

REVIEW

Masculinity lost: a systematic review of qualitative research on men with spinal cord injury

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Study design: Systematic, thematic, narrative review of qualitative literature.**Objectives:** To systematically review qualitative research that explores the impact of spinal cord injury (SCI) on the gendered experience of men with SCI.**Methods:** A systematic search of databases and hand search of relevant journals to provide a thematic narrative review of articles, providing sufficient depth of information, relevant participant quotes and phenomenological insight into the gendered experience of men with SCI. Identified studies are summarised and common themes extracted and discussed in relation to relevant literature on masculinity, disability and health.**Results:** Eight papers, representing four separate studies met the review criteria for relevance and rigour. Three broad, overlapping themes describing the gendered experience of men with SCI were identified: '*lost masculinity*', outlining the impact of SCI on traditional masculine identity, '*fighting back*', describing the battle to regain and reclaim masculinity and integrate disability into a revised identity and '*beyond hegemony*', referring to possibilities beyond adherence to traditional masculine scripts.**Conclusion:** This review demonstrates a lack of explicit focus on men as gendered beings within the available qualitative literature. The findings are consistent with the limited quantitative data, which indicates that grappling with altered gendered identity is a central feature of life for men with SCI. Masculine identity emerges in this review as vulnerable to the impact of SCI, and given the strong links identified between masculinity, rehabilitation and health, as an aspect of experience that warrants more attention than it has received.*Spinal Cord* (2013) 51, 588–595; doi:10.1038/sc.2013.22; published online 23 April 2013**Keywords:** spinal cord injury; gender; masculinity; qualitative systematic review

INTRODUCTION

The scarcity of literature on the female experience of spinal cord injury (SCI) evokes frequent comment.^{1–3} However, the lack of focus on the experience of men, other than as representative of general human experience, is overlooked and under-researched.^{4,5} Theories about gender and disability are scarce,^{6,7} and studies of gender often use gender as a synonym for women 'or open with a nod to gender and then glide on to women.'⁸ Women typically provide the focus of discussion on gendered health inequalities, whereas men become a background feature,^{9–12} whose gender-specific needs receive insufficient attention.^{13–15}

Men's health only became a specific area of policy concern in the UK in the early 90's¹⁰ and even later in Ireland.¹⁶ It is increasingly recognised that research and health interventions should include a focus on gender.^{4–6,17,18} Although the International Classification of Functioning, Disability and Health¹⁹ situates gender as a key feature of the environmental and personal context within which functioning and disability occurs, the complexity of personal factors, including gender, evade easy categorisation.^{17,20,21}

The predominance of white Caucasian men in SCI research is attributed to convenience sampling and epidemiological factors.²² The possible dominance of male concerns in the SCI and health literature results from a combination of factors, including the gender imbalance in sex distribution of SCI, (3.8/1 male to female),²³ and a general tendency

in health-care research to adopt a male norm^{18,24} or gender neutral focus.⁶

FOCUS OF REVIEW

The apparent lack of specific literature on the gendered experience of men with SCI prompted the current review, guided by the following question: What does qualitative research tell us about SCI and men as gendered beings? The objective was to systematically search for, and review, qualitative studies containing a focus on the gendered experience of men with SCI.

Qualitative literature, with its emphasis on the interpretation of individual experiences and subjective worldviews, has become increasingly established and acceptable within the field of health care^{25–27} and SCI.^{28–30} There is also a growing body of knowledge on systematic reviews of qualitative studies^{27,31,32} or 'qualitative evidence synthesis' to use the term favoured by the Cochrane Collaboration's Qualitative Research Methods Group.³³ However, incorporating qualitative research in systematic reviews poses daunting methodological problems,³⁴ methods remain underdeveloped and under-evaluated³⁵ and terminology is fluctuating and often conflicting.^{33,36}

METHODS

A typology of reviews defines a qualitative systematic review as a method for integrating or comparing the findings from qualitative studies, characterised by

an overarching narrative and the identification of themes across studies.³³ It is distinguished from a meta-analysis by being interpretative rather than aggregative, its strength lies in its ability to broaden understanding of a particular phenomenon, and its weakness stems from its relative newness and debate about the precise strategies to be followed.³³ The current review consists of the following phases: identification of focus of review and published papers, summary and identification of key themes in each paper, selection of common themes across papers verified against relevant participant quotes, and interpretation in light of extant literature.

IDENTIFYING PAPERS

A comparison of methods for identifying qualitative research in electronic databases concluded that simple search strategies using broad-based terms are as effective as complex ones.³⁷ CINAHL (Cumulative Index to Nursing and Allied Health Literature) is the most frequently cited database in qualitative health studies.³² A comprehensive search (Figure 1) was therefore carried out of CINAHL and four other electronic databases for the years 1991–2010: PsycINFO, PsychArticles, PubMed and Web of Knowledge using SCI in conjunction with the following terms: qualitative, gender, men, male and masculinity. The search was limited for pragmatic reasons to peer reviewed journals published in a 20-year period. In addition, the following Journals were hand searched for the same period:

- Spinal Cord
- Disability and Rehabilitation
- Qualitative Health Research

- Rehabilitation Psychology
- International Journal of Rehabilitation Research
- Disability and Society
- Clinical Rehabilitation
- Sexuality and Disability
- Men and Masculinity
- Studies in Gender and Sexuality

This selection of journals is based on previous experience of useful sources, as well as evidence obtained from the search process about the potential location of relevant articles. Bibliographies of retrieved articles were also checked. Papers on men with SCI were included, which:

- were qualitative or contained a strong qualitative component
- were published in English in peer reviewed journals
- had a significant gender focus or a specific exploration of gender as part of the interpretation of findings
- provided participant quotes supportive of interpretations

Two papers,^{38,39} specifically exploring men’s social and sexual experiences of dating behaviours and of disability identity following violently acquired SCI (VASCI), were excluded as they lacked an explicit gender focus. Almost no mention was made of men and masculinity beyond the inclusion of a male- only sample, and all findings could have applied equally well to women. Similarly, a study

