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ORIGINAL REPORT

REGAINING HEALTH AND WELLBEING AFTER TRAUMATIC SPINAL CORD INJURY

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Objective: Traumatic spinal cord injury is typically a devastating event, leading to permanent physical disability. Despite the severity of the condition, many persons with traumatic spinal cord injury manage to lead both active and independent lives. The aim of this study was to investigate the experience of health and wellbeing of persons living with a traumatic spinal cord injury for at least 20 years.

Design and methods: A qualitative design was used. Data was analysed using a phenomenological-hermeneutical method. Rich narratives were obtained from 14 persons with paraplegia due to traumatic spinal cord injury sustained at least 20 years ago.

Results: The key finding was that health and wellbeing were attained when persons were able to perceive themselves as being “normal” in everyday relationships and circumstances. The normalization process involved learning to negotiate and/or prevent potentially embarrassing situations by acting in a “parallel world”, covertly “behind the scenes”.

Conclusion: The subjective experience of wellbeing and health after traumatic spinal cord injury depends upon the ability to prevent or resolve potentially embarrassing situations without this being noticed by others. Performing this work “behind the scenes”, enables persons with traumatic spinal cord injury to interact smoothly with others and thereby be perceived as normal, despite substantial disability.

Key words: spinal cord injury; disabled persons; qualitative research; wellbeing; health; rehabilitation.

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INTRODUCTION

Traumatic spinal cord injury (TSCI) is typically a devastating event, leading to permanent physical disability due to infra-lesional sensorimotor deficits, disturbed functions in many organ systems, and increased vulnerability to complications, e.g. infections, pressure ulcers and musculoskeletal degenerative disorders (1). The annual incidence of TSCI in

industrialized countries varies between 10 and 50 cases per million inhabitants. In Sweden, approximately 120 people are affected annually (2). Long-term survival has improved dramatically, making successful rehabilitation outcomes and societal reintegration a matter of highest importance. Despite the severity of the condition, many persons with TSCI manage to lead both active and independent lives (3).

The post-traumatic adaptation process after TSCI is complex, comprising physical, psychological and social components. Factors influencing this process are insufficiently understood. Previous studies indicate that psychological factors contribute substantially to successful readjustment after TSCI (4, 5). For that reason, it is important to understand the cognitive and behavioural strategies that enable persons to achieve normal lives despite disability. There are strong indications that several “non-neurological” factors influence outcome. Notably, studies on quality of life (QoL) post-injury do not show a clear correlation with the medical-neurological severity of injury. In many cases, persons with severe disabilities report better QoL than those with less severe injuries (6). Westgren & Levi’s findings (7) also support the notion that QoL is related to factors other than merely the extent of paralysis.

Although the lived experiences of persons with TSCI have been studied previously (8, 9), most studies attempting to highlight the patient perspective have used questionnaires, based mainly on quantitative variables (10). Such methodology cannot capture all relevant aspects of this devastating life event and the subsequent adaptation processes. In the present study, a qualitative, phenomenological-hermeneutical method (11) was used in order to capture the nuanced subjective experience of regaining a sense of health and wellbeing after TSCI, from a perspective of 20 years or more after the injury.

The primary aim was to elucidate experiences of health and wellbeing after TSCI, from a first-person perspective, in order to provide a deeper understanding of such processes.

METHODS

Venues

Participants were recruited from 2 regional spinal cord injury (SCI) centres. One centre treats patients from urbanized and densely populated areas, the other serves patients from large, sparsely populated rural areas.

Participants

From the databases of the participating centres, potential participants were identified by the following inclusion criteria: persons between the ages of 40 and 60 years with traumatic paraplegia due to SCI (neurological level of lesion T1 or below) sustained at least 20 years ago. The 20-year cut-off was chosen to ensure that the participants had lived for many years as paraplegics and had probably adjusted to their situation. The restriction regarding the neurological level of injury was made in order to study independence in activities of daily living, which is typically obtained by persons with paraplegia, but not so often by persons with tetraplegia. Further inclusion criteria were that the participants were to have normal cognitive function, no major comorbidities and good communication skills in the Swedish language.

