

## Original Article

# Spinal cord injury rehabilitation: the experience of women

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**Study Design:** Qualitative study.

**Objectives:** To develop the knowledge base regarding women's experiences of spinal cord injury (SCI) rehabilitation.

**Setting:** United Kingdom.

**Methods:** Qualitative interviews with 10 women from four regional SCI rehabilitation centres were transcribed verbatim and analysed according to grounded theory.

**Results:** The central psychosocial problem identified for women during SCI rehabilitation was vulnerability. Vulnerability was amplified by lack of privacy within the rehabilitation centre, by negative staff interactions (associated with perceived lack of control and lack of respect) and by women's minority status in the rehabilitation setting, which at times left women feeling marginalized and inferior. Vulnerability was contained by: negotiating privacy and space; receiving support and encouragement from staff, other patients and family; and by adopting a positive attitude.

**Conclusion:** The SCI rehabilitation environment and interactions within it have the potential to influence significantly, either positively or negatively, women's feelings and behaviours as they begin to negotiate a revised identity as a disabled person. There is a need for further research to be carried out in this area in order that women's needs and concerns can be better understood and clinical practice developed accordingly.

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**Keywords:** spinal cord injury; women; gender; rehabilitation; disability

## Introduction

Spinal cord injury (SCI), a medically traumatic and psychologically devastating event<sup>1,2</sup> with profound and long-lasting consequences,<sup>3</sup> can happen to anyone at anytime.<sup>1</sup> However, spinal injury does not affect men and women equally; approximately 80% of people who sustain SCI are men.<sup>4</sup> This is because men more commonly participate in high-risk sports and physical occupations.<sup>5</sup>

Reflecting injury prevalence rates, women will therefore undergo the long duration of rehabilitation in specialist spinal injury rehabilitation centres among a predominately male patient population. Several authors have suggested that the minority status of female patients may negatively influence their rehabilitative experience with services being skewed to the needs of the male client.<sup>6,7</sup> However, understanding of women's experiences of SCI rehabilitation is limited due to a

paucity of relevant literature. SCI research relating to rehabilitation has primarily focused on quantitative outcomes rather than subjective experiences. The principal sources of information about subjective experience have been biographical or personal testimonial accounts,<sup>1,6,8</sup> which are limited in that such descriptive accounts tend to include minimal information about data collection or editing techniques. Moreover, such sources draw on retrospective reports that refer to experiences several decades ago and therefore describe services which may have evolved considerably. The minimal available qualitative research in the area includes only incidental reference to rehabilitation or focuses primarily on male patients accounts.

Within the available literature, women have reported that during their time in SCI centres, the emphasis and approach of rehabilitation was tailored towards male patients; this caused feelings of frustration, isolation, awkwardness, distress and a sense of being misunderstood.<sup>1,6,8,9</sup> Women have also indicated that their emotional needs were inadequately supported during

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rehabilitation.<sup>1,6,10</sup> Pentland *et al*<sup>9</sup> (p 19) for example, noted how women interviewed for a study on ageing and SCI, ‘spoke with much bitterness about the neglect of their ... emotional adjustment needs during rehabilitation’. Moreover, women have described a frustration with an overemphasis on sport, competition and physical outcomes during rehabilitation.<sup>1,6</sup> A frustration with available informational resources, perceived to be targeted towards men,<sup>11</sup> and thus inadequate as sources of advice and guidance,<sup>1,9</sup> has also been noted by women with SCI.

Relative to other aspects of rehabilitation, women’s experiences of sexual education during rehabilitation have been relatively well covered in the literature. The unequivocal message from research in the area has been a dissatisfaction among women with the quality, quantity and focus of sexuality information and counselling following SCI (see Forsythe and Horsewell,<sup>12</sup> for a review).

