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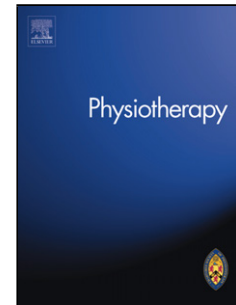
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Considering how athletic identity assists adjustment to spinal cord injury: a qualitative study

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Abstract

Objectives To establish how sport, and access to an athletic identity, has been used when adjusting to a spinal cord injury.

Design Qualitative study using semi-structured interviews.

Setting Private athletic club.

Participants Eight (six males and two females) athletes from a wheelchair badminton club participated in the study. The individuals had finished rehabilitation, and were aged between 20 and 50 years.

Main outcome measures A single semi-structured interview was undertaken with each participant.

Results Following the thematic analysis, two final themes were presented: (1) adjustment and paradox of chronic illness; and (2) the role and value of an athletic identity.

Conclusions Badminton provided participants with an opportunity to continue and develop a positive athletic identity. Identity may be used as a factor that can promote recovery, and is considered as a way to encourage and maintain positive long-term adjustment to disability.

Keywords: Qualitative; Sport; Identity; Adjustment

<A>Introduction

Worldwide, the annual incidence rate of spinal cord injury (SCI) is between 5 and 59 cases per million [1,2]. In Europe, approximately 252 people per million inhabitants have an SCI [3], and approximately 40,000 people live with an SCI in the UK [4]. In Australia, it has been estimated that the mean patient healthcare costs (>6 years post SCI) ranged between \$139,427 (moderate SCI) and \$297,453 (quadriplegia) [5]. In the UK, the annual cost of care exceeds £500 million [4].

An individual's identity can be severely affected by loss resulting from a chronic illness [6], such as an SCI. One particular identity that can be affected following an SCI is an individual's athletic identity [7]. The athletic identity for those previously involved in sport can represent the apex of identities in the identity hierarchy. Cases have been reported where a strong athletic identity before the SCI made adaptation difficult [8] or 'life not worth living' [9]. However, there are also examples of individuals with a strong athletic identity who are able to embrace and accept their disability [10]. This is important because accepting the disability that accompanies the SCI is a significant barrier to overcome to achieve positive adjustment [11]. As such, exploring how individuals who have a strong athletic identity can adapt and adjust to their SCI may be valuable in detailing how to facilitate positive adjustment.

Social identity has been defined as 'an individual's knowledge that he or she belongs to certain social groups together with some emotional and value significance to him or her of this group membership' [12]. As such, people's classification of themselves into various social categories or groups (e.g. I am a disabled-bodied sportsperson, or I am a badminton player) initiates a process of self-stereotyping, whereby one embodies the meaning associated with that category [13]. With regard to sport and for the purposes of this article, athletic identity represents the degree to which an individual feels that they belong to the athletic

group of choice, and the significance of this. Further, it is important to consider that our group memberships, and sensitivities to them, form the lens through which we interpret and respond to others' behaviours, and how we evaluate and justify our own behaviours. Thus, changes in our social identities (memberships of new categories and/or changes in the meaning of existing group memberships) will be accompanied with changes in our behaviour. With this in mind, the meaning and value of group memberships for individuals who have suffered an SCI could be associated with, or determine, the potential for positive adjustment. Indeed, recent quantitative research has provided evidence that supports this hypothesis [14], although further in-depth research using a participant's own words is required to explore and clarify this relationship.

Past qualitative research has not been able to demonstrate how post-SCI identity is associated with and expressed alongside the adjustment process [7,8]. Individuals with an SCI may not simply consider and use one distinct identity to represent themselves. One reason for this is that individuals with chronic illness often express the paradox of chronic illness [15–17]. The paradox suggests that individuals are simultaneously impelled to accept and defy the limitations of their disability. Further, the expression of which limitations individuals can accept or defy is likely to vary, change and evolve. One consistency in this experience may be the sport group with which individuals associate; that is, their athletic identity as a badminton player may help the process of acceptance and act as a factor that can support and facilitate adjustment. Thus, there is a need for research to consider the association between and influence of how a strong athletic identity can influence an individual's adjustment and hope following the onset of an SCI.