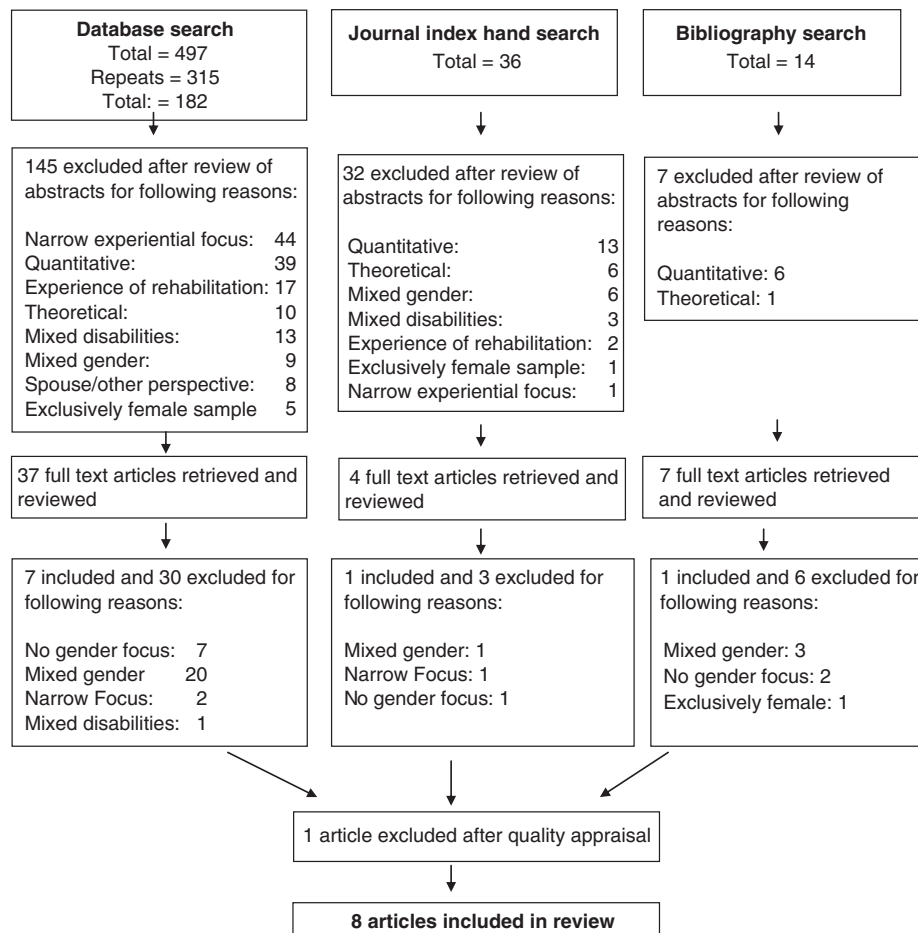


Figure 1 Literature search.

of fathers with SCI⁴⁰ was excluded as it lacked any emphasis on gender.

The procedure for evaluating qualitative research is not about judging strict adherence to rules or prescriptive criteria, but about weighing the appropriateness of various elements to the specific aims of the study.²⁹ Maximising the conceptual yield of papers is more important than determining the robustness of research design, and critical appraisals as used in quantitative syntheses may be inappropriate.³² A review of qualitative systematic reviews concluded that the variety of approaches to appraisal reflects ongoing disagreement about the characteristics of good qualitative research, 'but also on whether criteria for quality in qualitative research should exist at all'.³² Considerations of relevance to the review question and the illumination of subjective experience with supporting participant quotes therefore took precedence over a formal appraisal of quality or methodological rigour. However, a paper on sexuality⁴¹ was excluded on the basis that the authors presented an unexamined association between independence, masculinity and sexuality.

OUTCOME OF REVIEW

Eight papers, all seeking an insiders' perspective on the gendered experience of SCI, reporting on just four separate studies involving 32 participants (19–55 years), were reviewed. They were conducted in the UK, USA, Greece and Australia on men with paraplegia and tetraplegia (insufficient detail precluded determination of the exact proportion of each). Time since injury is not specified but spans at least a period of 6 months to 36 years. The review sought to identify themes and topics, which emerge when researchers explore, directly or indirectly, gendered masculinity. Relevant aspects of each paper are presented in Table 1.

RESULTS

Semi-structured interviews were the usual method of data collection, although the single-case study also included participant observation.⁴² Data analysis included narrative analysis,^{42–45} grounded theory^{46,47} and thematic analysis.^{48,49} Studies were carried out under the auspices of sports psychology, social work, anthropology and occupational therapy. A brief summary of each is followed by an integrative, thematic review of the impact of SCI on masculinity.

In a comprehensive study of 14 injured rugby players, gender provides a significant focus in three articles dealing with narrative identity dilemmas,⁴³ the use of common metaphors⁴⁵ and the construction of coherence following injury.⁴⁵ The embodied, masculine identities of these men, largely formed through athletic prowess, were fundamentally threatened by the experience of acquired disability. The desire to reclaim a restored self became a self-defeating quest for the majority, as reliance on dominant conceptions of masculinity acted to constrain the construction of new body-self relationships. The 'restitution narrative', characterising 11 of the 14 post injury stories, typified by metaphors of war, sporting battles, fights and comebacks expressed a strong, active desire to return to former valued lives. Such narratives are framed and constrained by social structures and available cultural narratives.

Sexual identity following SCI is explored in six Greek men, living in a culture, in which the authors argue, sexuality in relation to disability is a taboo subject and masculinity is strongly associated with physical action and the pursuit of sexual encounters.^{48,49} Prevailing societal attitudes about dominant masculinities and asexuality of those with impairments is considered to operate as external barriers to sexual expression for the disabled, while the focus on performative excellence

threatens masculine identity. The loss of social power, independence and traditional male traits is described as 'a metaphorical castration'.⁴⁹ Dominant societal values regarding masculinity, sexuality and disability created internalised oppression, and a submerging of male status by impairment and asexualisation.

In a study of men with VASCI, the experience of disability resulted in strong feelings of emasculation.^{46,47} SCI effected a schism in the lives of already impoverished men, further marginalised by disability and dependency. Participants spoke of the challenge to masculinity, and SCI manifested itself most explicitly in how participants perceived themselves as men. Constant comparisons between current and past lives were common, and participants experienced a lack of independence, inability to engage in traditional sexual relations, changes in body image and feelings of vulnerability. Male identity, and the contextual social understanding of man, defined by independence, sexual virility and the capacity and duty to defend self and loved ones, were violated by disability. Masculinity became a contested identity category and, unlike race or ethnicity, was continuously challenged by self and others.

