ORIGINAL ARTICLE

Qualitative evaluation of a Community Peer Support Service for people with spinal cord injury

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Study design: Qualitative study involving individual semistructured in-depth interviews.

Objectives: To evaluate peer support provided in general hospitals for people with spinal cord injuries (SCIs).

Setting: The South West of the United Kingdom.

Methods: Fourteen in-depth qualitative interviews were conducted with people with SCI and their close relatives, and with health-care professionals involved in their care. Transcribed interviews were coded inductively and analysed thematically. Themes were patterned around positive and less positive aspects of the experience of the peer support service.

Results: The psychological and emotional support provided by the peer support officer was highly valued by the participants. The peer support officer's direct experience of living with a spinal injury gave credibility to the practical advice, information and signposting provided; as well as to the empathy demonstrated by them during their involvement with people with SCI and their families. Health-care professionals appreciated their unique perspective and considered them as a valuable member of the multidisciplinary team.

Conclusion: Peer support is valued by the people affected by SCI. There is a need to further investigate the key aspects of the service, including the optimal timing for introducing this peer support as well as more formal training of mentors.

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INTRODUCTION

Peer support is based on the philosophy that the person who can be most effective in providing support is the one who has shared similar experiences.¹ It has been defined as 'the giving of assistance and encouragement by an individual considered as equal'.² Learning from peers has been described as vital in the context of rehabilitation³ and peer support, along with social support in general, has been shown to be a key factor in accomplishing the adjustments necessary for living with a spinal cord injury (SCI).⁴ Telephone peer support provided for women with an SCI in rural and remote areas provided emotional, affirmational and informational support, resulting in positive change and transformation.⁵ Support for the value of peer mentors has also been shown in a range of other conditions, including traumatic brain injury,^{6,7} HIV,⁸ cancer,^{9–11} kidney disease¹² and burns.¹³ In the United Kingdom (UK) patients rehabilitated in specialist spinal injuries centres usually benefit from access to peer support services. Those rehabilitated in general hospitals, however, have few opportunities to encounter peers and rarely benefit from peer support. This study aimed to evaluate the Community Peer Support Service provided by The Spinal Injuries Association UK (SIA) to patients in general hospitals in the south west of the UK, in the form of a Community Peer Support Officer (CPSO) who visited people in general hospitals who had recently received a diagnosis of SCI.

MATERIALS AND METHODS

This study was funded by a Plymouth University Community Research Award. This scheme encourages organisations to outline questions that they would like addressed by researchers at the University. The SIA wanted to evaluate the peer

support services they provided to individuals in general hospitals, who were not admitted to specialist spinal injury rehabilitation centres. The subsequent research proposal was developed by the University-based researchers, both of whom had experience in SCI rehabilitation (BH and JF), in collaboration with the SIA and their CPSOs. The aims and objectives of the study were therefore developed through detailed discussions between the service provider and the researchers. To ensure relevance, the topic guide was developed by an experienced qualitative researcher (LP), who first spent time with the CPSOs, conducted a formal interview with one of them, and also visited a specialist spinal injury centre. In addition, the researchers facilitated a designated online Chat-Room discussion, hosted by the SIA, which involved individuals who either had or had not experienced peer support during their time in a general hospital. These participants included people with SCI, therapists, SIA staff and CPSOs based in specialist spinal injuries centres. The discussions arising from this session significantly influenced the development of the topic guide.

A qualitative research approach, using one to one semistructured in-depth interviews and thematic analysis was used for the evaluation. Fourteen in-depth interviews were conducted, digitally recorded and transcribed verbatim. The interviews were structured by the topic guide but conducted with sufficient flexibility to enable participants to raise and discuss issues they considered as important. Interview transcripts were analysed thematically using NVIVO 8 software (QRS International, Doncaster, Australia). Inductive coding allowed for the emergence of themes which resonated with participants' own experiences although the concerns of the CPSO, the SIA and those emerging from the Chat-Room discussion guided interpretation. The emergent themes were initially clustered around positive and less positive aspects of the experience of the CPSO from the points of view of the various stakeholders. Data were interrogated to assess the extent to which there was consistency and divergence in participants' accounts, and to identify factors that influenced the way in which the CPS was experienced.

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All interviewees had experienced support from the CPSO. They comprised: five people with an SCI, four close relatives of these individuals, and five therapists working in general hospital rehabilitation units whose patients had been supported by the CPSO.