In summary, available literature suggests that there is incongruence between women’s concerns and needs and actual service provision during SCI rehabilitation. However, our understanding of women’s experiences currently relies on literature which is outdated, piecemeal and incidental. In 1995, Hammell<sup>13</sup> highlighted an ‘urgent need for thorough research into ... women with spinal cord injuries ... perspective[s] concerning the relevance of current rehabilitation programmes’ (p 273). However, 10 years since this recommendation, there have been no published studies in this area. The first author aimed to address this gap in the literature by conducting a qualitative study of women’s experiences of SCI rehabilitation.

## Materials and methods

Multi-centre research ethics approval and local research and development approval was obtained before commencing data collection.

### Methodology

A qualitative approach involving in-depth interviews was used to enable complex feelings and interpretations to be explored in detail.

### Participants

Ten participants were recruited from four NHS specialist spinal rehabilitation centres in the United Kingdom. All female patients were invited to participate provided they had been in rehabilitation for at least 2 months and were considered able to take part in an in-depth interview by their treating consultant. The sample is described in Table 1.

### Data collection

Research interviews took place in a quiet, private room at each spinal unit. Interview duration ranged from 30 to 90 min. One participant, for whom English was not

**Table 1** Description of participants

<i>Age (years)</i>	
Mean	50
Range	18–72
<i>Ethnic origin</i>	
White British	8
Other	2
<i>Injury aetiology</i>	
Fall	3
RTA	3
Medical condition	2
Surgical	1
Suicide attempt	1
<i>Duration in rehabilitation centre (months)</i>	
Mean	5
Range	3–7
<i>Lesion level</i>	
Cervical	5
Thoracic	4
Lumbar	1
<i>Female patients bed allocation in rehab centres<sup>a</sup></i>	
Range (%)	0–32

Abbreviation: RTA, road traffic accident

<sup>a</sup>Range based on beds specifically allocated to female patients out of total number of beds in the four centres from which participants were recruited

her first language, was interviewed via an interpreter. Interviews were recorded using a digital voice recorder and later transcribed verbatim. Interview questions were guided (but not dictated by) a semi-structured interview protocol.

Ambiguities in the collected data and hypotheses from the emerging theory were clarified by using increasingly focused and detailed questioning in subsequent interviews (theoretical sampling).<sup>14</sup> In addition, the theory was ‘tested’ by deliberately seeking variation among newly sampled participants (for example in age and injury level). No further data were collected at the point at which very few new concepts were being identified and it was assumed that the data were as close to theoretical saturation as possible.

### Analysis

Data were analysed according to Grounded theory,<sup>15</sup> a rigorous qualitative analysis approach which aims to create a theory firmly grounded in the gathered data, rather than reflecting predetermined hypotheses.

In accordance with grounded theory methodology, each transcript was analysed before progressing to the subsequent interview. Initial analysis on each transcript involved systematically coding every line of data in turn, defining central actions or events. Consistent with the ‘constant comparison’ method of grounded theory,<sup>15</sup>

data were then condensed by comparing categories at an intra- and inter-transcript level. Codes referring to common themes were subsumed under higher level, abstract categories. All relevant quotations for each category were collated into a new document to enable verification of internal consistency. The iterative process of continued data collection and meticulous further analysis led to an increasing refinement of categories and eventual identification of a central phenomenon linking all categories. The condensing process was facilitated by the visual conceptualization and manipulation of concepts via the software package Mindjet MindManager<sup>®</sup>.

A number of steps were taken to optimize the rigour of findings in line with grounded theory guidelines for good practice (see Chiovitti and Prian, 2003<sup>16</sup>) including careful recording of all analysis decisions, keeping a reflective diary, staying close to the data by maintaining participants' verbatim quotations throughout all stages of analysis and having a colleague verify the integrity of analysis decisions by following a 'paper trail' from the raw data to the final interpretation.

## Results

The central theme of vulnerability (feeling insecure, powerless and inferior) was identified as the primary psychosocial problem for women during SCI rehabilitation.

Two superordinate categories were identified which link to the core theme of vulnerability:

1. *Amplification of vulnerability*, which describes contextual and interactional factors that magnified vulnerability;
2. *Containment of vulnerability*, which encompasses conditions and strategies that helped participants to minimize vulnerability.