A single-case study provided insight into a particular interweaving of masculinity, sexuality and immigration.⁴² As in the description of restitution narratives,⁴⁴ the dominant metaphor was one of the battle in the face of invalidated adulthood and masculine identity. Robert labels himself as 'a child of war',⁴² and his relentless struggle to reconcile his infantilised and feminised body with a culturally scripted masculinity is described. As a former athlete and activist who valued success in traditionally masculine cultural domains, Robert was determined to recover lost status, adulthood, identity and invalidated masculinity. The case study illustrates the importance of paying attention to the embodied individual within the injured body.

THEMATIC SYNTHESIS

Three dominant, themes emerged from this review; '*lost masculinity*', '*fighting back*' and '*beyond hegemony*'.

'Lost masculinity'

Taken together, these eight papers tell stories of lost, diminished and vulnerable masculinity resulting from SCI. Participants were all men considered to be living their lives according to 'macho', hypermasculine scripts based on elements of physical prowess, athletic display, gang membership and bodily performance, socialised in cultural contexts emphasising dominant forms of masculinity. What emerges from these articles is a strong sense that traditional forms of masculinity are challenged by SCI, which impacts dramatically on men's self-presentation, body image, sexuality and relationships. Identity dilemmas, evoked by a sense of lost masculinity and damaged sexual identities, emerge as the central and salient topic around, which other changes are situated.

The authors describe how masculine identity for participants is questioned by SCI,⁴⁵ made precarious,⁴⁸ invalidated,⁴² complicated, challenged and diminished,^{46,47} thus highlighting the insidious power and limitations of contemporary masculinity⁴³ and the poverty of culturally endorsed masculine scripts.⁴² The sense of loss is powerful and, possibly for most participants, resulted in a preoccupation with previous levels of functioning and a yearning for what was or what might have been.

Each paper contains strong statements detailing participant's attempts to grapple with personal definitions of masculinity. Language used by participants is dramatic, poignant and evocative of loss, transformation and radical restructuring of bodies, selves,

Table 1 Focus of interest, gender focus and link between masculinity and spinal cord injury

| Authors | Participants | Focus of paper | Gender focus | Summary of links made by authors between masculinity and spinal cord injury |
|---|--|--|--|---|
| Sparkes, A Smith, B ⁴³ | Four injured rugby players (from sample of 14 in Smith and Sparkes larger study) | Narrative identity dilemmas of injured sportsmen Connections between sport, bodies, embodiment, masculi- nities and disability | The constraints imposed on mens' narratives of identity by the combined forces of the public narrative of heroic masculinity and the metanarrative of restitution re-storying of self-restricted by specific forms of masculinity | For many men, SCI disrupts a previous masculine sense of self as dominant, assertive and aggressive SCI linked to 'lost masculinity' SCI may precipitate search for restored self and prior body/self relationships Strength of athletic identity may exacerbate difficulty of recon- structing self following SCI Association for some men between SCI and loss of masculinity contrasting approaches -clinging to or redefinition of hegemonic masculinity SCI questions hegemonic masculinity |
| Smith, B Sparkes, AC ⁴⁵ | Two injured rugby players (from sample of 14 in Smith and Sparkes larger study) | To illustrate narrative practice in action The construction of a sense of coherence in the telling of two contrasting narratives of disability following spinal cord injury | Disruption of body self unity and loss of certain types of masculinity continuities and discontinuities with former masculine selves creation of alternative masculine cultures and relin- quishing of hegemonic masculinity | Guiding metaphors of war and sport, fighting and comebacks characterise the narratives of many sporting men following SCI and reflect a common restitution narrative Seeking a restored body self may constrain new body/self relationships and restrict emotional stories for men |
| Smith, B Sparkes, A ⁴⁴ | 14 Injured rugby players Age: 26–51 | The most common guiding meta- phors used by disabled men in the telling of their life stories and the impact of these metaphors on body self relationships | The relationship between metaphors of war and sport dominating the restitution narratives of 11 men, and the common cultural narratives of heroic masculinities and a restorable body self The affinity between the restitution narrative and the disciplined, dominating, male athletic body, which restricts the assumption of new identities | Impairment can lead to invalidated notions of adulthood, masculinity and sexuality Working towards recovery of masculinity and performative masculinity evident in battle metaphors Narrative of restoration may be less about a denial of disability than assertion of masculinity |
| Rapala, S Manderson, L ⁴² | Case study of a Polish man living as political refugee in Australia | The reconstruction, reinvention and recovery of adulthood, mas- culinity and sexuality invalidated through SCI, disability and migration. | Illustration of the narrative performance of masculinity Management of multiple losses, using metaphors of war and ongoing battles, via narrative, sport, sexuality and performance of culturally scripted masculinity | Dependency compromises masculinity SCI can result in a redefinition of sexuality and masculinity Some men overcompensate via a 'macho facade' to deter challenge to their masculinity |
| Sakellariou, D Sawada, Y ⁴⁸ | Six Greek men 20–50 years | The Greek male experience of sexuality with a focus on cultural dimension | Patterns identified in the struggle to redefine and reclaim sexuality in a cultural milieu of patriarchal sexuality, dominant masculinity and asexuality of people with disabilities New forms of enjoyment explored, barriers to sexual expression identified and impact on personal sexual identity outlined | Internalised oppression can result from societal, cultural and personal barriers to the expression of male sexuality following SCI - men can be asexualised not asexual Disabled identity may submerge masculine identity (spread phenomenon) |
| Sakellariou, D ⁴⁹ | Six Greek men (as above) | Identification of barriers that compromise sexuality of Greek men with spinal injury | 'Challenging masculinity' identified as one of the four major themes. Focus more on masculine identity than on disabled identity in four key areas: intimate partners, sexual encounters, body image and self-defence Struggle to redefine masculine identity following viola- tion of social understandings of what it means to be a man in specific-environmental context and a subjective shift from domination to dependency | Masculinity is challenged and men may feel 'less of a man' post injury resulting in sense of burden on partner, physical vulner- ability, lost sexual spontaneity, embarrassment re body, defen- celessness Masculine identity is more salient than disabled identity in some key areas Loss of independence challenges notions of (hyper)-masculinity and gender identity Impact on masculinity focused on more than on any other aspect of injury (eg race/ethnicity) diminished masculinity emerges in several life domains including relationships, sexuality, body image, self-defence, feelings of safety some men work vigorously to demonstrate and assert manliness following injury |
| Ostrander, RN ⁴⁶ | 11 men with violently acquired injuries (VASC) 18–30 years | How men with violently acquired injuries reconstitute identity fol- lowing spinal injury | Specific-gender-related barriers: ordeal of conforming to male body beautiful imperative, disabling societal beliefs and attitudes about disability, sexuality and masculinity, metaphorical castration and emasculation, conflict between social script and personal will, inter- nalised oppression | Masculinity is challenged and men may feel 'less of a man' post injury resulting in sense of burden on partner, physical vulner- ability, lost sexual spontaneity, embarrassment re body, defen- celessness Masculine identity is more salient than disabled identity in some key areas Loss of independence challenges notions of (hyper)-masculinity and gender identity Impact on masculinity focused on more than on any other aspect of injury (eg race/ethnicity) diminished masculinity emerges in several life domains including relationships, sexuality, body image, self-defence, feelings of safety some men work vigorously to demonstrate and assert manliness following injury |
| Ostrander, RN ⁴⁷ | 11 men with violently acquired injuries (as above) | How various components of iden- tity coexist in a VASCI population The reconstruction of masculinity following injury | Impact of injury on masculinity major focus of concern in contrast to little impact on racial or ethnic identity. Masculinity is a contested identity that battles with disabled identity and needs to be forcefully expressed following injury. Injury seriously complicates masculine identity status, which is continuously questioned as a consequence of injury by others and by self Change in body image, inability to engage in traditional sexual relationships, increased sense of vulnerability and reduced social status and access to power | Masculinity is challenged and men may feel 'less of a man' post injury resulting in sense of burden on partner, physical vulner- ability, lost sexual spontaneity, embarrassment re body, defen- celessness Masculine identity is more salient than disabled identity in some key areas Loss of independence challenges notions of (hyper)-masculinity and gender identity Impact on masculinity focused on more than on any other aspect of injury (eg race/ethnicity) diminished masculinity emerges in several life domains including relationships, sexuality, body image, self-defence, feelings of safety some men work vigorously to demonstrate and assert manliness following injury |

