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Experiences of peer counselling during inpatient rehabilitation of patients with spinal cord injuries

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Abstract

Study design Qualitative study

Objectives The aim of this study was to evaluate peer counselling during inpatient rehabilitation of patients with spinal cord injuries (SCI). This article describes the experience with peer counselling from the perspective of patients with SCI as well as from the perspective of the peer counsellors.

Setting Inpatient rehabilitation of SCI in the Swiss Paraplegic Centre.

Methods Six interviews with patients and one focus group interview with professional peer counsellors have been evaluated using qualitative content analysis.

Results Patients experienced the peer counselling sessions as solution-oriented, practical, motivating and especially appreciated the authentic, open demeanor of the peer counsellors. Conversations about recreational activities, hobbies and interests supported the development of interpersonal relationships. Peer counsellors experienced the initial visits with patients with high level quadriplegia as a special challenge. The regular presence of all peer counsellors in the hospital facilitated an easier exchange with the patients.

Conclusion Patients feel empowered by peer counselling. Special attention should be placed on the timing of the initial visit. Unplanned meetings between patient and peers seem to be essential and highly valued. Peer counsellors are confronted with stressful situations in their work, therefore the need for support and training of peer counsellors should be further investigated.

Introduction

Background

Spinal Cord Injury (SCI) is an extremely dramatic event for any person, which affects the rest of their life. [1] The incidence of SCI in Switzerland is 18 per one million people yearly. [2] The objective of rehabilitation is to ensure that functioning is maximized and that an individual can be as independent as possible, in order to be able to actively

participate in life. [3] Physical and emotional strengthening, self-management and empowerment are central elements in the rehabilitation of SCI and are essential for its success. [4, 5] Self-management aims to promote knowledge and skills and to motivate patients to handle their condition or disability, and its consequences, in an active and competent manner. [6] Using peers to strengthen self-management skills has proven effective in other conditions and environments. [7–9] Empowerment of individuals with SCI is an important element of self-management which may also promote self-efficacy. [10]

Only a few studies have been conducted concerning the benefits of peer counsellors in inpatient rehabilitation of SCI. [11, 12] Peers have a supporting role in finding solutions to everyday practical problems, offer emotional support and can have a substantial impact on wellbeing and quality of life of individuals with recent SCI. [13] In individuals with SCI, this support results in building up self-confidence as well as motivation and feelings of empowerment. [11] Veith et al. [11] and Haas et al. [13] mentioned

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in their studies that the initial meeting is of special importance, because it has an impact on the development of the relationship.

Veith et al. [11] addressed how the quantity of meetings with the peers influenced the quality of the relationship. While peer assignments are usually made based on the level of injury and the gender of the patient, timing of the initial visit, as well as planning and implementation of the visits can differ greatly. [11, 12, 14] Framework requirements and procedures for peer counselling in inpatient rehabilitation can differ and there are few insights about these procedures. Very little is known about the work experience of the peers and their personal needs.

Objectives and issues

The aim of this study was to evaluate how patients with SCI experienced peer counselling, especially the initial meeting, and how it affected their experience of empowerment. Secondly, the peers own perception of their counselling function was evaluated.

The following questions were addressed: what are the patients' experiences with peer counselling; which aspects of peer counselling support their ability to re-establish a self-determined life (empowerment) and what perceptions have the peer counsellors regarding their consulting work in terms of empowering the patients.

Methods

Peer counselling has been established for several years at the Swiss Paraplegic Centre, a specialized rehabilitation and acute care clinic. The peer counselling core team consists of four peers, who attend approximately 80% of the patients with a recent SCI. They serve approximately 150 patients per year. Other peers attend patients with other conditions than SCI or foreign language needs. All of them are employed by the hospital and are associated with the nursing teams. They frequently communicate with the nurses, occupational therapists and physiotherapists. There are other counselling services at the Swiss Paraplegic Centre such as vocational guidance, pastoral care and other services. Peer counsellors attend patients during therapy-free time periods, mainly in the evenings or sometimes in the afternoons. Patients are assigned to their peers primarily based on their level of injury and gender. The initial visit usually takes place after the first month of rehabilitation and further meetings are scheduled thereafter individually. Peers visit patients regularly in order to answer questions and to discuss relevant SCI-related topics. The peers are planning the visits themselves. The main purpose of peer counselling is the exchange of personal experience and addressing

specific questions with someone who is in a similar situation.