The people with SCIs were all male, with an age range of 39–63, mean age 52. Two had traumatic and three non-traumatic injuries. The relatives were all women; three wives and one mother of a person with an SCI. The therapists, four women and one man, were from three different hospitals and comprised three physiotherapists and two occupational therapists.

Participants were identified by the CPSO using the following selection criteria:

- Confirmed diagnosis of SCI (for the patient participants).
- Experience of using the 'Service' within the past 12 months.
- Able and willing to be interviewed.
- Minimum age 18 years.
- Family members or carers of the person with SCI who had been interviewed in the study.
- Experience of managing people affected by SCI who had used the 'Service' (for the therapists participating in this study).

Of eight people with SCI identified, one was not approached because of a recent bereavement, and two did not respond. The remaining five consented to contact by the researcher and were interviewed. Three of their wives also consented, and one mother was contacted after she had given consent for this approach, following a conversation with the CPSO. Ten health-care professionals whose patients had been supported by the CPSO were identified and approached. Of these, two did not respond, and one did not respond within the timeframe. Two people could not be interviewed because of research governance management consent issues. The remaining five health professionals agreed to take part and were interviewed.

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

RESULTS AND DISCUSSION

Results of the individual interviews are presented below from the point of view of the people with SCI, then their relatives and finally the health-care professionals involved in their care.

People with SCIs' experience of the Community Peer Support Service

The main benefits of the service described by these participants were being provided with:

- psychological and emotional support by a person with an SCI;
- advice on living with an SCI;
- practical advice and information;
- on-going support and friendship.

These echo the findings of other studies,^{5,14,15} which reported the value of non-specific psychological and emotional support through the input of a peer mentor:

He explained a lot of things to me. It's like things you didn't understand, and he came in, and he came beside the bed and he's there a long time, talking to me, and explaining what it was all about. 'Ronnie' (All names have been changed), 63 years old, traumatic injury, C8.

The fact that the 'listening ear' was provided by a person living with an SCI was a crucial aspect of the value attached to the support provided. The CPSO provided a role model of the quality of life and independence which was attainable with an SCI. Almost all the participants expressed the belief that information provided by

someone with an SCI was more meaningful than that provided by anyone else, including health-care professionals.

And, the carers and the nurses are very good but, obviously they haven't experienced it, and it was nice that somebody came along to offer a bit of help, who knew all about it from the receiving end. 'Sean', 49, traumatic injury, C5/6.

This view is supported by studies investigating important practical aspects of living with SCI, such as learning wheelchair skills, where peer mentors were shown to sometimes 'act as a critical corrective to instructions provided by rehabilitation professionals' (3, p 208). It may also apply more generally as mentees have been credited with being able to provide information holistically. This has been highlighted by Veith *et al*,¹⁴ who found that the credibility of the 'peer mentor' resided in the mentor providing the 'truth' about living with an SCI. This credibility was based on the fact that they can provide 'first hand' knowledge. No particular training seemed to have been required for this credibility to be afforded. Others have suggested that simply 'sharing an experience' is not sufficient and that the ability to empathise is a vital quality for a peer mentor.¹⁶ The manner in which the peer mentor provides input has also been highlighted as affecting the way in which the advice is valued by the recipient;¹⁷ 'autonomy-orientated' help being rated less favourably than 'dependency-orientated help'. Anecdotal reports from experienced clinicians in the field also highlight the need for clarity regarding the role of peers in order that they are fully accepted and that differences in approaches and opinions between professionals and peers are mitigated. The power differential that exists between professionals and peers can unfortunately limit peer involvement if there is no clarity regarding roles. Enhancing our understanding of important issues such as these will help to optimise the delivery of peer support services, for instance through the provision of appropriate training and support mechanisms to CPSO's.

Participants also valued the practical advice on such topics as bowel and bladder management, care of the skin, information on housing and sources of financial support, and about devices and appliances to support independent living with an SCI.

And he was saying about hotels that he stays in, because he drives a car and everything doesn't he? And he says not all hotels are what they're cracked up to be and you have to improvise and, all that. And, oh we were talking about skin care as well, because ['Officers' name] is quite obsessed with skin care. 'Dave', 59 years, non-traumatic injury, T10.