Table 2 Participant quotes supporting each theme

| Theme 1: lost masculinity | Theme 2: fighting back | Theme 3: beyond hegemony |
|---|--|---|
| <p>'when you are able-bodied you don't really think about being a man, not properly'⁴³</p> <p>'I'm useless as a disabled man...my manhood has been shattered'⁴³</p> <p>'I'm half of man...I'm always gonna need help'⁴⁷</p> <p>'Your masculinity goes. It's ripped right out of you'⁴⁵</p> <p>feeling like a man almost evaporates'⁴³</p> <p>'in a way you have lost your masculinity....one of the biggest shocks that you have to face when you become disabled'⁴³</p> <p>'they remember me healthy, strong. And now a wreck of that man'⁴²</p> <p>'that kinda take a little piece of your manhood'⁴⁷</p> <p>'I started thinking about my sexuality from the first moments after my accident. I felt like being castrated, emasculated...'⁴⁸</p> <p>'an issue that bothers me, when I have to ask a girl to help me with taking off my pants, because manhood is directly associated with having sex, doing.'⁴⁹</p> <p>'the body beautiful image makes me feel bitter and resentful'⁴⁹</p> | <p>'I'm certainly not going to give in and be weak or touchy feely and all feminised by the whole thing...I've got balls and I'll fight this'⁴⁴</p> <p>'will do everything to return, I will give everything, you know, to make a step on my own legs'.⁴²</p> <p>'To this day I fought, I fight, and I will continue to fight'⁴²</p> <p>'I'm gonna fight as long as I can fight'⁴⁷</p> <p>'I do think that I'll make a comeback and walk again at some point in time. I won't stop fighting until I can do that....I could never give up or stop fighting 'cos that again would be like saying I am a failure and really a bit of a wimp, not a proper man'⁴⁴</p> <p>'I look at it all as something that will be fixed'⁴⁵</p> <p>'It's like sport, disability is an enemy that I must beat'⁴⁴</p> <p>'one long battle against the body until medicine finds a cure and I can walk again'⁴⁴</p> | <p>'I am the same, I am still John... the only thing is, my wings are now trimmed'⁴⁹</p> <p>'I want to challenge other people and draw attention on me and I really do make a point of getting everybody talking with me'⁴⁹</p> <p>'I've come to think of my body as part of me and I accept that it doesn't do things that it could in the past'⁴⁴</p> <p>'I've been reborn, and have become a better person since becoming disabled'⁴⁴</p> <p>'I had to get out of that masculine thing if I wanted to move on...I'm secure enough now to reject this masculine crap'⁴⁵</p> <p>'I've a new lease of life. I feel as if I have been reborn, starting all over again'⁴⁵</p> <p>'Its an opportunity to explore yourself and become a better person'⁴⁴</p> <p>'I was hiding behind masculinity beforehand'⁴⁵</p> <p>'The satisfaction I get now is of a different kind and it can sometimes be more intense than the one I had before'⁴⁸</p> |

relationships and lifeworlds. Relevant quotes supporting each theme are presented in Table 2.

For most participants, SCI led, temporarily or permanently, to feelings of vulnerability, erosion of status and emasculation. Concerns about body image, sexual prowess, impact on partners and sexual relationships expressed in statements like '*I really don't want no relationship because of the chair and the luggage I bring*'⁴⁷ and '*would you like to go to bed with me...and my personal assistant*'⁴⁸ were also reflective of lost masculinity.

'Fighting back'

The male use of military metaphors to capture the illness struggle is noted in two papers in this review.^{42,44} The sense of loss and the challenge to identity proves overwhelming for some men, and the pull of past bodyselves precipitates a submersion in regret and a frantic search for recovery, restitution and a returned hegemonic masculinity. This common response is expressed in the language of war and sport, battle^{42,44} and culturally scripted masculine prowess.