<A>Methods

Design

A qualitative design was selected in order to obtain an in-depth description of athletic identity and the other psychosocial constructs under consideration. Semi-structured interviews were chosen as they allow flexibility and some spontaneity/adaption during the interaction. The final interview schedule consisted of eight categories around the topics of: identity, adjustment and the paradox of chronic illness (see Appendix A, online supplementary material). Not all questions were asked. These topics were based on previous research findings [16,17]. The corresponding author's expertise will have influenced the choice of topic.

Participants

A convenience sample [18] of eight (six males and two females) athletes who were members of a wheelchair badminton club agreed to participate in this project. The data generated from the interviews may not be representative of the SCI population as a whole because of the athletes' commitment to sport and their resulting athletic identity. The inclusion criteria were: (1) outpatients, post inpatient rehabilitation who had an ability to reflect on their experiences; (2) individuals who were at a stage of their adjustment where they felt happy and able to talk about the injury; and (3) age between 20 and 50 years (i.e. the typical range of young adults affected by SCI). Individuals were excluded if their SCI was identified as a birth defect.

Ethics

Ethical approval was gained following ethical review at the University of Birmingham. Potential participants received an information letter and were given 48 hours to consider participation. Following this period, the individuals who provided written consent

were interviewed. Participants were informed of the right to withdraw from the study at any time without giving a reason. No adverse effects occurred.

Procedure

Interviews took place in a familiar environment chosen by the participant in order to make them feel relaxed, such as their home or in a private room at a sports centre where they trained for wheelchair badminton. The interviews were conducted by the primary author. All interviews were recorded on a digital voice recorder and transcribed verbatim, whilst removing any personal information in order to ensure complete anonymity. Data were stored and accessed by AS and CH on a password-protected computer.

Analysis

A thematic analysis [18] was undertaken. Two authors (CH and AS) met initially to discuss how to conduct the analysis. Following this, CH began to analyse the transcripts (Phase 1). Findings were presented to AS who, acting as a critical friend, developed a conceptual map, the purpose of which was to re-name and associate themes (Phase 2). Next, CH reviewed the analysis to consider if the new categories could be supported from transcripts (Phase 3), looking for negative cases [19]. The findings from Phase 3 were presented to AS, who developed another conceptual map and a final summary table (Phase 4). During this process, saturation was achieved using a constant comparison method through Phases 1 to 3, where the revision of codes and the need for replication of categories from newly obtained data was essential [20]. A summary audit trail [21] was examined and approved by PC, who acted as the auditor for the process. The audit trail is available from the corresponding author.

<A>Results

Table 1 provides the demographic details of the eight participants. The mean age was 36.3 [standard deviation (SD) 8.1] years and the mean time since injury was 11.5 (SD 8.3) years. All individuals had taken part in sport before and after their injury (five males performed at national level, all others participated at local club level).

Following the thematic analysis, two themes emerged: (1) adjustment and paradox of chronic illness; and (2) the role and value of an athletic identity.

<INSERT TABLE 1 AROUND HERE>

Theme 1: adjustment and the paradox of chronic illness

The expression of the paradox began following the SCI; feelings of shock, disbelief and helplessness were all identified as the first experiences that acknowledged what had happened, although Participant 06 (P06) stated that no impact was felt. In contrast, P01 reported that acknowledging what had happened was extremely difficult. Clearly, acceptance was an individual process. For example:

‘The realisation of the injury came on gradually.’ (P07)

However, acceptance was challenged by participants when they considered their future; two participants (P01, P04) hoped for a cure, and this hope may have represented some difficulty in accepting that they may not become able-bodied again. P01 identified that there may be hope in the future and the possibilities this would bring, whilst simultaneously embracing the present. Such an embracement was also identified by P06, and represents a point where unconditional acceptance may exist, representing a form of transcendence. There were other aspects that were not easily accepted, such as changes in an individual’s life

including, but not limited to, not being able to provide for their family or loss of a job. This meant that full, unconditional acceptance of their present circumstances was not necessarily possible for all participants:

‘Part of me sometimes still doesn’t accept it.’ (P01)

Realisation or uncertainty about the future and being able to consider that a cure may not be possible provided a source of worry. For example:

‘I expect more deterioration in my physical state as I get older.’ (P07)

Emotional reactions were expressed by participants following the SCI and alongside adjustment. The main feeling identified by most participants was anger, and this was often associated with frustration and a loss of patience:

‘I was so angry and frustrated [pause] grieving for my able-bodied life.’ (P07)

P06 stated that the SCI had no psychological impact, although he acknowledged that he felt disappointed from his perception that he had let others around him down. The thematic breakdown of the theme ‘adjustment and the paradox of chronic illness’ is provided within Table 2.