The subcategories subsumed by these categories will be described in turn below.

### *Vulnerability*

The pervasive physical changes and profoundly disrupted life trajectory incurred by the SCI created a background of emotional vulnerability and sensitivity, which mediated reactions within rehabilitation.

... and you're vulnerable anyway you know your emotions are very vulnerable now

... having a spinal injury is not that easy to [pause] your mind is really working away with you, it's not on your side you can get very angry very quickly

Conversely, vulnerability was at times amplified by certain aspects of the rehabilitative environment and interactions within it, as well as by women's minority status.

### *Amplification of vulnerability*

*Rehabilitation environment and staff interactions* Participants perceived that control was taken away from them over and above that necessitated by their position as patients. A source of particular frustration for participants was when staff altered the conditions of the immediate surroundings, for example, switching lights on-off or opening curtains, without consulting them. References to being treated disrespectfully by staff were also made, for example nurses being overtly impatient, rough, critical, patronizing or withholding help.

Well if they're rough handling ... it could just be the words you know, 'love' or 'come along darling' ... or people who, say they're teaching you something, and they say, 'well we've told you that already' and then 'tut, tut, have to do it again'

The perceived unavailability, poor communication and autocratic manner of doctors seemed to exacerbate feelings of insecurity by leaving participants feeling uninformed and uninvolved in decisions regarding their medical care. Participants also felt that staff held lower expectations of female patients' capabilities compared to male patients. Not being 'pushed' or being treated 'gently' seemed to frustrate and discourage participants, perpetuating hesitancy and lack of confidence.

Older participants described feeling invalidated by implicit or verbalized staff assumptions about SCI being less distressing, and therefore more acceptable, for older patients.

... there is also an assumption that I should accept it cos I have had 50 odd years without it, well, I can't you know ... it has totally affected my life

In addition, older participants, as well as those with tetraplegia, described a poor fit between the rehabilitation focus and personal interests, which left them feeling excluded.

Violations of privacy within the rehabilitation centre emerged as a universal source of concern for participants. The presence of a constant audience to intense and, at times, overwhelming feelings evoked profound discomfort. The only available form of visual screening consisted of pulling the curtain around the bed; a physical barrier of thin protection and one providing no impediment to the transmission of private discussions or sounds of personal bodily care.

The only thing that's between you and the rest of the world is a curtain, well that's not enough - ... everybody on the ward knows what's going on ... you don't want that, you want your own personal space you know

Moreover, the privacy afforded by the curtain was undermined by the intrusion, often without warning, of other people, including nurses, male patients, cleaners and visitors into participants' bed area.

Privacy from male patients was a specific concern. Although participants were generally located in separate

female bays, actual privacy from male patients was often minimal due to open entrances to the bay and female bays being thoroughfares to other parts of the centre. Mixed sex bathrooms caused considerable distress for participants. At a time of physical fragility, loss of dignity and bodily unfamiliarity, carrying out personal care, while aware of the presence of men, seemed to magnify feelings of discomfort, indignity and vulnerability.

The way it is is horrible ... there is no showers for ladies ... no toilets for the ladies ... you just have to share a shower, there's a man in the next one, there's nothing you can do about that, that is not nice, that is one thing I did not find comfortable at all

In addition to perceiving that environmental conditions did not address their needs, women also noted that rehabilitative education at times overlooked female concerns. Participants were almost unanimous in perceiving that the impact of SCI on their sexuality was inadequately addressed. Participants were frustrated when concerns about sensation and orgasm were dismissed with reassurance of intact fertility, implicitly denying them of a sexual identity beyond reproduction.

... so I went to see her [nurse] and wanting to ask really about sexual function and you know can I have an orgasm, can I have sex, what do you do, she was just telling me all about fertility, I just thought I'm not interested ....

*Minority status* Several participants disclaimed the relevance of gender by emphasizing age and injury level as more influential variables or by citing the individualized goal-planning process as leading to tailored rehabilitation goals. However, analysis of the data indicated that the minority status of women and gendered comparisons significantly, if at times subtly, mediated experiences, leaving women sometimes feeling overlooked, inferior or different.