The double-edged role of a strong athletic identity is apparent in these studies. For the rugby players, SCI represented an end to a sporting career, whereas for Robert, a return to the 'testosterone-charged world of competitive sport'⁴² represented a reclamation of masculine identity. The fight to regain and reclaim masculinity largely emerges as a troubled endeavour, and, while many participants 'worked vigorously to show that they remained men'⁴⁷ it was often at the expense of integrating disability into a revised identity.

'Beyond hegemony'

This theme captures a sense of how men may negotiate the incompatibility between disability and masculine ideals. For participants in this review, possibilities beyond adherence to traditional masculine scripts were only glimpsed, but nevertheless emerged as viable for some. The focus on continuity in the midst of change, the appraisal of SCI as a challenge and grappling with the opportunity for change and transformation, provoked by a questioning of previous

identities, represent other possibilities. The quest narrative,⁴⁴ captures key elements of this process, including the need to 'move past the obsession with the body',⁴⁵ elicit meaning from the disability experience and reconstruct a differently valued self.

A rejection and redefinition of hegemonic masculine sexuality was identified for men able to appraise SCI as an opportunity to develop and become less self-focused.⁴⁸ Sexual performance for some was expanded and redefined through experimentation, improvisation and remapping of erogenous zones. The perceived burden on partners could be offset by improved intimacy and enhanced sexual responsiveness to their needs, leading to feelings for some participants of 'being more like a man' again.⁴⁷

The possibility of other versions of masculinity emerging was less likely in the VASCI group living in a social context, requiring the continuous expression of masculinity, thus increasing the challenge of living with disability, and militating against the integration of injury into new identities.^{46,47} Not surprisingly, a focus on defencelessness was specific to those with VASCI, but can perhaps be seen as an extreme and environmentally appropriate, expression of the vulnerability expressed by many, if not most, participants in this review.

DISCUSSION

This review provides evidence of a striking lack of focus on men as gendered beings within the available qualitative SCI literature. It also identifies a thematic consistency in that literature that supports classic papers^{50,51} on masculinity and SCI. The findings are consistent with the limited quantitative data that indicates that grappling with altered gendered identity is a feature of life after SCI, which warrants explicit consideration.^{5,14,22,52,53} It adds depth to an already existing body of knowledge, elucidating the impact of SCI on identity,^{43,54,55} and has implications for health-care professionals seeking to understand individual responses to SCI and to self-management of health during and following rehabilitation.

Although a range of potential effects of SCI on masculinity are identified in this review, it is constrained by a focus on a limited range of hypermasculinities, making it difficult to infer the meanings of lost masculinity for wider groups of men. The masculinity lost in these articles is of the hegemonic variety associated with dominance, assertiveness and aggressiveness. Participants were men who lived their lives according to 'macho', hypermasculine scripts, for whom the atrophy of the body posed a particular threat to identity. The impact of SCI on masculinity in this review is captured in three major themes; 'lost masculinity', outlining the powerful impact of SCI on identity and 'fighting back', describing a characteristic masculine response style and 'beyond hegemony', indicating possibilities beyond adherence to traditional conceptions of masculinity.

Gerschick and Miller⁵⁰ describe three dominant, interwoven frameworks that guide disabled men's relationships to hegemonic standards: reliance, involving continued attempts to meet traditional expectations; rejection, involving the creation of alternative masculine identities and reformulation, involving a redefinition of masculinity. This work has been criticised for being removed from the lived experience of interpersonal relationships.⁵⁶ However, themes identified in this review are consistent with Gerschick and Miller's formulation and provide support for some generalisation of current findings. 'Fighting back' is consistent with a reliance on dominant standards and 'Beyond hegemony' reflects rejection and recognition of limitations inherent in those standards. Reformulation, involving a redefinition of manhood along new lines is apparent in the use of rebirth metaphors and the appraisal of SCI as a vehicle for increased self-awareness.

Masculine identity is inescapably connected to sexual prowess.^{42,46,48,57,58} The redefinition of disabled masculine sexuality as less about sexual objectification and more about sexual intimacy, identified in this review has been previously described.⁵⁶ Review findings are consistent with conceptions of conflict between traditional masculinity and disability, and of acquired disability as a particular crisis for men whose identity construction is based on physicality, invulnerability and the ability to carry out conventional gender roles.^{52,58-60} While there may be several masculinities, it is likely that, among the many comparisons of self that men make as a result of injury, the one with hegemonic masculinity plays its part. The collision between masculinity and disability may then create an erosion of masculine status.⁷

Despite compelling evidence that disability strongly impacts gendered experience,^{7,61,62} that illness and disability affect men and women differently,⁶³ that gender has a key role in patterns of health and illness^{10,64} and is related to health beliefs and behaviours,⁶⁵⁻⁶⁷ the gendered experience of men with SCI is strikingly absent from academic papers. This despite, or even perhaps because, of the dominant male focus within the SCI literature. The lack of information is surprising, given the focus of qualitative literature on lived experience, the obvious impact of SCI on bodily functioning and body image and the theorised and experiential links between the body and masculinity.^{43,59,68-70} The body and bodily performance, made vulnerable by injury, is a basic constituent of being a man and the need to pay scrupulous attention to 'a leaky, unreliable and often troublesome' body,⁵⁷ 'feminised and infantilised' by injury,⁴² and experienced as a battleground,⁴⁴ is a daunting task.

The absence of gender focus may be attributed to the assumption of asexuality or infantilism linked to disability,^{21,58,71,72} the gender neutrality of health care,^{6,72,73} unexamined assumptions of the non-disabled community,^{74,75} the predominance of gender similarities over differences,^{76,77} the salience of disability over gender⁷⁸ or the tendency to see disability as the dominant identity marker.^{21,79-81}

SCI has multiple ramifications for personal, social, professional and domestic responsibilities and, while gender is not the only, and not even necessarily the most important, social identity, it is 'the most pervasive, visible and codified'.⁸² We cannot 'not do gender' as it is a fundamental part of identity formed in interaction with others.⁸³ As a concept, gender seems to go in and out of fashion and benefit from periodic revisitation.⁸⁴ Conceptualisations of both gender and masculinity are problematic,^{11,68,85} although clarification of the complexities involved is beyond the scope of this paper. It is clear that a nuanced understanding of the meaning of gender beyond sex roles or gender inequities, and of masculinities beyond a single hegemonic variety is required.^{11,68} It is also necessary to take the implications of intersectionality, or gender as only one of many categories of identity, into account.^{82,86,87}

The multiplicity of links between gender and health is increasingly being recognised and health behaviours seen as ways of doing gender.^{10,65,88-90} Given the prevalence of secondary complications⁹¹ and higher rates of contact with health-care services following SCI,⁹² all influences on health behaviours, including gender, warrant consideration. Ways of doing rehabilitation, like ways of doing health, are ways of doing gender.⁷⁰ Although there is much discussion of the potentially negative impact of masculine socialisation, some aspects of traditional masculinities have been linked to good outcomes.^{14,52,53} Rehabilitation may be a crucial time for men as illness can provoke an altered relationship with the self.^{69,70} Although men may have less self/body awareness than women in times of health, many are keen to maintain and become experts in times of ill-health.⁷⁰ Essential bodily monitoring and maintenance may therefore function to signify masculinity rather than loss of masculinity.