Sampling and recruitment

A qualitative approach was selected for the study and reported according to the COREQ criteria. [15] Data were collected in semi-structured interviews over a period of 5 months. The patients were interviewed individually. The peers' perceptions were collected in a focus group interview. The data were collected by the first author (KR) who is an administrative member of the nursing team but not involved in bed side activities on the ward. There was no personal or professional interaction between the study team and the patients before the start of the study. We included German-speaking patients with SCI during their initial rehabilitation, aged from 18 to 75 years and the cognitive ability to respond to questions during a half-hour interview. Patients had to have participated in at least one meeting with a peer counsellor before the interview. Therefore the interviews were conducted approximately 2 months before the patient's discharge. During the interview, the number of meetings and the experience with peer counselling was explored.

Peers who have been actively counselling for more than 1 year were invited to take part in a focus group interview.

All persons who participated in this study were informed both orally (by KR) and in writing about the study and its aim and their written consent was obtained before participation. The study was approved by the local ethics committee.

A total of 20 consecutive patients from the discharge list were screened for study participation. A total of 14 patients were excluded (not German-speaking (5), not interested to participate (7) and other diagnosis than SCI (2)). Thus 6 patients were included in our study. A total of 4 peers met the inclusion criteria and all of them agreed to participate in the study. All interviews as well as the focus group were led by the first author (KR) with no other persons involved. The patient interviews took an average of 20 min each and the focus group interview lasted 75 min. The demographic characteristics of the participants are presented in Table 1.

Interviews

The interviews were directed to investigate the research questions and were based on previous investigations. [13] The questions examined the following topics: experience of the initial visit, contents and procedures of any further meetings, relationship building and personal value gained (for more details see Table 2). Before the start of the study, the questions were run through a pre-test check to assess them for clarity. Additionally more in-depth questions were

Table 1 Characteristics of the participants

Code	Age [years]	Gender [m/f]	Level of Injury	AIS Score [A-D]	Cause of paralysis	Duration of rehabilitation at the time of interview [months]
<i>SCI patients</i>						
SCI1	25	m	C6	B	trauma	8
SCI2	28	m	T9	D	illness	6
SCI3	58	m	C4	D	illness	9
SCI4	48	f	C4	D	trauma	5
SCI5	29	m	C7	A	trauma	8
SCI6	73	f	C5	C	illness	4
Code	Age [years]	Gender [m/f]	Level of Injury	AIS Score [A-D]	Cause of paralysis	Duration for Injury for Peer Counsellors is presented in years
<i>Peer counsellors</i>						
P1	49	m	T4	A	trauma	29
P2	45	f	T7	A	trauma	10
P3	35	m	C5	C	trauma	15
P4	59	f	C6/7	A	trauma	37

SCI SCI patients, P peer counsellor, m male, f female, C cervical lesion, T thoracic lesion, AIS score American Spinal Injury Association Impairment Scale

Table 2 Key questions for the interview with patients and peer counsellors

Key questions
•Can you describe your experience at the initial visit?
•How did you experienced the timing of the initial visit?
•What was your impression coming away from the initial meeting?
•How did further meetings with the peer/the patient develop afterwards?
•Which topics came up in your conversations?
•What was particularly important for you in your exchange with the peer/the patient?
•Where there any particular experiences you made during the interview?
•What did you learn from the exchange?
•Were there commonalities between peer/patient?
•What else would you like to share?

presented when the conversation temporarily stopped, in order to get a better and more in-depth understanding of the statements. No interviews were repeated.

Data analysis

The individual interviews and the focus group interview were audio recorded without field notes, pseudonymized and then transcribed literally. The data analysis was carried out according to strict guidelines (Mayring's quality criteria).[16] This included the following steps: (a) Analyzing the transcripts line by line to extract meaningful content. (b) Paraphrasing the meaningful content in units in a concise and descriptive form. (c) Coding units and grouping those

into subcategories. (d) The subcategories were then combined into categories and compared multiple times with the original data, to ensure that they reflect the core message of the interview. Finally anchor samples were collected to illustrate the character of the subcategories. No transcripts were returned to participants for comment and/or correction. The analysis was performed by the first author (KR). To improve credibility, the analysis was discussed with the last author (AW) until consensus was reached.