Previous work¹⁸ found that this sort of practical advice has the potential to add to the knowledge base of patients, increase their self-efficacy and helps prevent medical complications; It has also been suggested that peer support has the potential to positively affect return to work or study.^{19,20}

It appears to take a particular sort of character to offer peer support to people with an SCI. It could probably be best summarised by friendliness, compassion and trust.

Because I remember him, he used to come in so quick, with his wheelchair and pop beside the bed. He was always jovial, always trying to bring you up like, you know? 'Ronnie', 63 years old, traumatic injury, C8.

The unique quality of the CPSO relationship probably contributes to its success. The literature¹⁴ has identified a number of

characteristics, which are suggestive of a good mentor-mentee match. These are flexible availability, similar age, interests and level of injury; a mentor of the same gender, who is also sociable, has a good sense of humour and is able to address the mentees personal learning style. In line with this, some have highlighted the need for a co-ordinated approach to establish appropriate peer mentor programmes,^{14,21} considering both the helpers' characteristics and the type of help provided,¹⁶ as well as the need for the training of skills such as reflective listening, maintaining a non-judgmental attitude and instructions about appropriate boundaries.¹³

Relatives' experience of the Community Peer Support Service

Relatives of people with SCI are important beneficiaries of the service; perhaps in the early stages more so than the injured person. This echoes the findings of a study of peer support for people with traumatic brain injuries and their relatives.⁶ The main themes emerging from interviews with relatives were

- psychological support;
- understanding and empathy;
- a role model of recovery and living with an SCI and explanations as to what to expect in the longer term;
- information and signposting;
- knowing someone is there if you need them.

Just as people with an SCI need a listening ear, so too do their relatives, particularly during a period of adjustment that is bewildering and frightening.

And I left a message for (the CPSO) and he actually phoned me back and we had a quite a long discussion about my concerns. And he was helpful in a very positive way. But it was just too offload, for me. It was great. I mean thank goodness there was someone out there who'd been through it. And I just said, I need somebody to talk to and that's for me, that was... Somebody that wasn't to do with hospital or anything else or Charlie or whatever, just somebody, you know. 'Pauline', wife of 'Charlie', 53 years, non-traumatic injury, T2–T8.

But at least you know somebody's there, don't you? That's the, I think that's the most important thing of all, to know that somebody's on the end of the phone. 'Penny', wife of 'Dave', 59 years, non-traumatic injury, T10.

For relatives, as for the injured person, it was the fact that the CPSO had himself been through the experience of having an SCI that was particularly helpful.

Health professionals' views of the Community Peer Support Service

The health-care professionals interviewed for this study were without exception positive about the service, and reported the main benefits as providing:

- psychological support for patients;
- help for patients with coming to terms with their injury; providing a role model of living well with an SCI;
- support for relatives;
- a useful addition to the therapeutic team, providing a holistic, humanistic element to care;
- links, liaison, feedback and continuity with other health-care units, for example, between specialist SCI centres and general hospitals.

The benefits highlighted by these health professionals provide a recognition of the importance of social relationships as part of health services provision.² Historically, health care has tended to focus on the physical aspects of disease, but the importance of psychosocial support is increasingly recognised as being important in guidance documents,²² as is the vital role that non-statutory agencies, such as charities, can play in providing such services.¹

Currently, there is no guidance as to when peer support services should be offered to the newly injured person with SCI. The appropriate timing of this intervention is thought to be critical, with some concluding that poorly timed support may create added stress on both the peer and the mentee.¹⁶ The health professionals interviewed supported this notion, expressing views on the best time for the CPSO to approach patients.

Timing is critical. Because (of) the bereavement process that quite often goes with, spinal injury, we have brought (the CPSO) in, in all levels of the bereavement process if you like; even into people that were in total denial in a way, blaming themselves, or others, for their injury. 'Martin', Senior Physiotherapist, General Hospital 1.

They used different strategies to deal with this, and recognised that there were times when people did not want to access the service

I let them usually read the information that there is, rather than introduce (CPSO name) straight away, in that there's somebody that could come and talk to them.... It's getting the right time to get him involved really. We don't want to force him on them.... And it's very much a choice and sometimes people will say no I don't want to speak to anybody. 'Sarah', Senior Therapist, General Hospital 2.

...that's why this particular patient wouldn't go and chat to him. Because it was just too confronting. 'Lianne', Occupational Therapist, Other Unit.

