

DISABILITY DISCOURSE, PHYSIOTHERAPY AND PHYSICAL ACTIVITY IN THE LIVES OF PEOPLE WITH TRAUMATIC SPINAL CORD INJURY

LIINA PÄÄBO, KADRI PILL

Institute of Exercise Biology and Physiotherapy, University of Tartu, Tartu, Estonia

ABSTRACT

The aim of this study was to explore the experiences with disability discourse, physiotherapy and physical activity (PA) of people with traumatic spinal cord injury (SCI). Eight men with traumatic SCI participated in the study. Semi-structured interviews were carried out with each participant. The participants emphasized the importance of peer counselling in coping with traumatic SCI but also identified several problems in their everyday lives: limited outside mobility during the winter months, limited accessibility, different disturbing societal attitudes and behaviours towards people using a wheelchair, and limited financial aid for people with disabilities. They had mostly positive experiences with physiotherapy and suggested that physiotherapists should focus on developing their general competencies and using an individual client-centred approach. The participants valued PA but were rather inactive due to function- and health-related, motivational and socio-environmental barriers. The combination of different barriers and facilitators to PA varied for each participant, thereby demonstrating the heterogeneity of their PA experiences. When looking at the described benefits of both physiotherapy and PA, the main forms of creating a strong sense of self-efficacy were represented.

Keywords: spinal cord injury, qualitative research, disability discourse, physical activity, physiotherapy

INTRODUCTION

People with disabilities face many problems that prevent them from engaging fully in the society. These include accessibility, participation and non-discriminatory health-care, and the need for improvement in these areas is emphasized

in different international documents [5, 16, 18]. The aim of this study was to explore the experiences of people with traumatic spinal cord injury (SCI) with disability discourse (e.g. accessibility and societal attitudes), physiotherapy and physical activity (PA).

Disability discourse encompasses attitudes towards disabilities and people with disabilities, medical knowledge, disability politics, media representation, social inclusion, accessibility, etc. Therefore, the dominant disability discourse in the society may have real (positive or negative) consequences for people with disabilities [18].

One health condition that may cause long-term disability and also have a profound impact on quality of life is traumatic SCI [14]. It is defined as neurological damage of the spinal cord following trauma which impairs motor, sensory and autonomic functions [8]. The incidence rate of traumatic SCI in Estonia from 1997 to 2007 was 39.7 per million population which is among the highest in Europe [14].

Physiotherapy aims to improve the health-related quality of life of people with SCI by improving their ability to participate in activities of daily life [8]. Because physiotherapy as a profession and an academic discipline aims at a holistic biopsychosocial approach, it should explore how people adapt to changing physical conditions that influence their capacity to move and act in their environment. In doing that, it should also include the experiences of people who are experts in living with a certain health condition [3].

What is more, both physiotherapy and PA aim to improve the participation level of people with SCI. However, people with physical disabilities, including people with SCI, are often physically inactive. This may restrict their functional independence and increase the risk for chronic diseases and secondary complications [10, 17]. Furthermore, PA may help to re-establish a positive identity after SCI. In order to promote and implement a physically active lifestyle among this population, it is vital to explore their thoughts about and experiences with PA [17].

MATERIALS AND METHODS

Study participants were found through the mailing list of the Estonian Union of Persons with Mobility Impairment, using snowball sampling method and with the collaboration of Haapsalu Neurological Rehabilitation Centre. Inclusion criteria were predefined as follows: wheelchair user after traumatic SCI for a minimum of 2 years, age 20–39. Semi-structured interviews were carried out with 8 participants from different parts of Estonia. They were all male, mean age 31 years, wheelchair users for an average of 7 years, 7 with cervical SCI

and 1 with thoracic SCI. Interviews were carried out from May to November 2011, the questions were open-ended and non-leading. The duration of the interviews was 1–1.5 hours, they were tape-recorded, transcribed (using the unfocused transcription method [6]) and thematically analyzed, i.e., the recurrent themes were categorized, compared and contrasted [6]. In addition, member checking process [3] was carried out: the analysis was sent to the participants and 3 of them gave feedback to the study. Research Ethics Committee of the University of Tartu approved the study.

RESULTS

Disability discourse

Traumatic SCI brought about sudden changes in the participants' lives. They had mostly experienced negative feelings after the trauma and had to readjust to their “new” body, decreased independence and changes in previous plans and dreams. However, each participant had different experiences with life after SCI and also a distinct understanding of disability.

In order to cope and adapt to the new situation, the participants emphasized the importance of learning from other people with SCI and having the opportunity to share their experiences. Before the trauma they had little knowledge of people with (physical) disabilities but afterwards felt that they belonged to a new community (of people using a wheelchair) that could understand them better than the general public.

The participants also identified several problems in their everyday lives: limited outside mobility during the winter months, limited accessibility to the physical environment (including health care facilities, municipal buildings and sports facilities), different disturbing societal attitudes and behaviours towards people using a wheelchair, and limited financial support for people with disabilities.

Physiotherapy

The participants had mostly positive experiences with physiotherapy. The benefits of physiotherapy were seen as activity-related (being able to dress, write and propel the wheelchair better), promoting general well-being (feeling stronger), providing positive emotions, preventing complications (contractures) and reducing negative symptoms (spasticity). In addition, the importance of a good client-physiotherapist relationship was emphasized: “having one's heart in it”, good communication skills, positivity, listening,

motivating, friendliness, trust and respecting client's autonomy were mentioned as important qualities in a physiotherapist.