Theme 2: the role and value of an athletic identity on adjustment

Participants were able to describe the losses and changes that they experienced. These losses often represented loss of the ability to be spontaneous and the freedom that they had

within their 'previous' life. The losses impacted on identities that were important to them, as well as functions that they used to perform. For example:

'There are obvious physical limitations like not being able to walk and not being able to function sexually like before.' (P07)

However, within these losses which challenged and affected adjustment, participants identified consistency in how they viewed themselves, as well as an increase in their social networks. Their athletic identity provided a foundation for this consistency:

'Socially, I have had no problems. I still have the same friends but I have met new ones through wheelchair badminton.' (P05)

Being able to continue playing badminton and retain and increase the social networks meant that their athletic identity remained relatively constant. This was a consistency in their life and was used as an anchor to illustrate they had not changed who they were. Thus, the magnitude of perceived loss to their identity was buffered by their athletic identity, and this acted to facilitate acceptance and adjustment. In addition, being able to participate in sport provided individuals with a chance to regain an experience that they had previously known and valued as part of their athletic identity:

'Sport makes me feel relaxed and when I play sport I almost forget I'm disabled.' (P04)

Thus, psychologically, participation in sport provided a period of time when they focused on the experience of sport, which allowed them to focus on a challenge, provided a

sense of freedom and promoted positive emotions. These experiences reinforced the essential role of badminton in their life, and highlighted the importance of their athletic identity. Finally, the fitness benefits of sport, such as weight control, strength gains and relaxation for their body, were highly valued by participants and helped maintain their athletic identity. The thematic breakdown of the theme ‘the role and value of an athletic identity on adjustment’ is provided within Table 3.

<INSERT TABLES 2 & 3 AROUND HERE>

<A>Discussion

These findings illustrate the importance of understanding the paradox of chronic illness and athletic identity for individuals with an SCI. Participants reported shock and disbelief at the magnitude of losses, and highlighted that their ongoing adjustment was influenced by losses from the past and worries about the future. Thus, the current losses, combined with uncertainty about the future, acted to diminish hope. However, hope was generated from being able to gain a sense of purpose, from expectation of a better future and the prospects of a cure in the future. The participants’ consistent athletic identity provided a buffer to the effects of loss and limitations due to the SCI. Hence, an individual’s athletic identity was used and valued as an essential factor that could assist in the adjustment process.

Hope – the paradox of chronic illness and adjustment to spinal cord injury

Participants tended to acknowledge, accept and adjust to the SCI rather than express defiance. Being unable to walk and being permanently wheelchair bound were the greatest impediments to effective adjustment due to a loss of independence and spontaneity; this finding supports previous research [22–24]. Some participants’ expression of defiance was

presented in the form of hope to be restored to their past identity or self; this hope for a restored self [6] or supernormal identity has been considered previously [7].

The expression of a paradox meant that individuals would not simply embrace their disability. For example, individuals could hope for a cure, express the wish to play able-bodied sport, and express worries for the future, while simultaneously accepting what had happened. The feelings of loss may be expressed by redefining their identity in a less positive way. This can be represented by the sentence ‘I still play sport, which is great, but now I play wheelchair badminton’. It may be this expression that reveals the loss felt by an individual, and something which suggests that adjustment and hope will be challenged in the future because of the loss. In the current study, loss was also expressed regarding their job, family role and independence, and these losses likely impacted on how they were able to adjust. When individuals are challenged by an SCI or find adjustment difficult, it may be their peers who are best placed to offer a different perspective or provide time to listen. Within the current study, this was likely undertaken by individuals who used their athletic identity as a positive factor that assisted their adjustment.