Rehabilitation professionals have a key role to play in providing gender-aware care and interventions.⁶⁰ However, the detached clinical gaze may ignore or minimise the impact of SCI on the embodied, gendered self.⁹³ In a review of the rehabilitation experience, the calibre and vision of the staff and the capacity to convey a sense of being valued as a human being has been identified as the most important dimension of the rehabilitation experience.³⁰ Being a human being necessarily entails being a gendered human being. It is crucial that professionals value long established gender identities for those grappling with newly damaged bodies. Gender, already rendered vulnerable, cannot be erased by the visibility of disability, and instead must be affirmed to bolster a sense of continuity at a time of considerable change. Although identity dilemmas may constitute the central issue for those rebuilding lives after injury,^{43,54,55,93} alterations in self-identity and a focus on body esteem do not fit easily with demands for achievable, time constrained goals and the pursuit of measurable rehabilitation outcomes. As men's adjustment to SCI is increasingly understood to be mediated by conceptions of masculinity,^{14,52,53} it is important to seek a deeper understanding of how multiple masculinities are lived out and how versions other than constraining, conventional ones may be promoted and fostered.

The notion of gender as something to be reconsidered and reconfigured following injury may be helpful in understanding some of the puzzling behaviours evident during, and following, rehabilitation for example, self-neglect as an indicator of failed hegemonic masculinity or macho bravado as a factor in apparently unconcerned or challenging behaviour. A compulsion to overcompensate, cover and minimise impairments and a refusal to reveal emotion may be a response to feelings of emasculation. Efforts to retain a masculine self may be implicated in apparent non-compliance during rehabilitation programmes or in neglect of critical self-care following discharge.

Bodily anxieties may be masked to preserve masculine identities ruptured by SCI and professionals need to be alert to the tendency for some men to create a defensive space within which to nurse wounded masculinity, or mask a terror of disablement. Men may become marginalised within the gender order as a result of injury, and may require additional supports to define masculinity in non-traditional terms.

A variety of rehabilitation interventions ranging from peer support and mentoring programmes to the exploration of individual narratives of masculinity, injury and health may offer men alternative images of masculinity. Group work and self-management programmes can provide an opportunity to reinforce the positive characteristics associated with traditional masculinity, as well as deliver strong peer and professional messages about less traditional masculine scripts. A strong preference for stories of heroic masculinity can, however, limit the telling of other stories and restrict the emergence of alternative versions of masculinity,⁴⁵ while an overemphasis on physicality may lead to the neglect of other forms of self-expression or identity development.^{51,57} Recently identified, innovative health promotion possibilities for men with SCI,⁹⁴ offer additional possibilities for the expansion of resilient masculinities.

LIMITATIONS

This review is limited by being arbitrarily restricted to papers published before 2011 and in peer reviewed journals, although many significant works appear in book, chapter or dissertation format. This absence of grey literature means the exclusion of a rich body of work on the personal autobiographical experience of SCI, as well as that contained in unpublished work. Additional work, including a recent qualitative study of health narratives, which contributes to a richer understanding of masculinity and SCI⁹⁴ is excluded from this review. Finally, without a companion study of women, the themes identified in this study cannot be exclusively attributed to men.

CONCLUSION

This review of 20 years of qualitative literature suggests a surprising lack of focus on men as gendered beings. Masculine identity emerges in this review as vulnerable to the impact of acquired disability and, given the strong links between masculinity, rehabilitation and health, as an aspect of SCI that warrants more attention than it has received.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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- 1 Quigley MC. Impact of spinal cord injury on the life roles of women. *Am J Occup Ther* 1995; **49**, 780–786.
- 2 Isaksson G, Skar L, Lexell J. Women's perception of changes in the social network after a spinal cord injury. *Disabil Rehabil* 2005; **27**, 1013–1021.
- 3 Chau L, Hegedus L, Praamsma M, Smith K, Tsukada M, Yoshida K *et al*. Women living with a spinal cord injury: perceptions about their changed bodies. *Qual Health Res* 2008; **18**, 209–221.
- 4 Robertson S. Men and Disability. In: Swain J, French S, Barnes C and Thomas C (eds) *Disabling Barriers, Enabling Environments*, 2nd edn. Sage Publications: London, 2004, pp 75–80.