Results

Perspective of patients with SCI

First impression—lasting impression

The memory of the initial meeting was characterized for several of the patients by the fact that for the first time, they had a conversation with another person in a wheelchair. Many of the patients were impressed by this first meeting and described it as a positive experience [see P1]. Several patients reported that this meeting left a lasting impression on them based on how an individual with SCI, confined to a wheelchair, can cope with life. One patient described her thoughts about the initial meeting as follows: "...I always thought: how can someone in a wheelchair prevail? Is life in a wheelchair worth living?...What a charisma she has. Just to meet someone (in a wheelchair) at all" [see P2]. The

initial meeting was very helpful for many of them, just to be able to ask questions and to exchange thoughts with someone in a similar situation [see P3]. All of the patients could remember the initial meeting and its timeframe well. Patients considered the timing appropriate [see P4]. (Table 3a)

To be able to talk about anything

In principle, all the individuals concerned had the impression that they could discuss any topic with their peer [see P5]. The following topics were discussed quite frequently: bladder and bowel management, sexuality and relationships, as well as travel and leisure activities. Patients stated that they preferred not to discuss some topics with the medical staff, because the peer could give them much better input. Information exchanges about personal care and everyday experiences were especially relevant. “They (the medical staff) provided the assisting equipment, but they couldn’t pass along the experience. I went straight to the peer...” [see P6].

Finding solutions together

Patients considered it particularly helpful to discuss different topics and also to apply and train practical solutions together. Different options were tried, until an optimal solution was found. It was helpful for the patients to develop their own solutions for everyday problems: “He showed me some tricks, but I later found a variation that simply worked better for me” [P7]. Patients really appreciated discussing everyday life topics. They also perceived this as different from the patient education they received from the professional staff [see P8].

Beyond the wheelchair

Finding similarities was considered important, especially with regard to the initial meeting [see P9]. The wheelchair was named as the most important similarity. Other important similarities were age and gender. Intimate topics were preferably discussed with a member of the same sex [see P10]. Age not only related to the age of the person but also to the number of years in a wheelchair [see P11].

However, for some patients, other similarities were more important [see P12]. The difference in the level of injury between patient and peer counsellor was not considered relevant by all patients. “That she’s a para and I’m a quadriplegic makes no difference...because in the end we all have the same issues” [see P13].

A positive attitude towards life is inspiring

Patients reported that the peers were able to motivate them in a number of ways [see P14]. This supported trying out

new things and acquiring a forward-looking attitude. Many of the patients found the peers’ positive attitude towards life helpful and supportive. They were encouraged, because they saw how active and positive the peers were in spite of their limitations. The peer was therefore perceived as a great role model: “My peer has also travelled a lot...he’s active in athletics and that’s certainly a role model” [see P15].

Trust was promoted through authenticity

It was not only the positive and motivating attitude of the peers that was truly appreciated by the patients; in addition, the fact that the peers were willing to address difficulties and problems openly was important [see P16]. The professional staff often passed on their instructions as they were outlined in the operating instructions. The counselling of the peers, on the other hand, focused more on real-life application. “I just think it’s more realistic...and not as strict. They understand that there’s still a life out there...” [see P17]. This open and honest approach was described as very authentic and helpful in establishing a trusting relationship.

From the peer counsellors’ view

To find the right moment

For the peers, the timing of the initial meeting was a challenge. It was important for them to find the best possible time, and to approach the patients only when they were ready. The level of injury was the most important criteria for their initial visit. “It was always a balancing act. Do you go now or wait a little longer? If I go too early they may think: what does he want here? I can’t even hold a cup in my hand. And here he is telling me that I’ll be able to do this and that, all by myself” [seeC1]. The peers noted that the most important factors on the initial visit, in their opinion, were to gain some first impressions and to get to know each other [see C2]. (Table 3b)

Meetings are not planned ahead

The peers highlighted the fact that even unplanned meetings were used to exchange ideas and experiences during the rehabilitation. These meetings were considered important, because questions could be addressed when they arose. “All these short conversations, which we just happened to have: in front of the elevator, or in the basement. These can be quite brief like: hey, is it true that a decubitus can develop in as little as 20 min?” [see C3]. The peers told us that these brief exchanges were highly valued by the patients, and that they were at times able to benefit from them greatly, sometimes even more than from the planned meetings [see C4].

