate in the study. Where participants agreed, interview times and locations were arranged. Participants completed a written consent form at the start of each interview. At this point participants were

also advised that they were free to withdraw from the interview, or indeed to turn off the tape recorder, should they wish to do so. All interviews were recorded with the permission of participants and they were later anonymised and transcribed. Anonymised interviews were stored on a password-protected computer for later analysis. Participants recruited from within ABI Ireland were advised in writing that agreement to participate had no implications on the availability of support services.

Interview Process

Participants were interviewed in their own home, or in a place of their choosing, on a prearranged and mutually agreed day. Most participants elected to be interviewed in their own home. A small number came to the University and another small number were interviewed in an ABI Ireland premises. All interviews occurred during May–October of 2016 and were conducted by one of three researchers (either OM, SW or MC). Interviews were semi-structured. An interview guide provided a loose structure within which to explore the topics of interest, and participants were prompted to expand on relevant and interesting responses. The interview guide was developed with due consideration to the difficulties that some participants might have in engaging in the process. We aimed for questions that were easy to answer, and would allow participants to talk about themselves, and their current and pre-injury lives. The intention was that broad and open-ended questions would facilitate a descriptive narrative that would include talk about any change in participants' perceptions of themselves, group memberships and their relationships with others. We had five central questions based on the following topics: (i) what life was like prior to their injury, (ii) any changes in their lives they perceived since their injury, (iii) an outline of a participant's usual day and week, (iv) their sense of life since injury, (v) any ongoing challenges participants face.

Interviews ranged in length from 45 minutes to 1 hour and 30 minutes. Because of the language and comprehension issues sometimes associated with ABI, interviews were at times difficult and establishing what a participant meant during an interview was, on occasion, slow. As a consequence, all interviews were intelligible and meaningful on transcription.

Participants

Fifteen ABI survivors (10 male; 5 female) were interviewed as part of this research. Participants ranged from 25 to 63 years, with the majority aged in their thirties or forties. All participants had lived with brain injury for some time, with a range of 4–18 years since injury. Causes of injury included road traffic accidents, occupational accidents, assaults, strokes, and tumours. With regard to injury severity, Andrewes (2001) highlights two distinct phases of recovery from ABI. The first is the acute phase that immediately follows brain injury. During this time, indications of injury severity such as the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974) are often used to determine injury severity (Wilson, 2009) and are important because of their ability to predict mortality. However, our study was completed with those in the post-acute phase of injury, those living with ABI as a chronic condition. Injury severity measures are less predictive of outcome during this phase of rehabilitation and are even viewed by some as problematic (Entwistle & Newby, 2013). Social and interpersonal aspects of brain injury are seen to be more central in the post-acute injury phase and clearly were of more interest to this work. Therefore, to avoid any suggestion regarding our belief in medical assessment of injury severity as defining, we decided against securing this information (e.g. Ben-Yishay & Diller, 2011), which was probably patchy in our community sample of those affected by ABI. However, it is worth noting that the impact of ABI in our sample was diverse. Some participants were living independently in the community whilst others had sustained life-changing injuries that transformed all aspects of their everyday life and now lived in full-time care or supported accommodation.

Data Analysis

Qualitative data was transcribed and analysed used thematic analysis (Braun & Clarke, 2006). Thematic analysis involves a number of stages of coding data in order to identify potential themes. Calculations of inter-rater reliability have been shown to be unsuited and of little value where qualitative analysis is guided by a theoretical position (Armstrong, Gosling, Weinman, & Marteau, 1997). Rather we used a process of coding that was verifiable and transparent. Initially the transcripts were read and re-read by two authors. The first author identified initial first-level codes, which remained very close to the data, and shared these with the second author. The second level of analysis involved both the first and second author reviewing the first-level codes and considering how they can be amalgamated into overarching elements and ensuring inclusion of the diversity of the many initial codes into higher-level sub-themes. Amalgamation of codes was informed by our theoretical perspective. We were particularly interested in themes of altered and maintained group memberships and social identities and related social resources. The third stage involved identifying and agreeing overarching themes which represented these original codes and outlining the themes as well as selecting quotes that illustrate the themes adequately. Our analysis resulted in four themes which are detailed fully below. All of our data was made publicly available via our NGO partner and participants and stakeholders were offered a synopsis of the analysis and an opportunity to comment upon it.