Procedure

Fourteen persons (5 females and 9 males) participated. They were selected by the head of the respective department according to inclusion criteria. They were contacted and asked if they would be willing to participate in the study. All contacted persons agreed to receive written information describing the study. In this written information they were informed that they would be contacted by one of the researchers by phone. The interviewers had no previous contact with the participants and no other role than that of a researcher. After receiving information about the study from the interviewer on the phone, all persons contacted agreed to participate. Interviews were performed by 2 of the 3 researchers. The taped interviews, each approximately 1 h long, were transcribed verbatim for subsequent analysis. The interview guide is shown in Appendix I.

Analysis

Data were analysed using a phenomenological, hermeneutical method (11). This method is phenomenological in the sense that all pre-suppositions, hypotheses or theories about the subject matter under study are put out of play, or "bracketed". The method is hermeneutical in that the narratives are interpreted. All 3 researchers participated in data analysis. After an initial reading, narratives were divided into so-called meaning units. The meaning units were then interpreted and organized in terms of relevance for the phenomenon under study, i.e. experiences of perceived health and wellbeing. The language of the participant was transformed into the language of the researcher in order to focus on the meaning of the text rather than the specific "factual" accounts. This comprises the first stage of transformation from recounted lived experience into the researcher's interpretation of the phenomenon. Each interview was then condensed into a so-called "situated structure", which is a summary of each particular narrative. Finally, the situated structures were analysed in relation to each other in order to identify common patterns, as well as specific differences in the material. The common patterns or general characteristics are found running through all or most of the interviews, whereas specific variations comprise the different ways in which these characteristics are manifested in the material. The analysis is completed when the material has reached "saturation", i.e. does not yield further significations.

Ethical permission

The study was approved by the regional ethics committee in Umeå, Sweden, No. 2010-402-31 Ö.

RESULTS

General characteristics

The attainment of a subjective state of health and wellbeing was reported by all but one participant. Health and wellbeing was experienced as the ability to be perceived as "oneself" in personal, everyday relationships with significant others. The

salient feature was to not be perceived as "one of the disabled". The attainment of an experience of health and wellbeing was expressed as an outcome of a "normalization" process beginning soon after the time of injury. In a state of post-traumatic confusion, the newly injured persons felt as if they had become one of "the disabled", signifying a loss of self in one's own eyes and in the eyes of others.

Thus, the first general characteristic involved in striving towards regaining a sense of self as "normal", was to internalize the conviction that persons with disabilities were still "normal" persons despite lost functions. This initial insight that one could achieve "normality" despite disability was typically attained during the primary inpatient rehabilitation process, through repeated discussions with co-patients and staff.

Once this mindset was achieved in the sheltered environment of the hospital ward, the next challenge was to experience "normality" in society, i.e. in a context where disability posed concrete physical, psychological and attitudinal barriers to fitting in. At this stage, several new skills and strategies had to be learned and implemented, in order to compensate for lost functions. They included learning to manoeuvre the wheelchair smoothly and expertly; to perform activities of daily living independently in new ways, e.g. emptying the bladder by self-catheterization; driving a car with hand controls, and so on. All such, activities had to be performed swiftly and smoothly so as to not stall other people. This often necessitated planning activities in painstaking detail and involved a constant monitoring of the environment (e.g. in terms of wheelchair accessibility). Furthermore, this advanced system of planning not only is typically unnoticed by others, it is *intended* to be unnoticeable, taking place "behind the scene". When expertly performed, such activities take place in a "parallel world" only known to the disabled person. This constitutes the groundwork for the attainment of normality in public life. Another aspect of achieving normality was to regain agency, i.e. being the person in charge, the person deciding, even in situations where help and assistance inevitably had to be sought. Thus, regaining control was an important part of the normalization process.

A third general characteristic was the perceived importance of role models. Role models (i.e. rehabilitated persons with a similar disability, active as staff or working in a patient organization) had typically influenced participants early in the rehabilitation process, showing them that it was in fact possible to regain a good life despite disability.

Having an explicit "philosophy of life", secular or religious, relating to the attainment of subjective health and wellbeing was mentioned by only 2 participants. In contrast, most participants had adopted a pragmatic, instrumental approach to life. This approach entailed the mobilization of a mental mindset of goal-orientation, stubbornness and positive thinking. Most participants understood their rehabilitation process, first and foremost, in terms of learning how to solve practical, everyday problems. The setting of concrete goals towards which to strive, not unlike those set when training in professional sports, was considered more important than any particular worldview or system of beliefs.