Most participants were aware of the numerical predominance of male patients and their minority status as female patients. Participants also alluded to an intangible 'laddish' atmosphere pervading rehabilitation. The salience of men seemed to be magnified by their ability to command space (as a result of enhanced wheelchair mobility) as well as their vocal dominance. In a context of severely restricted mobility, the perceived superiority of male patients in effectively summoning assistance was felt to effect rehabilitative care received: 'it's who shouts loudest gets'.

Participants described male patients' behaviours within rehabilitation as being both contrasting to, and superior to, female ways of coping. Male patients were described as physically stronger, more focused, determined and resilient. Male patients were also seen as less emotionally sensitive than female patients, whose

emotional expression and vulnerability were seen as unhelpful and inappropriate. In describing how best to cope in rehabilitation, it was commented

Be strong, not let things upset you which is something I'm not good at, I'm easily hurt and upset and if you're a tough person you don't let that happen

Participants felt that male patients' more positive and outgoing nature resulted in more involved, animated and dynamic interactions with staff than those between female patients and staff.

... the staff and the male patients have a more, not boisterous, that's not the word, um [pause], there's more to-ing and fro-ing and more joking between the men and what not, but with the women, they're rather more circumspect ....

Some participants felt that staff preferred working with male patients. A flirtatious dynamic between male patients and female staff was also described by several participants.

In addition to feeling overlooked and inferior as a result of their minority status, participants also felt that they faced additional challenges to those encountered by male patients during rehabilitation. First, women identified certain rehabilitative tasks, notably mobility and catheterization, as more challenging due to anatomical differences. Second, participants with young children commented that being a mother made rehabilitation additionally difficult. Mothers noted that while 'other' patients could prioritize self needs, they were continually preoccupied by concerns about their children's welfare. There was also a tension between wanting to 'get out' and return to their children and making optimum rehabilitative progress.

... at the end of the day they're all waiting, 'when is Mummy going to come home', 'what is she doing' ... it did make me think I really want to go, but then something else, I'm not ready to go ....

#### *Containment of vulnerability*

Three main strategies or conditions were identified that minimized vulnerability and increased feelings of security and self-worth: (1) negotiating privacy, (2) feeling reassured and encouraged and (3) maintaining a positive attitude.

*Negotiating privacy* Participants described creating privacy through screening methods, most notably by drawing the curtain around one's bed, as well as by spending time away from the ward. The privacy afforded by independent living units within the rehabilitation centres was highly valued.

Space of the unit, the best experience, there's an ADL flat and I was in it for 2 weekends and they were the best weekends we've had ... it was just so

lovely to be away from the ward, away from buzzers, to be away from lights ... it was just nice for me to um just relax, just have space and privacy, it was wonderful

*Feeling reassured, supported and encouraged* This category subsumed categories relating to the value of support from: (1) staff, (2) other patients and (3) family and friends in containing feelings of vulnerability and uncertainty about self-worth.

Staff. Key factors in vulnerability-containing staff interactions were sensitivity, encouragement and respect. Nurses had a central role in enhancing participants' feelings of safety through offering help and assistance. Moreover, within the frenetic environment of rehabilitation, in which participants often felt vulnerable and isolated, nurses simply 'being there', talking, listening and offering physical comfort was perceived to be extremely reassuring.

Well just you know a hug and a cuddle really and bringing you extra tissues and sitting on the bed ... rubbing your hand sort of thing until you've got over the worst and got your breath back ... is a great support

Physiotherapists and occupational therapists (OTs) had a specific and important role in containing participants' vulnerability due to the feelings of self-doubt and fear, which was often salient when attempting to learn new skills with an unfamiliar body. Encouragement, reassurance and believing in participants' ability were highly valued.