Findings

Four themes were identified subsequent to the analysis of all interviews. These themes outlined below were (1) Changed Social Relationships: *As soon as the words 'brain damage' are mentioned, people run away;* (2) Families as Identity Resources post-ABI: *They really did help bolster me up*; (3) Group activity as recovery post-injury: *We kind of treat each other like as if we're at work.* (4) *It's like getting reset:* Changing views of the Self as a Post-injury Social Identity Process.

1. 'As soon as the words "brain damage" are mentioned, people run away': Changed Social Relationships

Participants reported that their social circles were depleted by their injury, not only because of altered ability to engage with and maintain social relationships and occupational roles, but also because of how others perceive those affected by ABI. Turning first to the reduction in their social networks, participants often alluded to the loss of their occupational identities as well as the perceived impact of representations of brain injury. One participant, a former police officer, in recounting the changes in life since injury stated:

> P: Well obviously as soon as I had the blood clot and it left me epileptic that ruled me out of any work as does the shunt.
> I: Ok, yes.
> P: A physical job like inner city policing is not the place for someone with major problems.
> I: Yes, yes.
> P: And that was the first thing…. A lot of friends, I found that as soon as the words 'brain damage' are mentioned, people run away.
> I: Yes.
> P: They are scared you are going to sit in a corner and dribble at them.

In the above quote, the participant (P#14) highlights the value and importance she implicitly places on her previous occupational activity, namely *inner city policing*, by stating that it is not the place for someone with major problems. Indeed, her analysis accepts and legitimises her exclusion from her occupation. In the subsequent sentence she identifies this loss as *the first thing* and a *lot of friends* became the second social identity resource to recede. It is interesting to note that in describing this sequence that has contracted her social circle, it is *friends* that are referred to in the first instance, implying a loss of social relationships. However, she subsequently refers to those who fear *brain damage* and *run away* as *people*—a term that connotes strangers rather than friends with whom she shared social relationships.

Another participant links the ongoing speech and language issues associated with his injury to compromised social relationships post-injury. In this extract, the participant is talking about word-finding difficulties, which make communication, conversations and even texting difficult, and the subsequent interference of these difficulties on social relationships. He (P#10) states:

> ... Like I just say, like sometimes people get annoyed when you're trying to think of a word. It's like a stutter but you don't have a stutter. Do you know what I mean? And then it's the same thing. Like I was just saying there about spelling [for texting], sometimes it's because I do miss words or just don't know... when I'm saying something I mightn't know the name of a thing. I'd forget the name of a thing. And then you have to kind of go a long way trying to explain what it is. And people don't want that especially nowadays they want to know what you're talking about.

In this extract it is apparent that the particular difficulties experienced in relation to speech and language are perceived by the participant as having an impact on his social interactions with others. He believes that others are *annoyed* or fail to understand as a consequence of his expressive language difficulties. His depiction of the difficulties does not orient to his own frustrations. His account is informative and descriptive: *it's like a stutter but you don't have a stutter.* The problem as he sees it is not one that he perceives as frustrating, despite his having *to kind of go a long way trying to explain* something. Rather he experiences his expressive language problem in terms of how it impacts his relationships. His use of the phrase *especially nowadays* can be viewed as a rhetorical strategy that generalises his perception of those who *don't know what [he is] talking about* to wider society.

