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Difficulties adjusting to post-discharge life following a spinal cord injury: an interpretative phenomenological analysis.

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Abstract

Individual semi-structured interviews were conducted with seventeen individuals who had experienced a traumatic spinal cord injury, focusing on the participants' lived experience of spinal cord injury. The interviews were transcribed verbatim and were analysed for recurrent themes using Interpretative Phenomenological Analysis (IPA). Here we present three inter-related recurrent themes all concerning difficulties in adjusting to home life following hospital discharge: "Loss of camaraderie"; "Lack of post-discharge care" and "Other people's reactions to spinal cord injury". Participants reported that the camaraderie they formed with fellow patients during their rehabilitative stay in hospital generated feelings of security and community. This was discussed in stark contrast to the isolation and loneliness that they subsequently experienced post-hospital discharge. A perceived lack of physical, practical and psychological support coupled with negative and stigmatising reactions of the wider community served to make adjustment to home life post-spinal cord injury particularly difficult for the participants. The findings are discussed in relation to extant spinal cord injury literature and recommendations for future healthcare of individuals with spinal cord injury are made.

Key words: spinal cord injury; adjustment; post-discharge care; coping; IPA.

Introduction

Spinal cord injury (SCI) is a devastating form of neurological impairment (Gill, 1999) which has a profound effect on all aspects of the lives of the individual and their intimate others (Dickson, Allan & O'Carroll, 2008). It has been proposed that the consequences of SCI (e.g. incontinence and pain) may have a greater effect on quality of life than the actual degree of impairment itself (Dijkers, 1999; Westgren & Levi, 1998). The majority of SCI patients tend to be previously active (predominantly male) between the ages of 16-30 years with minimal reduction in life expectancy (Spinal Injuries Association, 2006).

Researchers have highlighted a number of factors which may influence an individual's ability to adjust to SCI, including personality factors (Krause, 1998; Nagumo; 2000; Rohe & Krause, 1999) purpose in life (Thompson, Coker, Krause & Henry, 2003); locus of control (Chan, Lee & Lieh-Mak, 2000; Krause, 1998; Macleod & Macleod, 1998); functional disability (Meyer, 1999); positive affect (Folkman & Moskovitz, 2000) and social support (Chan et al., 2000; Elliott et al., 1992). Other factors thought to influence adjustment are emotional maturity, education level, intellectual development, job security, financial status, levels of self-esteem and participation in social and leisure activities (Boschen, Tonack & Gargaro, 2003; Galvin & Godfrey, 2001; Sherman, DeVinney & Sperling, 2004; Weller & Miller, 1977). Individuals who are younger at the time of injury have also been found to be more likely to show positive adjustment, better social support and a return to positive employment (Krause, 1998). Despite the fact that SCI presents a number of threats to an individual's well-being, research has shown that most SCI individuals make a positive psychological adjustment (Kennedy, 2001; Kirshblum, Ho, House, Druin, Nead & Drastal, 2002) and that adjustment is enhanced over time (Krause, 1998).

Depression has been reported as the most common psychological disorder following SCI (more common in SCI patients than in their non-disabled counterparts) (Elliott & Frank, 1996). Rates of clinically significant depressive symptomatology range from 15%-35% (North, 1999) but have been found to be particularly raised in the first two years post-injury (Kennedy & Rogers, 2000). Major Depressive Disorder has been reported in 10-15% of people with SCI (Elliott & Frank, 1996). The extent of the problem is not to be underestimated- suicide has been reported as the leading cause of death in spinal injured individuals under the age of 55 years (Dijkers, 1996) and is 2-6 times higher in the SCI population than in the wider community population (Charlifue & Gerhart, 1991).

Social support plays a key role in both adjustment and depression. Individuals who report greater social support perceive themselves to be better adjusted to their injury, experience less emotional distress (Post, Ros, Schrijvers & August, 1999; Rintala et al., 1992) and report greater quality of life and life satisfaction (Dowler et al., 2001).