Table 3a Patients perspectives

Category	Subcategory	Anchor samples
First impression—lasting impression	<ul style="list-style-type: none"> -being impressed -lasting impression -meet someone in the wheelchair for the first time -good memory -appropriate timing 	<p>[P1] “That was a very positive experience for me...Up until then I didn’t have many interactions with other people in wheelchairs. He has been in a wheelchair for 10 years. That really helped me a lot. Everything that has changed since then and what he is now able to do...”</p> <p>[P2] “...I always thought: how can someone in a wheelchair prevail? Is life in a wheelchair worth living?...What a charisma she has. Just to meet someone (in a wheelchair) at all”</p> <p>[P3] “I thought it was very helpful. It relieved a ton of stress for me. It helped to explain things that I was worried about...”</p> <p>[P4] “I didn’t think the visit was too early...and also not too late. The time was right for me...You start looking a little toward the future”</p> <p>[P5] “Actually, my peer made me feel like I could talk with him about anything”</p>
To be able to talk about anything	<ul style="list-style-type: none"> -talk about everything -common topics -input differs from health professional 	<p>[P6] “They (the staff) did issue the assisting equipment, but they couldn’t pass along the experience. I went straight to the peer...”</p> <p>[P7] “He showed me some tricks, but I later found a variation that simply worked better for me”.</p>
Finding solutions together	<ul style="list-style-type: none"> -trying new things -individual solutions -unlike the health professionals solution 	<p>[P8] “I believe that the outlook you form about the issue is different from that of the staff. I think it’s more realistic... You have to find out for yourself what suits you...more so than what’s written on paper...”</p> <p>[P9] “... You could immediately see the common denominator...” (points the wheelchair)</p>
Beyond the wheelchair	<ul style="list-style-type: none"> -common ground: wheelchair -gender is important too -same age -years in wheelchair -same hobbies 	<p>[P10] “From man to man...I can’t discuss this in the same way with a woman...even though they might have the professional expertise”</p> <p>[P11] “We were both young when our injury occurred...It’s different when you talk to someone who was confined to a wheelchair at age 50”</p> <p>[P12] “If I had met a non-athletic person at that time...we wouldn’t have had the same connection”.</p> <p>[P13] “That she’s a para and I’m a quadriplegic makes no difference...because in the end we all have the same issues”</p> <p>[P14] “When I started sports again he said: it’s really super that you’re trying...you just have to try, and then if it’s not possible, well that’s okay too...”</p> <p>[P15] “My peer has also travelled a lot...he’s active in athletics and that’s certainly a role model”.</p> <p>[P16] “Many (staff) stated right at the beginning that anything is possible in a wheelchair...And he (peer) stated that one can really still do a lot. It’s good to concentrate on positive things, but not everything is okay...”</p> <p>[P17] “I just think it’s more realistic...and not as strict. They understand that there’s still a life out there...”</p>
A positive attitude towards life is inspiring	<ul style="list-style-type: none"> -encouraging patients -getting motivated through peer 	
Trust was promoted through authenticity	<ul style="list-style-type: none"> -addresses difficulties and problems -more realistic, open and honest -focused on everyday applicability 	