2. 'They really did help bolster me up': Family relationships as cure and curse

In their accounts of their injuries, participants emphasised that family members were sometimes first to their aid in the aftermath of the injury. Moreover, family were portrayed as being in it for the long haul, staying the course, and offering support through arduous recovery journeys. The importance of family was amplified by the fact that participants felt that ABI often had a negative consequence in terms of access to their pre-injury social and occupational friendship networks (theme 1). Families often supported in the acute, medium- and long-term management of participants' social and health care needs. For the most part, participants told stories of incredible family loyalty, generosity and diligence in supporting their needs. For instance, one participant (P#1) recalled an extended period of family support abroad after he sustained his injury. He stated:

> *I:* So when did you move back then from [names places in UK]?
> *P:* My family spent the best part of—I was in a unit in [names places in UK] for about nine months after I had come out of my coma—and it was a massive, my parents had just retired before my attack happened. So I mean it was a massive change. I mean massive upheaval for my whole family. So they would travel every week or they would travel every week during the week to the UK from Ireland to be able to visit me and my sisters when they were off work, my brothers at the weekends, they were travelling the weekends... They all rotated as well, I was never on my own. I was never on my own. And you know it was that sense of support I mean they really did help bolster me up.

In the above extract, this participant recalls his family spending the best part of nine months offering their support by being present in the rehabilitation unit where he was being treated in the aftermath of his injury. His account emphasises the taken-for-granted nature of his connection and identification with individuals in his family who are unassumingly defined with reference to himself: *my family, my sisters, my brothers.* His account emphasises his sense of his family acting as a cohesive group (*my whole family*) where he was, at the time of his injury, prioritised and made central to how this family group structured their lives despite the *massive* personal cost for them. Because he was working abroad at the time, the centre was in the UK and he reports that his family members took a systematic approach to travelling to visit him (*They all rotated as well*). The result was that this participant had a strong sense of social support from his family as indicated by stating twice for emphasis *I was never on my own. I was never on my own.* Indeed, by his own reckoning, over a long period of hospitalisation, it was this support that *really did help bolster me up.*

Despite the very many accounts of the clear value of family, in terms of practical and emotional support,

paradoxically family support was also evidenced as problematic. One participant (P#11), for example, stated that ... *my wife is my carer, still she doesn't really let me go anywhere on my own you know. Now, I done a test with the Wheelchair Association about, I didn't drive for ten years after my accident, and I done a driving test with the wheelchair crowd, it was six years ago...*.

In this example, one participant who described a close and warm relationship with his wife earlier in the interview subsequently articulates an altered relationship with his wife, recategorising 'his wife' as his 'carer'. It is clear he is accepting of his wife's support and authority as his carer because he accepts her positioning of him as someone that is not 'let' *go anywhere on my own you know*. And although he draws our attention to his pursuit of independence in passing his driving test through the use of the word 'now' in the next section of the conversation, the use of *you know* suggests that his wife's position in not permitting his driving is self-evidently correct and would be agreed and understood unquestioningly by the listener. From a social identity perspective there has been a shift in self-categorisation whereby this participant now identifies himself as someone who is 'cared-for' which he did not do prior to his injury. This is in direct contrast to the distance he inserts between himself and the service provider that offers driver testing for wheelchair users (of which he is one), whom he refers to somewhat dismissively as the *wheelchair crowd*. In this way the autonomy offered by the service provider together with his own achievement can be seen to be undermined by his wife's authority as his carer. Paradoxically the support offered through his primary carer has a cost in terms of his independence post-injury.

3. 'We kind of treat each other like as if we're at work': Group activity, support and adjustment post-injury

Our third theme related to the role of activity and engagement with others in promoting adjustment post-injury. Participants reported encountering practical difficulties to activities as a consequence of physical limitations, such as paraplegia, hemiplegia and blindness as well as cognitive changes to their memory, attention and emotionality. Perhaps because of the different way that those affected by ABI are treated by both their families (theme 2) and their wider social and occupational networks circles (theme 1), many participants saw value and meaning in group activities with others affected by ABI. Consider the following where a participant (P#6) is commenting on the differences in his pre-and post-injury life:

> You feel kind of important because you're good at your job and because people treat you that way... They ask you to do something and they know you're going to do it. And now it's different. People don't ask you stuff because they are not sure if you know. ...You kind of lose your standing a little bit.