...sort of the Occupational Therapists, it's all hands on and they'll keep you motivated and they'll sort of tell you that you're improving, which makes you feel better, and the same with the Physio's you know ... they'll sort of jog you forwards, give you the confidence and encouragement to make you go on

Doctors also helped to minimize vulnerability and uncertainty through the provision of information about the patient's physical condition and treatment. In addition, psychologists and psychiatrists had had an important role for two participants in helping to contain feelings of vulnerability by offering a valued opportunity to express difficult feelings in a neutral, safe and accepting context.

Other patients. Encapsulated in the frequently used phrase 'we're all in the same boat', participants described a sense of commonality and unity with other patients. This seemed to contain vulnerability by reducing feelings of difference and isolation associated with their disability.

Peer advice was viewed as crucial in adjusting to both the SCI and the rehabilitation environment; it reduced feelings of anxiety and isolation, offered hope and helped motivate patients by clarifying the real-life implications of skills being taught.

... some things you really don't understand why they're [staff] trying to get you to do them, but then that's where the support from other people comes from – 'if you don't do this, when you get home you're not going to do that are you', and then they're talking to you in like their language whereas physios and OTs are talking a different language and you think well no they're right I can't, I'll go back and do it again ...

Although male patients were seen as supportive, the closeness, nurturance, kindness, sensitivity and mutual understanding offered by other female patients was perceived as uniquely valuable. Within a context of high dependency, being able to offer support to other patients also emerged as important, increasing feelings of competence and value.

Family and friends. Family and friends were universally identified as a valuable source of support and motivation. The continued concern and interest from these pre-existing relationships affirmed participant's self-worth, helped to increase feelings of hope and facilitated a sense of a continued identity.

I mean it's because they believe in you, you know what I mean? And they can see the light at the end of the tunnel where you can't ...

*Adopting a positive attitude* Several participants noted the importance of inner resources and cognitive processes in facilitating adjustment. Acceptance of SCI and changed life orientation was viewed as crucial.

... something's happened and your life's had to change whether you want it or not and you have to look at forward and not past because if you keep dwelling on the past you don't go any further forward ...

The importance of self-belief and cognitive strength, often denoted by the phrase 'mind over matter', was also emphasized by many participants.

... you think tough, you thinks to yourself, I've got to do it, and that's the way I am when I go to Physio and I've got to do it ... mind over matter

Strikingly reflecting descriptions of perceived masculine responses within rehabilitation, self-focus, stoicism, emotional suppression and positivity were strongly recommended by participants.

You've got to stay positive though, I'd say that to anybody coming here, you've got to keep your head up and you've got to keep smiling otherwise you're just making it so much worse for yourself ...

## Discussion

From the emergent findings, it might tentatively be suggested that the rehabilitation environment and

interactions within it have the potential to significantly impact on patients, their mood, feelings and actions; either amplifying or containing feelings of vulnerability.

In the section that follows, some key themes to arise from the data will be discussed with consideration given to clinical implications that may warrant further reflection.

#### *Clinical implications and links to literature*

*Violations of privacy* These initial findings suggest that women's needs for personal boundaries and space (a key aspect of privacy stipulated in the 2001 Department of Health 'Essence of Care' document)<sup>17</sup> are not being met during SCI rehabilitation. Further investigation of the privacy needs of female (and male) patients may be a useful area for future research. Clinical practice developments might consider the benefits of:

- Enhanced privacy on the wards and in the bathrooms through improved architectural design;
- Avoidance of mixed sex wards and bathrooms;
- Facilitation of time away from the unit, including via use of independent living flats.

*The impact of staff interactions* In interactions with staff in SCI rehabilitation centres, patients are co-constructing a new identity as a disabled person. Participants' perceived that at times staff treated them insensitively. Disrespectful attitudes, communications and behaviours of staff may compromise patients' individuality, dignity and self-identity.<sup>18</sup> Of particular concern are interactions which foster a sense of powerlessness and loss of control as such experiences are associated with hopelessness, lack of confidence in one's ability to cope<sup>19</sup> and depression,<sup>20</sup> conditions which undermine the aim of facilitating optimal independence.<sup>13</sup> Preliminary results from this study suggest that it may be valuable to consider facilitation of self-directing patient behaviour, for example through encouraging patient choice, involvement and control in care (an empowering approach).<sup>21</sup>