When it comes to negative aspects, there was a general concern about the limited access to physiotherapy, i.e., the participants felt that the government-funded physiotherapy was not sufficient and, at the same time, they could not pay for physiotherapy themselves due to insufficient social benefits.

The aforementioned topics were also mirrored in the participants' recommendations for physiotherapists (and physiotherapy students): they wanted a collaborative relationship, to be motivated to achieve further goals and to be involved in the decision-making process.

Physical activity

All participants found PA to be an important part of their lives and had positive experiences with PA. Nevertheless, their independent activity levels varied greatly: some participated in competitive sports, some exercised independently but not regularly, and PA experiences of some participants were limited to physiotherapy.

They were motivated by several perceived benefits of PA: it provides more functional independence, forms the basis for other activities (e.g., working, sitting for a long time, writing on the computer), promotes general well-being (feeling stronger), provides positive emotions, improves sleep, reduces stress, prevents complications (contractures), and reduces negative symptoms (spasticity, intestinal problems). Those who participated in competitive sports said that it promotes their self-esteem and also provides a social aspect to their lives. Overall, PA was perceived to improve everyday functioning and prevent secondary complications.

Many constraining factors to PA were also identified: lack of financial resources, problems with transportation and accessibility to sports facilities, health problems, pain, lack of motivation, need for assistance (e.g., if a person is unable to transfer independently), lack of time, spasticity, lack of suitable sports to participate in, and functional limitations (associated with the level of injury, e.g., weak/no grip). Thus, the participants identified function- and health-related barriers to PA in addition to motivational and socio-environmental barriers.

DISCUSSION

Disability discourse

It is very common to experience negative feelings, especially immediately after the traumatic SCI [12]. What is more, the traumatic SCI brings about a “biographical disruption” [7] in the participants’ lives, i.e., it breaks the illusion of a predictable future and makes people with SCI rethink their values and priorities. This was demonstrated by the fact that all participants divided their life in terms of the traumatic event and expressed the “loss of an able identity” followed by “rediscovering self” which are important steps after traumatic SCI [2, 11]. A prevalent finding from this study and other studies carried out among people with SCI is the importance of peer counseling and mentoring which facilitates the coping process [2, 11].

Limited accessibility expressed by the participants can be problematic both at the individual level because it might hinder coping with SCI [4], and at the societal level because it reflects the attitudes and priorities in the society [11]. One aspect of limited accessibility is limited mobility during the winter months which was a major concern for the participants. Similar problems have also been identified in Canada [13]. This demonstrates how climate conditions have to be taken into account when looking at the barriers/facilitators that people with disabilities face.

However, it should be emphasized that despite these common features each participant had a distinct understanding of disability and the heterogeneity of disability experience is a significant aspect to consider when studying people with disabilities.

Physiotherapy

The positive physiotherapy experiences were described in terms of improving functioning and preventing secondary complications. When it comes to qualities valued in physiotherapists, the results of this study add to the understanding that, in addition to professional competencies, general competencies are very important for health care specialists [15]. One aspect of general competencies is the importance of client-centeredness: if physiotherapists consider their clients’ perspectives and thereby increase their involvement and empowerment, this might help to achieve better physiotherapy outcomes.

The main problems related to physiotherapy service are: limited access, irregularity and long waiting lists, which make it difficult to access physiotherapy on a regular basis or according to need. This indicates that access to physiotherapy services according to need might not be guaranteed in Estonia.

Physical activity

Participants were motivated to participate in PA due to different perceived benefits but they also identified several constraining factors, which might hinder their social inclusion if not addressed. It is essential to remove the socio-environmental barriers and thereby increase accessibility to PA. Creating more possibilities for being physically active is the prerequisite for tackling motivational, function- and health-related issues. The heterogeneity of the PA experience of people with SCI should also be taken into consideration, that is, there is no single facilitator or barrier, but rather a unique combination of different factors which justifies the use of a holistic, individual and client-centred approach [9, 11]. This aspect should be taken into account in PA promotion among people with SCI.

Self-efficacy

When looking at why the participants perceived both physiotherapy and PA as beneficial, it can be seen that the four main forms of creating a strong sense of self-efficacy [1] were present: mastery experiences (e.g., increased distance for propelling the wheelchair, using more resistance in strength training), vicarious experiences provided by social models (e.g., other people with SCI engaging in PA), social persuasion (e.g., physiotherapists motivate people to progress in therapy), and enhancement of physical status, reduction of stress and negative emotions and correction of misinterpretations about bodily states (e.g., increased stamina and new acquired skills in physiotherapy and participation in PA). Thus, using the concept of exercise self-efficacy [10] might be beneficial in physiotherapy and PA.

To conclude, the results of this study demonstrate that on the one hand, participants with traumatic SCI faced many similar problems with accessibility, attitudes, physiotherapy, PA etc, but on the other hand, each participant had their own unique set of experiences, reminding us that there is a vast heterogeneity even among a small group of people with a similar condition.

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Correspondence to:

Liina Pääbo

Institute of Exercise Biology and Physiotherapy

Faculty of Exercise and Sport Sciences

University of Tartu

Ravila 14a, 50411, Tartu, Estonia

E-mail: liinapaabo@gmail.com