People are nice to you too. People are all the time helping you out and making allowances for you and stuff. That's why I like the [names the woodwork] group—because we don't here. We kind of treat each other like as if we're at work. Do you know that? If you're making shit of something we'll tell you, you did. It's all good fun, no one loses their temper or anything. But yes, it's different.

This extract reflects several themes that have already arisen. This participant has clearly felt a loss of status (*You kind of lose your standing a little bit*) as well as reduced ability to help others in a significant way (*They ask you to do something and they know you're going to do it*) since his injury. This extract also highlights the impact of his injury on others' perceptions (*People don't ask you stuff because they not sure if you know*), which speaks to the inadvertent disabling of people affected by ABI (*People are all the time helping you out and making allowances for you and stuff*) outlined in theme 2. On the other hand, this participant highlights the value of meaningful activity provided in a local rehabilitation group (in this case, the woodwork group) he attends. This peer network and associated activity is likened *to work*, as is the interactions between group members. Here there is no soft soaping around under-performance, *if you're making shit of something we'll tell you*. In the repeated use of the term *we* at the close of the extract there is a strong sense that as well as a sense of this group as a collective enterprise, this sense of connection and activity with others affected by ABI provides a *different* and therapeutic space (*That's why I like the [names of woodwork] group—because we don't [make allowances for you] here*). Ironically, it would appear that this group organised for those disabled by ABI is the one place where our respondent does not feel disabled by others.

Participation in supported activities and associated social contact and seeing other people was recognised by participants in this study as evidence of being in a better place. The ability to undertake 'meaningful doing' (as described by Gallagher, Muldoon, & Pettigrew, 2015) facilitates social engagement and building friendships. Being and doing with others are viewed as positive outcomes in their own right. For example one participant (P#12) stated:

> ...You know but in the day now I have, since I have joined ABI, I am doing kind of more crafty things like, I have discovered loom knitting, you can do that with one hand and I am amazed, that's brilliant and I am doing weaving. I mean it sounds really boring but I am 50 it's time to do stuff like that, but, yes...But, if I didn't have ABI I wouldn't be doing my weaving and stuff, I would probably be sitting there crying and so I am getting out and you know, out and about and just... you know I am in a much better place now than I was sort of say, even four years ago I didn't really, I didn't really see anybody... I didn't really know anyone.

So this participant explicitly states that the craft activity she has learnt through participation in training with the NGO Acquired Brain Injury Ireland (here referred to as ABI) has given her a sense of pride. Her pleasure in this activity is clear from her statement that *you can do that with one hand* as she suffers from hemiplegia. Our participant checks her zeal for this craftwork by orienting to the interviewer, who might think it *sounds really boring*. She accepts this charge by an age-related stereotype stating *I am 50 it's time to do stuff like that*. In so doing she avoids the more damning and stigmatised connotations of basket weaving as a suitable activity for the brain injured and intellectually disabled (Cameron, 2007). She attributes involvement in this activity as central to her recovery and, in particular, managing her distress. Without this activity this participant thinks that she *would probably be sitting there crying*. She closes by identifying another element of value to this activity, namely that she has increased social contact from four years ago when she *didn't really see anybody… I didn't really know anyone*. Engaging in this activity facilitates not only a sense of achievement but also has increased her social network and social engagement with others, which she recognises as an indicator of better post-injury adjustment.