* Participants’ athletic identity and the value of sport*

Whilst some aspects of the person’s identity were lost and could not be regained, an individual’s athletic identity was retained, continued or strengthened. The potential of strengthening one’s athletic identity supports a speculative finding by Tasiemski and Brewer [14]. In the present study, the badminton group helped participants to embrace their disability. In other words, badminton helped promote positive adjustment through gaining or maintaining a strong athletic identity; being part of an ‘in-group’ [25]. Levins *et al.* [26] noted that participants associated disability with an inability to do things (e.g. the loss of a job or a role); sport was an exception to this, and provided a unique environment that created

accomplishment, and allowed freedom and spontaneity. In this way, sport gave the participants a way to explore the boundaries of their athletic and physical identity, which is important for physical and emotional growth [27]. In addition, the social network that surrounded the sport was a likely positive influence on participants' adjustment; this finding supports a previous suggestion [14].

Implications for practice

- An individual's identity heavily influences adjustment and hope. These aspects are likely to be very interdependent.
- Adjustment is unlikely to be a purely positive experience, even with those who may have embraced the effects and limitations of their SCI.
- Sport provides the ability to give purpose and engage positively with adjustment as it provides a stable platform for adjustment. Sport is able to provide a sense of purpose and value for individuals, as well as an experience of freedom.
- Two key questions may assist physiotherapists in treating patients with SCI: (1) are there aspects of their previous life that can be continued? If so, is it possible to encourage them to maintain this identity, redefine their identity or consider a particular identity; and (2) what are the losses that can no longer be regained?
- Further research is required longitudinally to see how the adjustment process changes over time and at different stages of participants' lives.

Study limitations

This research study had a small sample which consisted of elite badminton players with an SCI. This is not representative of the whole population of individuals with an SCI. The analysis process limited within-subject comparison, and other types of analysis may be

useful when considering the patient's journey and influence of previous identity on the process of transition. A consideration for any gender, level of performance (club vs national) or type (individual vs team) was not possible, and other quantitative research [14] should be considered for such aspects. Finally, the primary author used a specific view of adjustment and hope which may restrict the analysis and interpretation of results.

<A>Conclusion

To conclude, adjustment for participants in the current study was a continuous process that involved realising and acknowledging the physical, psychological and social loss that had occurred. Participants were challenged by their present circumstances and the loss of important identities; they were also challenged by considering an uncertain future. However, the participant's athletic identity represented a consistency in their life, and provided access to a network of social support from their peers. Their athletic identity was used to illustrate that they had not changed how they viewed themselves. Thus, a participant's athletic identity was used to buffer the psychological effects of the SCI and promote a more positive adjustment.

Ethical approval: Ethical approval was gained following ethical review at the University of Birmingham (Protocol Reference Number: PEAJ 005).

Funding: The study was funded by the primary author.

Conflict of interest: At the time of the investigation, the primary author provided physiotherapy treatment to individuals at the club and had established therapeutic relationships with individuals.

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Table 1

Demographic characteristics of individuals

Participant	Gender	Age (years)	Time since injury	Classification of injury	Previous profession	Current profession	Current sporting level
P01	Male	22	4 years, 6 months	C4 Tetraplegic incomplete	Student	Unemployed	National
P02	Male	46	18 years	T12 Paraplegic incomplete	Scaffolder	Unemployed	National
P03	Male	43	26 years	T3 Paraplegic incomplete	Gas pipe fitter	Rural payments agency, case worker	Club
P04	Male	33	8 years	T4 Complete	Software engineer	Software engineer	National
P05	Female	42	8 years	T4 Complete	Horse stable manager	Artist	Club
P06	Male	38	5 years, 3 months	T12 Incomplete	Welder and landlord	Landlord	National
P07	Male	38	19 years	T6/7 Complete	Student	Guitar tutor and computer assessor	National
P08	Female	28	3 years, 6 months	T6 Complete	Receptionist	Receptionist	Club