For most people, however, the CPSO provided on-going psychological support, helping them with coming to terms with their injury; they were a role model and example for living well with an SCI. This notion that the peer support relationship allows for redefining of the self and learning how to heal from a traumatic injury has also been noted by others.²³ Alongside this, and in line with previous research in the field^{12,15} the health professionals highlighted the marked impact that the CPSO can have on patients' levels of motivation, in a way that they were not able to do themselves, empowering them to actively engage in rehabilitation, and giving them hope for the future.¹³

That feeling of being helpless, that feeling of just being useless is pretty apparent sometimes, like 'I can't, what's the point, I might as well give up because I can't use my arms, I can't use my legs, so I'm just going to be a lump, just sat here, not doing anything'. But to let them see, seeing I think is the most important thing, seeing someone, you know, two or three years post or, ten or fifteen years post, and how well they can cope and how they can live a normal life, that I think is the key.... and obviously I'm not in their position so I can't say it. 'Emily', Physiotherapist, General Hospital 2.

What I've found is that when you have somebody who's in a wheelchair living independently that kind of takes their barriers down in accepting that person with, 'their disability', allowing

them to accept themselves with 'their disability'. 'Barbara', Occupational Therapist, Other Unit.

Relatives have a great many questions of both a practical and a personal nature, and there may not be the opportunity, or the inclination, to discuss these with busy clinical staff. It was notable that health professionals in this study as well as elsewhere in the literature¹³ regarded the peer mentor as an invaluable member of the therapeutic team, providing a dimension to care which health professionals cannot offer, by being able to focus on patients' and carers' emotional and psychological needs rather than clinical imperatives, and by being willing to share their own experiences.

This particular guy that was in denial (about not being able to walk again), he spent a lot of time with their family, and they had streams of questions and he answered them all, you know, and he really managed their expectations, which was really helpful for us. 'Lianne', Occupational Therapist, Other Unit.

Health professionals also suggested that the CPSO made a major contribution to maintain and improve standards in their individual units, providing advice on the latest research and developments in relation to people with an SCI.

His support for us is also good as well because he has an idea of what's going on, he's very knowledgeable of what's going on in around the country, so that's great for us as well....if the service was not there, it would be a tremendous loss for us as well. 'Martin', Senior Physiotherapist, General Hospital 1.

No study to date has investigated the view of health professionals regarding peer mentors. The very positive nature of the views expressed by the participants in this study is encouraging and warrants further exploration.

Conclusions

Participants of this study have expressed a view that peer support is essential to patients who undergo rehabilitation in a general hospital. This type of support is highly regarded by patients, their relatives and health-care professionals. For patients, the support provided by an individual who shares their experience of sustaining and living with an SCI can be empowering and help them towards coming to terms with their injury. For their relatives, especially in the early days following injury, the CPSO was able to talk them through their anxieties and explain from personal experience what to expect, as well as providing practical advice and signposting to services, agencies and sources of funding which will enable successful rehabilitation. Health-care professionals valued the role for the liaison it provides between different sorts of health-care units and for the contribution the CPSO makes to service improvement through participation in education and planning. Specialist spinal injury rehabilitation centres frequently provide peer support formally as an integral part of the overall service. The critical mass of patients with similar experiences also creates opportunities for informal opportunistic contact between patients and relatives. Patients who do not undergo rehabilitation in a specialist centre therefore miss out on both formal and informal opportunities for this invaluable social support. The preferential association with others who have faced and mastered a similar crisis has been described elsewhere.²⁴ This lack of a peer may therefore have a significant effect on wellbeing and quality of life. It is therefore important that commissioners and providers of health services are

mindful of the fact that people with spinal injuries not only require specialist professional services but also opportunities to engage with their peers from an early stage.

This study has highlighted a number of areas that may benefit from future research. First, the possibility that there is an optimal time to visit a newly injured patient should be considered and explored further. Allied to this is the need to evaluate aspects of service delivery; for instance in the hospitals in this study, peer support was largely reliant on informal, *ad hoc*, referral systems, which may have impacted on the timing, and hence the effectiveness of the support officer's visit. Evidence-based guidance with regard to referral would be beneficial to clinicians, managers and commissioners of services. Finally, this study focused on the peer support from the viewpoint of the mentee. The needs of the mentors or CPSOs were not formally explored. Informally, they reported that they felt well supported by their organisation, but would also appreciate more formal opportunities for training. Therefore, the issue of preparation, training and on-going support needs further exploration.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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