4. 'It's like getting reset': Changing views of the self as a post-injury social identity process

Many participants in their accounts of their injury and their lives post-injury, despite serious physical and cognitive impairments, claim they feel fortunate, not least because they are aware of the more difficult circumstances of others affected by ABI. For example one participant stated *I am lucky, a very lucky case, because I have seen a lot of the other patients*. This is not to suggest that there is not talk of loss (see themes 1 and 3); however, there is also evidence of considerable acceptance, and willingness to re-engage with others. Also, adjusting and accepting life post-injury was linked to social identity change—particularly not seeing himself as different from those unaffected by ABI. In this extract, our participant (P#3) states:

Well there's no 'us and them'. It can happen to anyone, you know my brother used to come into the hospital 'Oh why did it happen to you? Why did it happen?'. It has to happen to somebody, it can happen to anybody. You can't look at someone and go you know, I will never be in that situation because you could be and I have kind of got around it in my head by saying whatever happened to me could happen to anyone and there but for the grace of God you know. So you know get out there and I would say to people persevere and mix with everybody and you now just accept other people, you know, into your life and you'll be the better for it.

In this interview, our participant explicitly acknowledges group-based 'us and them', thinking that can act

to exclude those affected by ABI. He describes how those in his own network in sympathising bemoaned the situation in which he found himself. He goes on to describe a having to *g[e]t around in his head* how he was no different from others—other than in terms of the situation he was in. In stating that it was the situation that distinguished him from others, he places the key characteristic upon which he is differentiated by his brother and by wider *us and them* constructions as being something that is external to him. What happened to him *could happen to anyone*: He differs only in terms of circumstance. In highlighting this dimension of difference, attributable to bad luck, he implicitly articulates the commonality he shares with others unaffected by brain injury. This perspective facilitates his orientation to 'persevere and mix' with others—indeed the use of the word 'persevere' suggests that it is something that requires effort on his part. In short, this appraisal of there being no *us and them*, 'ABI affected' and 'unaffected', allows him, despite inherent challenges, to proactively engage and pursue connections with others.

In the below extract, a participant (P#8) who experienced considerable changes in his life talked about the role of his own and others' views of his altered capacities in adjusting to life post-injury. He stated:

And there should be a thing where they talk to the relatives as much as the person themselves… People have these things, hurt their heads and people think because they look the same that they should be the same person. And unless they've got a limp or they're missing a limb or something they can't see that they're broken, that they're not the same person. It's like getting reset. Some parts of your head get reset and it makes you a different person and that's it. And I spent the first couple of years trying to be the other person that everyone thought I was and not understanding why I couldn't be that way anymore. And it was only when I kind of gave in, that I kind of relaxed a little bit and things started making sense again to me.

In this extract our participant states that he spent his first years after brain injury *trying to be the other person that everyone thought I was*. He uses the word *everyone* to offer his sense of how who he was was linked to how those in his own social network thought of him. In this way, and consistent with the social identity approach, we can see his sense of self is derived most explicitly in this quote from relatives—his family group—and earlier in the interview—his occupational and sporting group allegiances. He believes there *should be a thing where they (health professionals) talk to the relatives as much as the person themselves* to get a sense of the changes and challenges being experienced by those affected by ABI as *people that that have these things* and *hurt their heads* may look the same without *being the same person*. He then goes onto describe how the clash between expectations others had of him and his

post-injury capacities was something he had to negotiate as he had no *understanding of why I couldn't be that way anymore* at least in the early days post-injury. And so he believes that when he stopped trying to live up to others' expectations and meet the demands of his pre-injury self (*kind of gave in*) that he *relaxed*. In closing he states that *things started making sense again to me* to indicate what this change in his thinking facilitated. In short, relinquishing a set of social identity demands built on his pre-injury capabilities facilitated his *resetting* his sense of himself to be more accepting of his changed sense of himself post-injury.

Discussion and Conclusions

To summarise, in the wake of their brain injury, our participants articulated social identity loss and associated changes in their social identity resources in their post-injury lives. However, consistent with emerging evidence from social identity research (e.g. Walsh et al., 2017), our participants also reported social identity continuity. Participants talked about family, and how identification with their family, community supports and group activity was an important resource they relied upon in their most difficult times. This fits with social identity theorising which suggests that belonging to groups, and the support these groups offer, are an important factor in life after brain injury (Walsh et al., 2014).