Table 2

Adjustment and the paradox of chronic illness

Category	Code	Data
Acknowledgement	Shock	P01: 'Obviously it was a big shock. There was a sense that it was unreal.'
	Helpless	P03: ' In a word helpless, from being a really active, good-looking 17 year old to a person lying in a ditch and couldn't even move to get out.'
	Emotional	P01: ' [initially] I just couldn't believe what had happened and just [pause] very emotional and depressed.'
Family acknowledgement	Shock/blow	P03: 'They just couldn't believe it had happened. You hear of these things happening to other people but you never expect it to happen to your family.' P05: 'They were in as much shock as me; it was just a big blow on life.' P04: 'My family expected much worse than I did. Generally in India, a paralysed person is on his bed till death. So they were surprised when I resumed work and things.'
	Disbelief	P01: 'I didn't want to do anything and didn't want to know anyone. I couldn't believe it had really happened.'
Acceptance	Personal realisation	P03: 'When the consultant told me I will never walk again, from that day I knew that I would have a rocky life.' P01: 'When I came out of the spinal unit I realised that this is real and I have just got to get on with life.'
	Factor of time	P03: 'I think after a few years when I was just clinging to hope of movement, after that and nothing really changed, I thought it was time to accept my situation as it is and make the most of life.' P07: 'The realisation of the injury came on gradually.'
	Why me?	P01: 'Sometimes I start questioning why it happened' P01: 'I do question why did it happen to me?'
	Don't accept No impact socially or psychologically	P01: 'Part of me sometimes still doesn't accept it.' P06: 'My injury hasn't affected me psychologically or socially.'
Hope and defiance	Hope for a cure	P04: 'I do hope there will be a cure for SCIs in the near future.' P01: 'A small part of me still thinks I will walk again and although I don't let it take over my life, I still have hope with the advances of medical research.'
	Hope in possibility Transcended hope	P01: 'I hope things will get better in the future.' P06: 'Life is too short to worry.' P01: 'Make the most of life' P05: 'I just had to be strong minded and focus on the now rather than the past.' P06: 'Stay positive and always look ahead, don't dwell on what happened.'
	No hope of a cure	P03: 'In my lifetime, SCIs will not be overcome, SCIs will only truly be overcome when there is a cure...unfortunately in my lifetime, there will not be a cure for SCI.'
Hopelessness, uncertainty and future worries	Uncertainty and no expectations	P03: 'Scared, not knowing what the future held.' P05: 'I didn't know what to think. All I wanted was some reassurance that everything was going to be ok.' P06: 'I don't have any expectations, literally anything can happen.'
	Coping when older	P07: 'I expect more of deterioration in my physical state as I get older.' P02: 'I do worry now I am older and now I am starting to get injuries... I worry about another 10 years down the line about how I am going to be as in getting in and out of bed and into the car.' P05: 'I know as I get older physically I am going to get worse, but I know that the more active I stay now, the better I will be when I am older.'

	Future worries or doubts	P02: 'I do doubt myself sometimes which makes me doubt my future.' P05: 'It makes me worry about the future and it does make me miss my old life.'
Intermittent and intervening feelings	Angry	P07: 'I was so angry and frustrated [pause] grieving for my able-bodied life.'
	Frustration and a loss of patience	P03: 'I get frustrated especially when I can't do simple tasks which I used to be able to do so easily.' P04: 'I do get frustrated when I can't do simple tasks like I used to be able to.' P06: 'I would say I am not as patient as I used to be.'
	Depressed	P07: 'My depression can be a real problem as it prevents progress in my life. I feel very down about my injury sometimes.' P07: 'I have suffered from depression several times over the 19 years due to finding normal daily activities hard to do.' P01: '[initially] I just couldn't believe what had happened and just [pause] very emotional and depressed.'
	Letting others down	P06: 'I was [pause] disappointed. I felt like I had let people down close to me.'