Table 3b Peer Counsellors' perspectives

Category	Subcategory	Anchor samples
To find the right moment	-Challenge to find the right timing	[C1] "It's always a balancing act. Do you go now or wait a little longer? If I go too early they may think: what does he want here? I can't even hold a cup in my hand. And here he is telling me that I'll be able to do this and that, all by myself"
	-being ready for visits	[C2] "I introduce our program. What we have to offer"
Meetings are not planned ahead	-introducing each other	[C3] "All those short conversations, which we just happened to have: in front of the elevator, or in the basement. These can be quite brief like: hey, is it true that a decubitus can develop in as little as 20 min?"
	-explain peer program	[C4] "Actually, I think they (means unplanned meetings) may sometimes be much more important"
An informal environment promotes conversation	-coincidental meetings in clinic are important	[C5] "... When we go downstairs, they start talking a whole lot sooner. Or they'll know at the next visit that unplanned talks are more important than planned visits"
	-doing something together as learning situations	[C6] "If it is a group and one or two start, they suddenly take part... but if nobody would start the topic and we wouldn't mention it either, nobody would...say anything"
Impact of the level of injury on the work of the peer counsellor	-better talk in groups	[C7] "And I say especially Quads... they don't ask hardly anything at all"
	-single conversations for intimate themes	[C8] "It would be easier for me to accompany a paraplegic rather than a quadriplegic. Because they could see that even as a quadriplegic one can still do quite a lot"
Setting goals helps in finding new joy in life	-Challenge high level of injury	[C9] "When I go and visit a quadriplegic they think, you can do everything anyway and I can't"
	-daily routines and questions are better talked through with the same level of injury	[C10] "My focus is always to help them find their joy in life again. Some kind of motivation...that makes it worthwhile"
Peer counselling requires boundaries-trusting, open relationship	-setting new goals	[C11] "So that they could see that we're able to be there first thing in the morning. Showered, well-groomed and ready to go to work...this really does have an effect..."
	-to find joy in life	[C12] "...all the talks, they connect us."
Peer counselling requires boundaries-trusting, open relationship	-seeing a role model	[C13] "We have to be careful to not be affected too greatly...we have been there too. To be mindful that we don't get too reflective..."
	-network with health professionals	[C14] "They can let us know and don't need to worry that it will be passed on. We can use the network..."

An informal environment promotes conversation

The peers usually chose a place other than the hospital ward for the meetings. They shared that the conversation was difficult at times, when they were just sitting across from each other. Being outside the patient's room and doing something together was helpful in initiating a conversation. In addition, these outings can be utilized as training situations. "...When we went out of the ward, they start talking a whole lot sooner. Or they will know at the next visit that they are supposed to be catheterized and in the wheelchair before we take off..." [see C5]. The peers emphasized that they often experienced patients to be more open in a group exchange, rather than in an individual conversation [see C6].

Impact of the patient's level of injury on the work of the peer counsellor

During the conversations, the peers repeatedly realized how important the level of injury was. In particular, patients with high-level quadriplegia needed more time to ask questions and to bring up topics [see C7]. Furthermore, the level of injury was particularly relevant when everyday practical issues were being discussed [see C8]. It was therefore considered to be especially challenging to counsel patients with high-level quadriplegia. "When I (peer counsellor) go and visit a quadriplegic patient, he thinks, you (paraplegic peer counsellor) can do everything anyway and I (quadriplegic patient) can't" [see C9].

Setting goals helps in finding new joy in life

Encouraging patients to set goals was very important for the peers. They focused on defining a goal together with the patient and working on it together. This helped the patient to become more forward-looking and to enjoy life again. "My focus is always to help them find their joy in life again. Some kind of motivation...that makes it all worthwhile" [see C10].

The peers were aware of their influence and knew that their own attitude towards life would make an impression on the patients [see C11].

Peer counselling requires boundaries

The peers had a very close relationship with the patients [see C12]. They emphasized how important it was for them to maintain some space between them and the patients. Some of the conversations brought up strong memories of their own trauma. "We have to be careful to not be affected too greatly...we've been there too. To be mindful that we don't get too reflective..." [see C13].

The fact that they are employed (including job descriptions) as peers at the rehabilitation clinic made it much easier. The confidentiality obligation facilitated discussions about very intimate topics and helped to build trusting relationships [see C14]. They found knowing the hospital personnel well was also very helpful.

Discussion

The objective of this study was twofold: first to understand how patients experienced peer counselling with regard to empowerment and secondly, to examine the records of peer counsellors during their work. The results showed that patients felt empowered and encouraged by peer counselling. The perspective of the peer counsellors showed a need for training and support in order to better cope with stressful situations.