Specific variations (i.e. ways in which the above general characteristics manifested themselves in the material)

Three specific variations of the general characteristics of the phenomenon health and wellbeing after SCI could be discerned: (i) the process of normalization; (ii) responsibility and independence; and (iii) being the instigator of change.

Normalization. The wheelchair, the paralysed limbs and the distorted body posture are examples of “stigmas” that could easily influence how others could perceive the person as not normal. How to achieve “normality” in the presence of such stigmas? The aforementioned work “behind the scenes” gives a glimpse of how this is possible:

“[After my accident] I studied at the University and was studying sports education, and everybody did sports like crazy. So I started to do it too. That meant that you had to take a shower pretty often. And this takes longer being in a wheelchair, but I got to be amazingly fast, eventually. Everyone else walked, I was the only one in the class in a wheelchair, and they shouldn’t have to wait for me, so that’s a typical example of how you try to improve as much as you can so you fit in, so you get accepted so they don’t say “Oh, let’s not bother (with him), we won’t call him because it takes such a long time before he’s ready, we’ll miss the movie”.”

Several participants had experienced various physical problems and complications related to the TSCI, but none, with one exception, experienced their physical problems as reducing their overall feeling of wellbeing and health. They maintained that they experienced good health, despite severe physical limitations, as long as they could live normal lives

“I am comfortable with life. I always have something going on that I want to do. I do have a hip that bothers me at times, and some burning pain, but I feel fine[...]. I have nothing to complain about. And since I have a family and all that, I get on, I meet people, so I can, like, um... the most important thing is having contact with other people, so I feel absolutely fine.”

Responsibility and independence. Most participants were clear that no one but themselves could, or should, take responsibility for their lives. They explained how important it had been for them to learn to fend for themselves from the earliest post-injury period. It was critical to be open to, and try out, different solutions, and to not ask for help unnecessarily. Taking responsibility for oneself was experienced as an intense desire for independence. Independence meant freedom, to not having to rely on others. An example mentioned by several participants was the first occasion when they were able independently to lift the wheelchair into their car and drive away:

“Freedom was being able to come and go as you like instead of sitting out in the rain waiting for a taxi that never shows up. Then you’re stuck. So it was a real... that period was so stormy..., you hurt and you cry, you laugh, you do everything, it’s like a spin, you spin around and cry a while. Fifteen minutes later you light up a cigar or something, you’re so labile, I would say, your thoughts just spin. But to get a car,

it’s a feeling of freedom; you get a grip on your own life. You make decisions over your situation. There is nobody else there deciding for you.”

For most participants this experience was gradually obtained during the rehabilitation process after consolidating a personal “competence bank” (i.e. a set of skills in managing activities of daily life), whereby it becomes clear what one actually can, and cannot, do. It was only when they had identified their skills and limits that they felt comfortable asking others for help. The next step was to learn to confidently ask for, and accept, assistance in performing those tasks that lay beyond one’s capacity. There were those who reported having no problems asking for help, even though, generally, they preferred to ask help from people they were acquainted with, while others intensely disliked having to ask anyone for help. To be a well-functioning adult in society meant to take responsibility for oneself, within the limitations of one’s disability and not become too dependent upon others. Some participants expressed concern that too much assistance early on in the rehabilitation process could limit the opportunity to maximize abilities, resulting in “learned helplessness”.

Being the instigator of change. All participants (except one) saw themselves as being the instigator of change in the rehabilitation process, meaning that they realized that they themselves were responsible for their own progress. In the initial phase, one is necessarily very passive and dependent. However, the injured person can soon become the agent in the rehabilitation process. We found several factors aiding in this process. Sports participation, role models emulation and contact with patient organizations were all described as motivators in the task of adjusting to life in a wheelchair. Having been previously active in sports had benefitted several participants. Specific personality traits, such as not being afraid, being stubborn, believing in oneself and thinking positively were all mentioned as useful mental resources. Another salient factor was a basic willingness to solve problems. Several participants stated that without such an attitude, their case would have been lost.

The single participant who experienced (the lack of) health and wellbeing in terms of physical factors (in this case pain) had a different attitude towards being the instigator of change. This participant understood his/her current ill health as the result of mismanagement by the healthcare providers. S/he expected science eventually to find better ways to cure the injury. For him/her, the instigator of change was clearly others.