While extant SCI literature has tended to take a quantitative approach, the aim of our research was to capture the lived experience of SCI from the perspective of the individuals who live with it. Interpretative Phenomenological Analysis (IPA) is particularly suited to doing so and is frequently applied to research in the field of health psychology (see Brocki & Wearden, 2006 for a review). IPA aims to explore how individuals perceive and make sense of the world around them and is concerned with meaning constructed by the individual themselves regarding their personal (and social) world. For more on IPA, please refer to Smith and Osborn (2003) and Smith, Flowers and Larkin (2009).

Method

Sampling

Seventeen individuals with a SCI were recruited via the Clinical Director (4th author) at a National Spinal Injuries Unit. Inclusion criteria were that participants should be adults (over the age of 18years) who had experienced a C5, C6 or C7 SCI and who were at least one year post-injury. The injury unit's database generated 36 names matching this profile; of these, 12 were not contactable and 7 chose not to participate. Of those not participating, age ranged from 30- 70 years with the mean being 42 years. The remaining 17 participants agreed to participate in the research and a time and location for the interviews to commence was arranged at the convenience of the participant.

Participants were fourteen males and three females between the ages of 26 and 62 years (mean = 46 years). Time since injury ranged from 17 months to 32 years and the most common cause of injuries included road traffic accidents, assault and falls. Participants varied in socio-economic status with only five employed at the time of interview. The participants reported the extent of their impairment as an explanation for their unemployment post-injury.

The interviews were conducted by the second author (a white male able-bodied academic researcher) either in the injury unit (*n*= 2) or in the participants' own homes (*n*=15), depending on which was most convenient for the participant. The interviews lasted an average of one hour and travel expenses were reimbursed for the two participants travelling to the injury unit to partake in the interview.

Procedure and Interview

Ethical approval for the study was obtained from both the host institution and the relevant NHS board prior to the research commencing. An interview schedule was prepared prior to the interviews which consisted of open-ended, non-directive questions such as “Tell me about your experience of acquiring a SCI”, “In what ways (if at all) has your life changed since you experienced a SCI?” and “Which areas of your life has your injury impacted on most?” However, the aim was to allow the participant to direct the content of the interview, to allow them to prioritise events or experiences which they believed to be key to their SCI. In order to achieve this, a process of reflecting (e.g. “you said there that…”) and probing (e.g. “tell me more about that”, “what did you mean by that?”) was adopted. The interviewer often requested further details to elicit rich, insightful accounts and asked for clarification wherever necessary. This inductive approach served to ensure that the participants had every opportunity to tell their *own* story in their *own* words and to ensure that the researcher was interpreting the participants’ accounts accurately. All interviews were recorded on a digital voice recorder and were subsequently, transcribed verbatim.

Analysis

Transcripts were analysed by the 2nd author for recurrent themes using Interpretative Phenomenological Analysis (IPA) (Smith and Osborn, 2003). IPA has origins in both phenomenology (Giorgi, 1995) and symbolic interactionism (Denzin, 1995) which suggest that human beings interpret and make sense of their world by creating their own biographic stories in a way that they can understand as opposed to simply being passive perceivers of an objective reality. IPA acknowledges that the interaction between the participant's narrative and the interpretation of the analyst is fundamental to the analytic approach. IPA is concerned with the individual's *own* account of the phenomenon under investigation: it is not concerned with producing an objective record of the phenomenon. However, purposive sampling is appropriate in order to generate a homogenous group (e.g. here, a group of individuals who have all acquired a SCI) and to present recurring themes in the form of interesting, insightful and transparent narrative accounts. In order to achieve this, verbatim extracts provide credence for the researchers' claims (Osborn & Smith, 1998).

The 2nd author took the lead on analysis, analysing all 17 transcripts but the 1st author independently analysed a sample of the transcripts (n=5) and provided credibility checks for all other remaining transcripts (e.g. ensuring coding was appropriate). The process of analysis involved several key stages, as suggested by Smith, Flowers & Larkin (2009) (see our previous articles (anonymised) for details on this analytic process).