Haas et al. [13] noted that the timing of the initial visit should be thoroughly considered. To date, there have been no recommendations regarding the best time for the initial visit with newly injured patients, in order not to overwhelm them. In this study, the initial visit has been described as a lasting, positive memory by all patients. It was especially important for those involved to see that life can go on in spite of the wheelchair. While the meeting was very emotional for the patients, the primary focus of the peer counsellors was more on structural and contextual aspects. The informational settings of the meetings with the patients and the possibility for 1:1 teaching of special tasks were mentioned specifically. For the peers, it was challenging to find the optimal time point for the initial visit, especially for patients with high-level quadriplegia. The acute phase of a person with a high-level quadriplegia is usually longer than that of a person with paraplegia, and thus persons with high-level SCI may be overwhelmed at their initial visit. [17] The timing of the initial visit should therefore be considered based on the likely duration of rehabilitation and the level of injury.

Individuals with SCI found the exchange regarding leisure time activities, common hobbies and interests during their first contact with the peer counsellors very helpful. This exchange promoted communication in general and helped to build good relationships. Talking about personal, intimate topics and everyday practical skills was considered beneficial and useful. This observation is consistent with other studies [18] and also reflects the opinion of the peers.

The peers highlighted a very interesting and novel aspect. They explicitly described how valuable spontaneous conversations during unplanned meetings with the patients in the hospital were. The fact that the peers were employed by the clinic and were often in hospital, especially in the afternoons and evenings, made unscheduled contact with

the patients possible. This facilitated uncomplicated discussions of current topics and other questions. Unplanned peer-patient exchanges were extremely helpful for patients and should therefore play a more important role in the rehabilitation process.

Although gender and level of injury are key factors in the assignment process, it was shown that these parameters were not always relevant for building relationships. In contrast to the perspective of the peers, some patients found a similar level of injury and the same gender much less important. Common interests, hobbies and age were more important for the patients. They wanted to exchange ideas with someone they shared similarities. The level of injury was of greater importance to patients with quadriplegia than to those with paraplegia. Counselling became more difficult for paraplegic peer counsellors the higher the level of injury in quadriplegic patients was. Patterson et al. [17] also reported that more focused support was necessary for peers and patients when lesion levels differed much between peers and patients.

The patients confirmed that the contact with the peer encouraged them, that they felt more motivated and that life became worth living again. Conversations about everyday situations helped to develop new perspectives. The honest and authentic manner of the peers supported the patients to envision how their lives can go on in spite of the wheelchair. Other studies regarding peer support during rehabilitation have also shown that peer support helps with the adjustments necessary for the new life after SCI [11] and also facilitates the learning process. [12, 19] Peer counselling during the initial rehabilitation phase can lead to better self-efficacy and therefore to improved health outcomes. Interestingly, a recent review of peer counselling in the outpatient setting showed quite similar findings. [20] Peer counselling facilitates empowerment of patients through a unique learning environment, responds to important unmet needs and represents an underappreciated potential. [20]

The peer counsellors' perspective offered new aspects. The importance of unplanned meetings with patients and the careful planning of the initial visit was shown. Furthermore, this study has shown that peers can feel burdened because of their close personal contact and emotional support. Clearly defined roles and task profiles for the peer counsellors within a rehabilitation clinic are therefore important. [21] Further support should be considered in order to better cope with these stressful situations. Training to deal with difficult situations or supervision for the peer counsellors would be beneficial.

Limitations

The present study consisted of six individual patient interviews and one focus group interview with peer counsellors.

The sample size did not allow to check, if saturation was reached, however, it gave important insights into the framework of peer counselling. The situation of peer counsellors should be investigated in further studies, and more interviews will be needed to generalize the results. Further, it may have been helpful to have several analysts studying the material with regard to the inter-observer reliability. [22]

Conclusion

It has been demonstrated that patients were encouraged and felt empowered by peer counselling. Unplanned meetings between patient and peers were essential and effective. Common interests, hobbies and the exchange of information on leisure activities helped in developing relationships. Framework conditions, such as initial visit timing, peer assignment, as well as various opportunities for exchange were important for a successful peer counselling program. Their positive attitude towards life and the authentic and honest nature of the peer counsellors were of great benefit to the patients. However, close contact with patients can sometimes lead to stressful situations for the peers. The need for support and training of peers should be examined in future studies.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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