A novel finding in our study is that family groups exert both positive and negative effects that appear to constitute both a social cure and a social curse. Post-injury adjustment is driven by social identity processes that can cut both ways. Families were the site of social enrichment, facilitating engagement with services and transport to and from important health care and rehabilitation activities (Miller, Colella, & Green, 2013). However, the complex array of changes wrought by ABI also meant that people within families are recategorised as 'carers' and 'cared for'. As such, our results suggest, close family groups with the best of intentions can inadvertently disempower those affected by ABI because of the way in which social identities are reconstructed and changed in the aftermath of injury. This finding is important because the literature indicates that family responses to brain injury have not been subjected to rigorous research (Ponsford, 2013). Our results suggest that concerned responses of significant others in the aftermath of the injury can result in altered social identities that can, sometimes, be a social curse. This finding offers a more rounded understanding of the positive and negative social identity changes that may follow life-changing injuries. The idea that social identity change can be a social curse is also potentially of practical importance as social identity reconstruction is an important element of rehabilitation models (Jackson & Hague, 2013).

Our findings also suggest that the social identity loss our participants associated with their life post-injury could be countered with worthwhile group-based activity. The alterations participants reported experiencing in their lives post-injury meant that many had occasion to enact their new ABI identity, most notably in group-based activities offered by rehabilitation services. These findings add to the growing body of evidence to support rehabilitation efforts built on engagement in meaningful activity (Walsh et al., 2015; WHO, 2001). Of further theoretical importance, our study is the first to suggest that participation in group-based and meaningful activities is an important element of rehabilitation because it facilitates access to alternative social identity resources. We argue that given the depletion of the social and occupational networks reported by our participants in the aftermath of their ABI, group-based activity is an important conduit for building social resources post-injury and in particular for those who feel 'othered' by their injury. Indeed this may be the only avenue to identity resources for those living with brain injury.

Our findings suggest that acceptance and adaptation to life post-injury was implicitly linked to gains in social identity resources. For many, and indeed for the participants in our study, social and community reintegration post-injury rather than recovery is the relevant goal (WHO, 2001). Our findings suggested that meaning was often achieved by being with others and doing group activities. Increased social contact and connections with others, whether peers, family or friends, were used by participants as markers of improvement and recovery. This finding taken together with a recent study that highlights the social identity processes underpinning post-traumatic growth (Muldoon et al., 2017) represents an important avenue for further research. It is entirely plausible, for example, that post-traumatic growth is a social identity-based phenomenon (see also Grace, Kinsella, Muldoon, & Fortune, 2015). At a minimum, our findings suggest that identity processes are central to adjustment to this chronic and disabling condition, which represents an important addition to the existing literature.

Overall, our findings highlight the centrality of collective dimensions of identity to adjustment to ABI. This adds to a growing body of evidence that argues that long-term social identity management, rather than disability management per se, is crucial to support those affected by chronic conditions such as ABI. Similarly whilst using a more individualised model, Bowen, Palmer, and Yeates (2010) argue that rehabilitation following ABI is not a short-term intervention, but rather a process of long-term disability management that requires individuals to negotiate their brain injury via their relationships with others. In practical terms, this management requires support of existing social identities and, more particularly, new groups that offer access and engagement with meaningful activity. This is likely to be particularly challenging in community settings where transport, budget, access and mobility issues are writ large.

To conclude, notwithstanding the limitations of our method and sample size, the present study demonstrates the potential identity benefits and burdens associated with acquired brain injury. Our findings highlight the reduced identity resources available to those affected by ABI. Participants report a narrowing of social and occupational identities and resources and family support sometimes appears to be disempowering. On the other hand group, activities that facilitated belonging and associated access to ABI-affected peers were important and valued identity resources and represented social identity gains. This enactment of identity via group activity enabled identity-driven social cure effects which were also implicated in successful post-injury adaptation to this often chronic and disabling condition. Examining social identity change quantitatively among those affected by traumatic events and injuries is an important avenue for future research. Future work could also usefully orient to the therapeutic value of social identity management of chronic conditions to support the rehabilitation and recovery in conditions such as ABI.

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