This article presents three recurrent themes, all inter-related and concerning difficulties adjusting to life post-hospital discharge: (1) Loss of camaraderie; (2) Lack of post-discharge care and (3) Other people's reactions to SCI. These themes occurred spontaneously. However, Table 1 details the number of participants reporting each theme in addition to displaying potential questions from the interview schedule which may have related to these themes.

[Table 1 around here]

A number of other recurrent themes were found in the present study, including biographical disruption, change in identity and incontinence issues. These will be presented elsewhere. It is noteworthy that the extracts presented herein have been selected because they capture the essence of a recurrent theme. Al participant names are pseudonyms.

It is also worth noting that in terms of discharge, patients are now provided with a folder which includes their 24 hour care plan and literature covering all aspects of their long term care. Social Work support is instituted and life long out-patient reviews are augmented by follow-up by Liaison Nursing Sisters and an in-house Psychologist. Access is provided to Voluntary Support Groups who help with socialisation, employment and recreation activities.

Results

Loss of camaraderie

Twelve of the seventeen participants reported ongoing difficulties in adjusting to home-life following the prolonged rehabilitative period where they remained resident in the injury unit. While participants reported that a lack of follow-up care and negative reactions of other people contributed to difficulties in adjustment, they prioritised a loss of camaraderie as being particularly difficult to come to terms with. This camaraderie was reported to have a number of benefits for participants, for example, the fact that patients were all experiencing similar difficulties served to alleviate feelings of embarrassment (e.g. regarding incontinence) and created a shared bond between the patients:

> *" When you're in the hospital um it's like you know you've got camaraderie around you, you know everyone is in the same boat*

> *more or less and you really feel quite secure"* [Barbara].

The unit was reported to be a "safe haven"- participants were bonded by similar experiences and they considered their fellow patients as "family"; as one participant stated, they felt:

> *"Just like brothers and sisters actually"* [Paul].

While this camaraderie appeared to facilitate coping during the rehabilitative period, participants reported that this automatically "vanished" the moment they were discharged home. Participants reported the stark contrast of the busy, bustling unit where they were surrounded by a SCI community to the quiet isolation of their own homes:

> *"Oh, it was strange, I didn't want to leave them [fellow patients]. I mean that sounds terrible, I had a young son to come home to but I think because I had been there so long that it felt like my home and I was in amongst people the same, with the same problems and I thought that's me going back to a flat that had stairs, I was going to be isolated again and I just didn't want to go home. I felt that as if that [injury unit] had been my home for so long and I was in with all these people"* [Lucy].

Lucy's account captures the inner turmoil that participants faced upon discharge- she highlights her son's excitement to have her come home and yet, she is consumed by a feeling of vulnerability and insecurity. It appears that Lucy, like many of the participants, felt a stronger sense of belonging with her SCI "family" as opposed to her actual family and she appears to struggle to cope with the guilt she subsequently experiences. Indeed, the prolonged nature of the participants' stay in the injury unit and the common bond that they shared with other patients seemed to generate a sense of fear about returning home- at home, they would be "on their own" and they would have to deal with the harsh reality of their injuries. In the injury unit, all residents had a SCI- that became the participants' reality, their "norm". In contrast, at home, they would be "different" (both in comparison to their pre-SCI selves and to other people), they wouldn't be able to function as they once had and they would have to learn how to cope and live without the back-up of their fellow patients and instant access to health professionals. Indeed, the move from being part of the "in-group" (e.g. living in a SCI community) to the "out-group" (e.g. living in a predominantly able-bodied community) was a daunting prospect which left participants feeling somewhat exposed.

While many of the participants came to consider the injury unit as "home", a familiar, comfortable and safe environment where SCI was "normal", a few participants did consider it to have institutionalised them:

> *"I was in the hospital for over a year and it really broke it down to, you know the time you come out the hospital you were scared, you know, you were institutionalised sort of thing. And you were, when you came home you were wanting to get back [to injury unit] again"* [Paul].