- 5 Sheldon AP, Renwick R, Yoshida KK. Exploring body image and self-concept of men with acquired spinal cord injuries. *Am J Mens Health* 2011; **5**, 306–317.
- 6 Thorne S, McCormick J, Carty E. Deconstructing the gender neutrality of chronic illness and disability. *Health Care Women Int* 1997; **18**, 1–16.
- 7 Gerschick TJ. Toward a theory of disability and gender. *Signs* 2000; **25**, 1263–1268.
- 8 Turshen M. Gender and Health. *J Public Health Policy* 2007; **28**, 319–321.
- 9 Sabo DF, Gordon DFE. Men's health and illness. *Gender, Power, and the Body*. Sage Publications: Thousand Oaks, US, 1995.
- 10 Cameron E, Bernardes J. Gender and disadvantage in health: men's health for a change. *Social Health Illn* 1998; **20**, 673–693.
- 11 Connell RW, Messerschmidt JW. Hegemonic masculinity. *GenD Soc* 2005; **19**, 829–859.
- 12 Connell RW. Change among the gatekeepers: men, masculinities, and gender equality in the global arena. *Signs* 2005; **30**, 1801–1825.
- 13 Shakespeare T, Gillespie-Sells K, Davies D. *The sexual politics of disability: Untold desires*. Burns & Oates: London, 1996.
- 14 Schopp LH, Good GE, Mazurek MO, Barker KB, Stucky RC. Masculine role variables and outcomes among men with spinal cord injury. *Disabil Rehabil* 2007; **29**, 625–633.
- 15 Varanka JJ. Mainstreaming men into gender sensitive health policies. *J Mens health* 2008; **5**, 189–191.
- 16 Richardson N, Carroll PC. Getting men's health onto a policy agenda-charting the development of a National Men's Health Policy in Ireland. *J Mens health* 2009; **6**, 105–113.
- 17 Scherer MJ, Dicowden MA. Organizing future research and intervention efforts on the impact and effects of gender differences on disability and rehabilitation: the usefulness of the International Classification of Functioning, Disability and Health (ICF). *Disabil Rehabil* 2008; **30**, 161–165.
- 18 Niemeier JP. Unique aspects of women's emotional responses to disability. *Disabil Rehabil* 2008; **30**, 166–173.
- 19 World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. World Health Organization: Geneva, Switzerland, 2001.
- 20 Imrie R. Demystifying disability: a review of the International Classification of Functioning, Disability and Health. *Social Health Illn* 2004; **26**, 287–305.
- 21 Lutz BJ, Bowers BJ. Disability in everyday life. *Qual Health Res* 2005; **15**, 1037–1054.
- 22 Krause JS, Broderick LE, Broyles J. Subjective well-being among African-Americans with spinal cord injury: an exploratory study between men and women. *NeuroRehabilitation* 2004; **19**, 81–90.
- 23 Wyndaele M, Wyndaele JJ. Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey? *Spinal Cord* 2006; **44**, 523–529.
- 24 Emslie C, Hunt K. Men, masculinities and heart disease. *Curr Sociol* 2009; **57**, 155–191.
- 25 Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998; **8**, 341–351.
- 26 Yardley L. Dilemmas in qualitative health research. *Psychol Health* 2000; **15**, 215–228.
- 27 Sandelowski M. Using qualitative research. *Qual Health Res* 2004; **14**, 1366–1386.
- 28 Duggan CH, Dijkers M. Quality of life after spinal cord injury: a qualitative study. *Rehabil Psychol* 2001; **46**, 3–27.
- 29 Hammell KW. Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord* 2007; **45**, 124–139.
- 30 Hammell KW. Experience of rehabilitation following spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord* 2007; **45**, 260–274.
- 31 Finfgeld DL. Metasynthesis: the state of the art—so far. *Qual Health Res* 2003; **13**, 893–904.
- 32 Dixon-Woods M, Booth A, Sutton AJ. Synthesizing qualitative research: a review of published reports. *Qual Res* 2007; **7**, 375–422.
- 33 Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J* 2009; **26**, 91–108.
- 34 Dixon-Woods M, Fitzpatrick R, Roberts K. Including qualitative research in systematic reviews: opportunities and problems. *J Eval Clin Pract* 2001; **7**, 125–133.
- 35 Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy* 2005; **10**, 45–53B.
- 36 Hughes N, Closs SJ, Clark D. Experiencing cancer in old age: a qualitative systematic review. *Qual Health Res* 2009; **19**, 1139–1153.
- 37 Flemming K, Briggs M. Electronic searching to locate qualitative research: evaluation of three strategies. *J Adv Nurs* 2007; **57**, 95–100.
- 38 Bastanfar RB, Crewe N. A qualitative study of the dating behaviours of men with spinal cord injury. *SCI Psychosoc Proc* 2005; **18**, 76–82.
- 39 Hernandez B. A voice in the chorus: perspectives of young men of color on their disabilities, identities, and peer-mentors. *Disabil Soc* 2005; **20**, 117–133.
- 40 Duvdevany I, Buchbinder E, Yaacov I. Accepting disability: the parenting experience of fathers with spinal cord injury (SCI). *Qual Health Res* 2008; **18**, 1021–1033.
- 41 Basson P, Walter S, Stuart A. A phenomenological study into the experience of their sexuality by males with spinal cord injury. *Health SA Gesondheid* 2003; **8**, 3–11.
- 42 Rapala S, Manderson L. Recovering in-validated adulthood, masculinity and sexuality. *Sex Disabil* 2005; **23**, 161–180.
- 43 Sparkes AC, Smith B. Sport, spinal cord injury, embodied masculinities, and the dilemmas of narrative identity. *Men Masc* 2002; **4**, 258–285.