*Minority status* Participants' stating of masculine ways of coping as ideal, references to a 'male atmosphere' and a perception that staff prefer working with male patients indicate masculine norms may prevail in rehabilitation. This adds support to suggestions made by authors in the area that the majority status of male patients in the SCI population may impede the prioritization of women's needs.<sup>1,13,22</sup>

Research has consistently identified gender biases among health care professionals, such as tendencies to conceptualize female patient behaviour more negatively and 'out of frame' compared to a male norm.<sup>23</sup> It could be speculated that minority status of female patients increases such gender stereotyping, constraining the diversity of 'acceptable' responses for women (and men).

This could explain why women feel marginalized and advocate traditional masculine styles of coping.

Integrating a consideration of gender issues into research would help to increase understanding and awareness of gender differences<sup>24</sup> in SCI rehabilitation. Interesting areas for clinical practice development might include:

- Staff training to improve gender sensitivity;
- Collaborative goal-planning programmes to help ensure rehabilitation goals reflect the patient's aspirations and individual needs;<sup>13,25</sup>
- Informational resources targeted at female patients;
- Formalized peer support systems.

*Emotional inhibition and positivity* Participants' assertions of emotional containment and positivity as advisable strategies for dealing with difficult feelings, along with their admiration of male emotional control, suggest that during rehabilitation displays of emotion may be poorly tolerated or not enabled.

It has been suggested that SCI rehabilitation staff may encourage patients to adopt a positive disposition to help curb the distress associated with exposure to patients' severe physical disability.<sup>26</sup> Suppressing difficult emotions, however, may have negative psychological effects<sup>27</sup> for patients. Discouraging emotional discussion may also impede identification of beliefs and feelings inhibiting patients' engagement in rehabilitative tasks, potentially creating a negative cycle of staff frustration and patient withdrawal.

Areas for consideration in clinical practice and future research might include exploration of the psychological benefits for women of accepting and facilitating emotional expression, as well as investigation of support available for staff exposed to patients' difficult feelings.

#### *Limitations and directions for further research*

This study has helped to extend a previously limited knowledge base regarding women's concerns and needs during rehabilitation. It should be noted, however, that the findings should be treated cautiously given the preliminary nature of the study and the small sample used. To ascertain the transferability of the study to a wider population, there is clearly a need for replication of the study with broader participant samples and additional rehabilitation units. Replication of the study with male patients would provide interesting insight into the extent to which rehabilitation concerns, such as issues of control, privacy and emotional expression, represent non-gender specific issues for spinal unit patients.

Participants' accounts indicate that staff interactions are central to their experiences; research seeking staff's perspectives of working with female patients would give valuable insight into the other side of these dyadic interactions. The first author has collected initial data in this area, which suggests that some staff regard the minority status of women, and their perceived

emotionality, as resulting in additional professional challenges compared to those encountered when working with male patients.

While qualitative methods used in the study facilitated the collection of rich and complex data about women's experiences, the perceived constraints regarding acceptable responses within rehabilitation may have resulted in a reluctance to report certain experiences within a one-to-one interview. Future research may benefit from quantitative techniques to enable larger scale investigation of patients' experiences and to facilitate empirical evaluation of the mediating influences of various individual and rehabilitation related factors.

## Conclusion

Following SCI, the psychological process of negotiating a revised identity is initiated within the rehabilitation environment. This study suggests that environmental conditions and interpersonal interactions within the context of the micro-society of rehabilitation may have a powerful influence on women's emotional adjustment, self-identity and, potentially, rehabilitation outcomes.

It is hoped that this study will provide a stimulus for future research. Within a context of evidence-based practice, it is essential that the knowledge base in this area is expanded and updated to ensure that services may be tailored appropriately to the needs of female patients. During a time of such challenging physical and emotional upheaval, improvements in service provision may have profound implications for women's well-being and adjustment.

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