Paul's account focuses on the sense of frustration he felt in not being able to settle at home. Indeed, participants struggled to come to terms with the fact that they no longer felt as though they "belonged" at home in the same way that they did in the injury unit; they no longer experienced that same community "spirit". This coupled with periods of time alone (something they did not have during their time in the injury unit) made adjustment to home life, particularly difficult:

> *"Ma went out and she was only gone for an hour and a half or so. And once that door shut and that quietness came, I felt more vulnerable than*

> *I'd ever felt in my life. Because going from, like 24 hour support to 48 hours later nobody (….). I just wanted to go back in hospital honestly and for somebody who was so keen to get out, I wanted to get back to my support group"* [Ewan].

It appears that for Ewan, the unfamiliar quietness he experiences at home is deafening. The stark contrast from a busy, bustling ward with 24-hour care and comradeship to the silence and loneliness of his own home was unbearable. Ewan, like many of the participants reported a sense of vulnerability at home- they did not feel safe or secure as they had in the injury unit. Jack best describes the nature of this vulnerability:

> *"It's [injury unit] like a safety zone, it's like your zone and anything goes wrong you just press a button, shout, anything, somebody will be there urgently. To suddenly be in…you need to deal with it yourself (…) I was delighted to get back home but at the same time it was scary because you're leaving the place where you were most cared for"* [Jack].

Jack's quote again reinforces the safety, security and sense of belonging that the participants felt during their stay in the injury unit. While the participants were pleased to return home to their loved-ones, they seemed to feel that they were sacrificing their care and amity in doing so- they were now entirely "on their own". There is no doubt that this loss appeared to make adjustment to SCI post hospital-discharge more difficult.

Lack of post-discharge care

Participants reported that the care and support they had received in the injury unit was "first-class". However, following discharge, they reported simply being "left" to "just get on with it". This was in regard to both physical and practical care and also in terms of psychological support. Indeed, participants reported that they had a "terrible time" seeking physical support (e.g. physiotherapy, chiropody) post-discharge:

> *"Like I said the hospital was wonderful but when you get out you're left high and dry- it was awful"* [Barbara].

As with the loss of camaraderie, it appeared that the level of healthcare participants received while in the injury unit was unsustainable within a community environment. Even when participants were pro-active and successful in securing some level of physical support, they reported a lack of personal (and community) resources to actually sustain it:

> *"After you leave the hospital, you're as fit as you're ever going to be. I was home about six weeks and the physiotherapist comes out and says "Right, what can you do?" and you can do quite a lot because you've been training for eight months….. she said "Oh, that's great here's a sheet of exercises to do" and obviously not having the facilities to train your fitness level drops and you can't do exercises (…) so the exercise sheet you've got is a total waste of space"* [Ian].

Ian, like many of the participants, experiences frustration at his inability to maintain his level of fitness post-discharge. Here, Ian reports being "built up" by the injury unit to peak fitness only to discharged home and be "left" to physically de-condition. Participants experienced a sense of uselessness and helplessness in the face of their deteriorating physical status- without the necessary resources to sustain it, they seemed “beaten” by their injuries.

Although participants were frustrated by a lack of resources to fulfil an exercise programme and were concerned about how they would possibly sustain their level of fitness, they appeared more concerned about a lack of psychological support:

> *“I’m quite sure I’m not the first person to get depressed after finding out you’re crippled for the rest of your life. But what I’m surprised about is the fact that routinely there isn’t some sort of follow-up. You’d just have thought that would be just normal. I mean they spend enough time looking at your bum to make sure you haven’t got any sores on it. You’d have thought they’d look at your brain to see whether you’ve got any problems up there. But yeah, I had problems up there and none down there so..”* [Colin].

Colin’s matter-of-fact account highlights his astonishment and disappointment in the lack of provision of psychological care post-SCI. Here, he attempts to emphasise the profundity of psychological trauma post-SCI and the commonality of that trauma within the SCI population. Here, he appears more violated by the lack of psychological follow-up he received than the routine physical examinations that he did.