- 44 Smith B, Sparkes A. Men, sport, and spinal cord injury: an analysis of metaphors and narrative types. *Disabil Soc* 2004; **19**, 613–626.
- 45 Smith B, Sparkes AC. Men, sport, spinal cord injury and the construction of coherence: narrative practice in action. *Qual Res* 2002; **2**, 143–171.
- 46 Ostrander RN. Meditations on a Bullet: violently injured young men discuss masculinity, disability and blame. *Child Adolesc Social Work J* 2008; **25**, 71–84.
- 47 Ostrander RN. When identities collide: masculinity, disability and race. *Disabil Soc* 2008; **23**, 585–597.
- 48 Sakellariou D, Sawada Y. Sexuality after spinal cord injury: the Greek male's perspective. *Am J Occup Ther* 2006; **60**, 311–319.
- 49 Sakellariou D. If not the disability, then what? barriers to reclaiming sexuality following spinal cord injury. *Sex Disabil* 2006; **24**, 101–111.
- 50 Gerschick TJ, Miller AS. Coming to terms: masculinity and physical disability. In: Sabo DF and Gordon DFE (eds). *Men's Health and Illness: Gender, Power, and the Body*. SAGE Publications: Thousand Oaks, California, USA, 1995.
- 51 Hutchinson SL, Kleiber DA. Heroic masculinity following spinal cord injury: implications for therapeutic recreation practice and research. *Ther Recreation J* 2000; **34**, 42–54.
- 52 Good GE, Schopp LH, Thomson D, Hathaway S, Sanford-Martens T, Mazurek MO *et al*. Masculine roles and rehabilitation outcomes among men recovering from serious injuries. *Psychol Men Masc* 2006; **7**, 165–176.
- 53 Burns SM, Hough S, Boyd BL, Hill J. Men's adjustment to spinal cord injury: the unique contributions of conformity to masculine gender norms. *Am J Mens Health* 2010; **4**, 157–166.
- 54 Yoshida KK. Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociol Health Illn* 2008; **15**, 217–245.
- 55 Carpenter C. The experience of spinal cord injury: the individual's perspective—implications for rehabilitation practice. *Phys Ther* 1994; **74**, 614–628.
- 56 Shuttleworth R. Disabled masculinity: expanding the masculine repertoire. In Smith BG and Hutchison B (eds). *Gendering Disability*. Rutgers University Press: New Brunswick, NJ, USA, 2004.
- 57 Seymour W. *Remaking the Body: Rehabilitation and Change*. Routledge: London, UK, 1998.
- 58 Shakespeare T. The sexual politics of disabled masculinity. *Sex Disabil* 1999; **17**, 53–64.
- 59 Murphy RF. *The Body Silent. A Journey Into Paralysis*. Norton: New York, USA, 1990.
- 60 Good GE, Schopp LH, Thomson D, Hathaway S, Mazurek MO, Sanford-Martens T. Men with serious injuries: relations among masculinity, age, and alcohol use. *Rehabil Psychol* 2008; **53**, 39–45.
- 61 Shakespeare T. Cultural representation of disabled people: dustbins for disavowal? *Disabil Soc* 1994; **9**, 283–299.
- 62 Cheng RP. Sociological theories of disability, gender, and sexuality: a review of the literature. *J Hum Behav Soc Environ* 2009; **19**, 112–122.
- 63 Charmaz K. Stories and silence: disclosures and self in chronic illness. In Brashers E and Goldsmith D (eds). *Communicating to Manage Health and Illness*. Taylor and Francis Routledge: New York, 2009.
- 64 Charmaz K. Identity dilemmas of chronically ill men. *Sociol Q* 1994; **35**, 269–288.
- 65 Courtenay WH. Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Soc Sc Med* 2000; **50**, 1385–1401.
- 66 de Visser R, Smith JA. Mister In-between. *J Health Psychol* 2006; **11**, 685–695.
- 67 Charles N, Walters V. 'Men are leavers alone and women are worriers': gender differences in discourses of health. *Health, R Soc* 2008; **10**, 117–132.
- 68 Connell RW. *Masculinities*. Polity Press: London, UK, 1995.
- 69 Seidler VJ. Masculinities, bodies, and emotional life. *Men and masculinities* 2007; **10**, 9–21.
- 70 Robertson S, Sheikh K, Moore A. Embodied masculinities in the context of cardiac rehabilitation. *Sociol Health Illn* 2010; **32**, 695–710.
- 71 Esmail S, Darry K, Walter A, Knupp H. Attitudes and perceptions towards disability and sexuality. *Disabil Rehabil* 2010; **32**, 1148–1155.
- 72 Miers M. Developing an understanding of gender sensitive care: exploring concepts and knowledge. *J Adv Nurs* 2002; **40**, 69–77.
- 73 Krieger N. Genders, sexes, and health: what are the connections—and why does it matter? *Int J Epidemiol* 2003; **32**, 652–657.
- 74 Reeve D. Negotiating psycho-emotional dimensions of disability and their influence on identity constructions. *Disabil Soc* 2002; **17**, 493–508.
- 75 Hughes B. Being disabled: towards a critical ontology for disability studies. *Disabil Soc* 2007; **22**, 673–684.
- 76 Shackelford M, Farley T, Vines CL. A comparison of women and men with spinal cord injury. *Spinal Cord* 1998; **36**, 337–339.
- 77 Hyde JS. The gender similarities hypothesis. *Am Psychol* 2005; **60**, 581–592.
- 78 Rohmer O, Louvet E. Describing persons with disability: salience of disability, gender, and ethnicity. *Rehabil Psychol* 2009; **54**, 76.
- 79 Watson N. Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability. *Disabil Soc* 2002; **17**, 509–527.
- 80 Galvin RD. Researching the disabled identity: contextualising the identity transformations which accompany the onset of impairment. *Sociol Health Illn* 2005; **27**, 393–413.
- 81 Deal M. Aversive disablism: subtle prejudice toward disabled people. *Disabil Soc* 2007; **22**, 93–107.
- 82 Shields SA. Gender: an intersectionality perspective. *Sex Roles* 2008; **59**, 301–311.
- 83 West C, Zimmerman DH. Doing gender. *GenD Soc* 1987; **1**, 125–151.
- 84 Macintyre S, Hunt K, Sweeting H. Gender differences in health: are things really as simple as they seem? *Soc Sci Med* 1996; **42**, 617–624.
- 85 Annandale E, Hunt K. Masculinity, femininity and sex: an exploration of their relative contribution to explaining gender differences in health. *Sociol Health Illn* 1990; **12**, 24–46.
- 86 Cole ER. Intersectionality and research in psychology. *Am Psychol* 2009; **64**, 170.
- 87 Hankivsky O. Women's health, men's health, and gender and health: implications of intersectionality. *Soc Sci Med* 2012; **74**, 1712–1720.
- 88 Robertson S. 'I've been like a coiled spring this last week': embodied masculinity and health. *Sociol Health Illn* 2006; **28**, 433–456.
- 89 White A. How men respond to illness. *Mens Health J* 2001; **1**, 18–19.
- 90 Lohan M. How might we understand men's health better? Integrating explanations from critical studies on men and inequalities in health. *Soc Sci Med* 2007; **65**, 493–504.
- 91 Guilcher S, Craven BC, Lemieux-Charles L, Casciaro T, McCol MA, Jaglal SB. Secondary health conditions and spinal cord injury: an uphill battle in the journey of care. *Disabil Rehabil* 2012; 1–13.
- 92 Dryden D, Saunders L, Rowe B, May LA, Yiannakoulas N, Svenson LW *et al*. Utilization of health services following spinal cord injury: a 6-year follow-up study. *Spinal Cord* 2004; **42**, 513–525.
- 93 Nolan M. The experience of living with spinal cord injury in the early months following discharge from rehabilitation: a qualitative study on a male sample. Doctoral thesis. Department of Health and Human Sciences, Essex University of Essex, 2011.
- 94 Smith B. Disability, sport and men's narratives of health: a qualitative study. *Health Psycho* 2013; **32**, 110–119.