DISCUSSION

The key finding in this study is that obtaining the skills and mindset to enable one to constantly monitor the environment and plan ahead is a necessary pre-condition for living a normal life despite disability. This acquired skill prevents stigmatizing events from occurring in a social context. Furthermore, this activity is intended to be covert. It is precisely because no one notices the elaborate measures that constantly take place for a person with a severe disability to act “normally”

that the person may enjoy the experience of being a normal individual in society. By attaining social acceptance, the person then “mirrors” him/herself in this normality and finds further motivation to achieve these skills and state of mind. Thus, a positive circle is created.

The many challenges that arise for persons with TSCI have been documented previously (12). Our study shows that the lived experience of a healthy life is crucially linked to achieving a specific mindset that includes “behind the scenes” work, i.e. constantly planning, preparing and paying meticulous attention to the environment when participating in everyday social activities. One attitude enabling this taxing work is the perception of oneself as the instigator of change, which is corroborated in the literature. Carpenter (13) defines this in terms of “rediscovery of self”, while Yoshida (14) proposes a model of “pendular reconstruction” of self and identity among adults with TSCI.

This adjustment process has also been discussed in terms of “community re-integration”. Although there are different views on what constitutes a “normal” (re-integrated) life (15), this process of re-integration seems to be connected to the one we describe here. The fact that persons with a disability may offer valuable support for newly injured persons has also been reported previously (12, 16).

The concept of independence is complex. At a basic level, independence hinges on the acquisition of a set of skills that make it possible to perform personal and instrumental activities of daily life as self-sufficiently as possible, given the neurological impairment. This level of independence was reflected in our findings. However, it was also seen that independence may be obtained “by proxy”, i.e. by delegating certain tasks to others, while retaining agency. Thus, perceived independence is not just a matter of autonomy. This interpretation is in agreement with results from previous studies (17, 18).

In practical rehabilitative terms, the goal thus might not simply be to strive towards the highest possible level of independent functioning, but also to help build a sense of agency with regard to the new life situation.

This line of thinking may be linked to the “self-determination” theory of Ryan & Deci (19), who showed that the ability to change requires not just the internalization of new skills but also a sense of autonomy and competence. In our study, once the sense of agency was regained, participants were again able to return to “normality”. Regaining a sense of agency was compared to the experience of practicing sports, which is noteworthy, as the use of sports is a common component in modern rehabilitation (20). This suggests a role for sports psychology in rehabilitation.

Further studies are needed to elucidate the importance of meaning in relation to successful coping and rehabilitation after TSCI. Our finding that a religious philosophy of life was seldom used as a coping strategy is similar to the findings reported by Pollard & Kennedy (21). However, others have reported that a religious/spiritual approach to life is one of the most important coping strategies (22). This area could be the focus for further qualitative research, as rehabilitation will always be influenced by social and cultural contexts (23, 24).

As to the strengths and limitations of the study, interview data provided a rich source of material, which is needed when attempting to capture complex phenomena. The authors have varying academic training (neurology, psychology, philosophy, psychiatry) and varying degrees of prior knowledge about TSCI, helping the researchers to keep pre-suppositions at bay. It would have been helpful to perform additional interviews in order to further explore certain findings, although due to practical constraints this was not possible.

In conclusion, our key finding is that obtaining the skills and mindset to be able constantly to plan for and monitor the environment is a key pre-condition for being able to regain the experience of living a normal life, which in turn gives the person a sense of being “oneself”, which is experienced as health and wellbeing. This capacity reduces experiences of stigmatization in various social contexts. In order to function, this strategy has to be covert and unnoticeable by others. Through this work, one eliminates barriers to being perceived as “normal”. By achieving acceptance from others, the person can perceive him/herself as normal, creating a positive circle which reinforces the use of these skills and mindset. This knowledge can be useful in designing optimal rehabilitation programs.

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APPENDIX I. Interview guide

Tell me about the first situation that pops into your head when I ask you to describe a situation where you experienced wellbeing.

Can you describe another experience than the one you just told me about?

How would you describe your health today? Can you give me a specific example of your health or ill health?

Describe the process of achieving health and wellbeing for you. Can you give some examples of specific situations when you felt like “Now I have really made some progress”?

Have you had someone you consider to be a role model in your rehabilitation process? Who was that person and how did s/he help you?

Do you have any personality traits that have helped you manage to live a good life after the injury? What are they? Can you give some examples of when you have made use of them?