A lack of psychological support was also reported *during* the rehabilitative period. Participants stated a lack of psychological preparation for their return home and were disappointed that such care was not provided. Subsequently, they felt that they themselves would have to be pro-active in seeking such support pre-discharge, should they require it:

> *"We were never ever given an opportunity to sit down and have the kind of lengthy consultation going through the bad news of, you know, this is what's happened to you- this is the extent of the injury, and this is what's likely to be the future. There was nothing like that. The psychologist who's there [injury unit] is (…) just run off her feet firefighting because can you imagine a place with more psychological turmoil than a place with, I can't remember how many there are, but you know, every single person there has to have an enormous psychological need"* [Lee].

Here, Lee presents an image of a vast, chaotic and emotionally unstable environment where patients were exceptionally fragile and where basic, necessary psychological needs were unmet. One explanation offered by participants for their lack of psychological care was that "normally", SCI patients did not ask for help and therefore, there was not felt to be a need for it. However, participants felt a sense of injustice in their having to ask for help- the consensus being, that standardised psychological support should be routinely provided, even if it is not considered necessary by the patient:

> *"Unless you really, really wanted to open up and say "Look, I need to speak to somebody, I dare say they would probably get somebody for you, but it's not a norm, you know that they would say "Look do you want to speak to a counsellor or something". And I think sometimes people need that"* [Owen].

Many of the participants reported experiencing a “debilitating depression” which “dragged them down”. A few participants also reported feeling suicidal at times following discharge from the injury unit and indicated that suicidal thoughts were “not far from their minds”:

> *“I just wanted to die, you know I just did not want to live at all or continue (…). And that was in my mind a lot (…) you know and that was really what I thought about 24-7”* [Barbara].

These accounts serve to reinforce the importance of psychological support post-discharge. Indeed, the participants reported that it would not be “human” not to experience psychological trauma post-SCI. One participant (Colin) reinforced the point that many SCI patients are often so debilitated by their depression that they cannot ask for help and speculates whether or not help would be provided should someone request it:

> *“You don’t hear about mass suicides amongst SCI people but I dare say there are a few. You just don’t hear about them I have to say. But you know, I have to wonder if people who do harm themselves in some way or another how many of them have asked for help? I would have thought the chances probably very few. Because I don’t know if you asked for help I don’t know whether you’d get it. But what I do know is if you don’t ask for it, you know, nobody comes and offers”* [Colin].

Therefore, the participants appeared to be caught in a catch-22 situation; they were either so consumed by their depression that they could not ask for help or if they were able to ask for help, they feared it may not be provided anyway. What emerges here, in these accounts, is a stark contrast to the trust and security generated by the physical care provided in the injury unit. While the patients felt that they had been physically prepared to their absolute "peak" for discharge, they felt emotionally weak and highly vulnerable to the psychological trauma that, for many of the participants, ensued. Once more, this lack of psychological support appeared to directly contribute to difficulties adjusting to SCI and more specifically, post-discharge life.

Other people's reactions to SCI

Many of the participants reported negative experiences with other people which were directly related to their being in a wheelchair. Participants reported that other people's reactions made them feeling as though they "had two heads" and that long-standing friends would "body-swerve" them in the street. They also reported that in the wider community, there was a general assumption that if a person appeared physically impaired, then they were also mentally impaired- as one participant claimed (Todd) "if their body's broken then their brain's broken". As a result, participants reported a feeling of being invisible- people would talk to whoever accompanied them in their wheelchair as opposed to them directly:

> *"You get angry, you know, and go "Why do they act the way they act?"*
> *It's just condescending you, patronising. They're not even talking down*
> *To you, they're talking over you (….) Just talking over the top of you*
> *All the time, you know. You're not existing"* [Ian].

A clear sense of frustration and disappointment is expressed in the above extract. Ultimately, the way in which people responded to participants, often made them feel inferior and worthless and these experiences appear to be key in contributing to further feelings of diminishing levels of support. The idea that people no longer consider Ian to “exist” suggests that he feels he is dead to some people- they have written him off post-SCI. It is also possible that Ian feels that not only is he not living, but he does not even exist and this highlights the profound and devastating impact on his quality of life post-SCI.