Table 3

The role and value of an athletic identity

Category	Code	Data
Physical and environmental changes, loss and limitations	Can't function like before (getting around, wheelchair bound, not being able to walk)	P02: 'I can't walk and I am permanently in a wheelchair.' P06: 'I use a wheelchair 95% of the time. I am unable to walk as I cannot feel anything below my knees.' P01: 'It obviously affects me physically as I use a wheelchair for mobility. I have other problems as well as the spinal cord injury such as my bladder and bowels are affected and I have a lot of spasm in my legs.' P07: 'There are obvious physical limitations like not being able to walk and not being able to function sexually like before.' P08: 'The big thing that I found difficult to come to terms with was that I was never going to be able to have children and of course I would never walk again.'
	Time taken on daily routines Planning	P01: 'Everything that I do everyday has changed; for example, it takes me longer to get ready in the morning.' P04: 'Everything needs to be planned like whether it has the right access, if it has disabled parking and if it has accessible toilets.' P05: 'Everything takes 10 times longer to do now and if I go out anywhere, I always have to plan it to make sure they have disabled facilities.'
	Susceptibility to illness Access and adaptations	P01: 'Because my immune system is lower, I generally get a lot more illnesses.' P02: 'In my house, everything has to be level, no steps at all, everything has been lowered like light switches so I can reach them in my wheelchair.' P05: 'I had adaptations done in the house, like I had surfaces lowered. Also, I have a hand control in my car as I can't use the pedals because I have no use of my feet.'
Losses of identity	Socio-economic impact (e.g. job changes, change in career path)	P01: 'It has completely changed my life. I was going off to Bournemouth University beforehand, but because of my SCI, it changed my whole direction in life.' P03: 'After my accident, I had to re-train; unfortunately, office work suited my condition the best for both access and conditions.'
	Old life	P05: 'It makes me worry about the future and it does make me miss my old life.' P05: 'I do get down a lot because I do miss my old life.' P04: 'I have lost lots of my freedom and do miss being spontaneous.' P04: 'I lost my freedom to do what I like.'
Aspects which are consistent in identity	Social (additional friends, same friends)	P06: 'I still see all my old friends, nothing has changed socially.' P08: 'I am still in with the same groups of people, nothing has changed there. [Pause] I have made new friends at wheelchair badminton too now.' P01: 'I have kept all my friends that I had before my accident, which has been great, but I have also met new people through wheelchair badminton and the SCI centre.' P02: 'It has not affected my social life at all.' P05: 'Socially, I have had no problems. I still have the same friends but I have met new ones through wheelchair badminton.'
	View of the self	P02: 'I have changed the way I look as I am in a wheelchair.' P05: 'I am physically different now as I am older and I am in a wheelchair but I am the same person other than that.' P03: 'My identity has not changed. I just go about things in a different way and do things slower.' P04: 'I hear people say I have done amazing things, but for me, I am still the same person, just living my life in a different way but enjoying it as much as I can.' P02: 'Sport has always played a big role in my life.'
Psychosocial value of an athletic identity on adjustment	Making friends in similar circumstances	P05: 'It has allowed me to make friends with people who are in a similar position. They are all great.' P01: 'It allows me to meet people and be with people similar to myself.'

Valued and complete	P02: 'It makes me feel important, valued and worthy.' P04: 'It plays such a big role. It helps me relax, socialise and challenge myself. Most of all, it makes me feel complete.'
Provides a focus, challenge and a sense of unity and purpose	P01: 'It makes such a big difference to life because sport gives me a focus and a drive.' P06: 'Sport has giving me something to focus on.' P05: 'Sport has been a life saver really. It gives me something to focus on.' P04: 'I love the challenges it brings.' P07: 'It is helpful with giving people a sense of achievement, also a team spirit and gives a sense of community for those involved.'
Provides a sense of freedom	P04: 'Sport makes me feel free and it is an important part of my social life. When I am playing I feel free.'
Helps emotions and feelings (buzz relaxation, stress relief)	P01: 'Sport makes me happy and makes me feel good about myself so it generally makes me feel happier in my everyday life and I have less periods of darkness now.' P04: 'Sport makes me feel relaxed and when I play sport I almost forget I'm disabled.' P05: 'It's a great way to get rid of stress.'
Benefits and maintains the body	P01: 'It relaxes my body whilst playing because obviously I am stretching.' P08: 'It keeps my muscles strong and flexible. And it's a good all-round way of keeping fit and active.' P02: 'It's important because if you're in a wheelchair or have a spinal cord injury, you don't want to become grossly overweight. It helps you keep fit.' P03: 'Spinal cord injured people are sat down pretty much in one position, and without sport, the ability to burn up the calories would be very difficult.'