Many of the participants emphasised the sense of embarrassment, worthlessness and uselessness that such situations made them feel:

> *“ You feel, you’ll feel embarrassed and you feel, you feel ashamed actually. You feel like you’re in the road [in the way], you know. You feel you’re sort of, you should nae be there sort of thing. I mean when you’re, a lot of people think cause you land in a wheelchair you’ve got to, you’re supposed to sit in a room or sit in a nursing home or sit somewhere out of the road”* [Paul].

Once more, we see the idea that the participants perceived that they were being treated as inferior to their able-bodied counterparts. As a result, participants often felt as though they were a nuisance, a burden on others and they no longer felt that they “belonged” to that environment. This again serves to reinforce the loss of camaraderie that the participants experienced and the subsequent loneliness and isolation that ensued. This rejection by the wider community was so great that some of the participants reported withdrawing completely from social situations:

> *“People just looking at you going past and looking at you and say well “What am I here?” Ken [understand], just like an object. So I dinnae go to anything at all. Not a thing”* [Paul].

Many of the participants also seemed puzzled by people's reactions and some were keen to emphasise how they would have liked to have been treated by people- that is, they wanted to be treated as their former, pre-SCI selves:

> *"When they see people in a wheelchair it's a stigma (…). When they look at me, I just want them to see me. Forget the wheelchair, just see me"* [Geoff].

Despite the commonality of such accounts, one participant (Jack) did acknowledge that he could have been overly-sensitive to other people's reactions to his SCI. The following account highlights that his interpretation of other people's reactions may not necessarily be representative of their actual reactions:

> *"We'd go into a restaurant but I felt really out of place, I was in a wheelchair. You felt really out of place and you felt folk were looking at you, terrible. But I mean when I'd been out before and seen somebody in a wheelchair… just a fleeting glance and no more and you'll think about it when you're in a wheelchair and you think everybody's actually staring at you"* [Jack].

Jack's account suggests that it is his own self-consciousness and discomfort that may indeed shape his interpretation of other people's reactions. It is possible that Jack has not yet accepted his post-SCI self. This may underpin his discomfort within the wider social environment and influence how he perceives the reactions and behaviours of others.

Discussion

This article has highlighted just how critical the discharge period is in terms of adjustment for individuals living with SCI. The research adds to the growing body of literature on coping and adjustment in two ways: first it is novel in its focus on the loss of camaraderie as a form of social support and coping; and second, it is original in its use of IPA to explore post-discharge difficulties following a SCI from the perspective of the research participants themselves.

While there has been an extensive body of work reporting the importance of social support for adjustment post-SCI, it has largely overlooked patient-patient relationships (described here as camaraderie) as a source of peer social support. With the exception of Sherman et al. (2004), who highlighted the importance of peer mentoring as a means of facilitating adjustment, the instant loss of this camaraderie upon hospital discharge has not been previously explored as a barrier to adjustment. Perhaps the inductive nature of our study (where the participants were given the opportunity to talk openly about their experiences of SCI) accounts for the emphasis on a loss of camaraderie as a barrier to adjustment here. The instantaneous loss of camaraderie post-discharge appeared to shape the SCI participant's subsequent psychosocial experience. In stark contrast to the safety, security and camaraderie of the injury unit, the participants reported a loss of a sense of "belonging" in the wider community environment and they felt rejected because of their SCI. Stigmatising attitudes and misperceptions of their disability made re-integration into the community particularly difficult for participants. As we found in our previous study (anonymous), many participants reported no longer feeling as an "equal" and feeling "invisible". As we proposed previously, this may well reflect findings within the wider disability literature (Galvin, 2005; Goffman, 1963). Our participants reported that the saliency of their physical disability led to misperceptions of them also having a mental impairment. Similarly, value is key as it is obvious that a SCI has negative connotations (e.g. confinement to a wheelchair, increased dependency on other people).

The subsequent rejection and isolation that participants reported may be applied to the minority group model. This model proposes that negative attitudes towards the minority group (e.g. the disabled individuals) are a consequence of discrimination and prejudice and that a lack of acceptance in an able-bodied society (the majority group) of the minority group creates a loss of social and occupational connections for the person with the disability. In our study, misperceptions of SCI by the majority group appeared to promote social withdrawal in some participants. For all participants, however, it did serve to make re-integration into a community environment and access to social support particularly difficult. Given the importance of social support and re-integration for adjustment, this, therefore, was a significant barrier to adjustment following SCI.

Some researchers have proposed that depression is an inevitable consequence of the loss associated with SCI (Stewart, 1977) and that depression is necessary for adjustment (Elliott & Frank, 1996; Weller & Miller, 1977). However, there are problems with the term “depression” here as it can range in meaning from low mood to a clinical diagnosis of major depressive disorder. While we agree that the magnitude of loss for a newly acquired SCI individual may lead to depressed mood, we propose that an inability to sustain key relationships (camaraderie) with fellow patients, a lack of post-discharge care and rejection by the wider able-bodied community can exacerbate affective symptoms. The affective consequences of SCI may be prevented (or at least minimised) by a) educating society on what it is to live with SCI and on the importance of accepting disabled individuals into the community; b) greater contact with fellow SCI patients post-discharge, in order to promote successful adjustment to their injury and c) greater psychological support and more effective transition from hospital to home.

A heightened sense of worth may also be promoted by the provision of a more holistic, person-centred approach to care. Preparation (both physical and psychological) for discharge is key- the recently SCI individual must have realistic expectations of what community life will entail. One way of doing this, may be to utilise peer mentoring services from fellow SCI patients (now offered in the injury unit) as this has been shown to promote coping post-SCI (Sherman et al., 2004). Encouraging access to local support groups may also promote adjustment (Boschen et al., 2003; Mukai & Costa, 2005). Indeed, communication with other people who live with similar injuries (within the wider community environment) may promote adjustment and generate a heightened sense of normality and belonging for the injured individual.

From a more clinical perspective, the psychosocial needs of the SCI individual must be assessed pre and post-discharge, as this is a critical period in the individual's life when physical loss and psychological disruptions appear overwhelming. There is a profound need for attention and support at this time. Psychological progress (in addition to physical progress) must be monitored frequently during this critical period if the individual is to successfully overcome the barriers leading to successful adjustment and quality of life. One way of achieving this would be to optimise any continuing liaison with the hospital (or spinal unit) with regular follow-up visits. This may help to preserve the attachment to the unit and maintain feelings of camaraderie. Optimum community visits and access to secondary support services (e.g. social workers, community nurses, physiotherapists, counsellors, psychologists etc) are essential. The provision of a supervised transactional phase (Boschen et al., 2003) where specialist staff continually assess the needs, requirements, progress and degree of adjustment of the individual to their post-discharge life may also facilitate coping. While the participants in our research prioritised a need for psychological support prior to discharge, it is worth noting that since this data was collected, the spinal injury unit now have a full-time, resident clinical psychologist who fulfils this service.

We conclude by considering the limitations of our study. First, there may have been a selection bias regarding the recruitment procedure- it is possible that those participants who agreed to partake may have differed in affective status from those who did not. We are, therefore, unable to determine whether the difficulties reported in this study are representative of a particular stage in the adjustment process. Second, our findings are representative of this particular cohort of SCI individuals only and should only be generalised to the wider SCI population with caution. Longitudinal qualitative research exploring the process of adjustment post-hospital discharge, including other SCI groups, is warranted.

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Table 1: Details of Recurrent Themes

Theme	**Exemplary Interview Schedule Questions**	**No. of Participants Reporting Theme**
Loss of camaraderie	How did you adjust to your injury? What kinds of things helped you to get through the day? Have there been any positive aspects of your injury? If so, please elaborate.	**12**
Lack of post-discharge care	What is the worst part of having a SCI? Why?	**10**
Other people's reactions to SCI	How have your relationships with other people changed following your injury? What is the worst part of having a SCI? Why? What aspects of your life has your injury most affected? In what ways has it affected them?	**10**