RETURNING TO WORK AFTER SPINAL CORD INJURY: EXPLORING YOUNG ADULTS’ EARLY EXPECTATIONS AND EXPERIENCE

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Abstract

Purpose. The study sought to explore experience and expectations about paid work among young adults on sick leave after spinal cord injury (SCI).

Method. Eight participants with traumatic SCI, who were 20–34 years of age, and had not yet returned to work 1–5 years post-injury, were interviewed. Selection was made with purposive sampling. Data were analysed using a constant comparative method.

Results. Four main themes emerged as relevant: ‘finding your way to an everyday life where work is possible’, ‘at the crossroads, expectations of work through education’, ‘expectations of paid work as part of a desired future life’ and ‘expectations of finding a solution within oneself or with help from others’. The findings reveal high expectations of work ability but at the same time difficulties to plan for return to work and lack of support in this process.

Conclusions. The participants represent a vulnerable group in vocational rehabilitation due to their young age and recent injury. Without formal training or suitable work experience, they need tailored work support as part of their general rehabilitation.

Keywords: Spinal cord injury, return to work, vocational rehabilitation, participation, expectations, young adults

Introduction

Return to work and reintegration into society are considered two of the most important aspects of rehabilitation after spinal cord injury (SCI) [1–3]. While relatively high levels of life satisfaction after SCI are reported [4], reduced levels regarding participation are indicated [5,6], especially in work and leisure [2,4,7,8]. A majority of persons who sustain traumatic SCI are below 30 at the time of injury [9]. For young adults, long-term sick leave can, apart from the negative effect on life satisfaction, also disrupt their entry into the labour market and the housing market, consequently affecting personal and local economy [10].

Understanding the complexity of returning to work requires a wide perspective and the voices of those most intimately involved. The majority of research conducted in the field has been descriptive and focused on valid predictions for return to work. Traditionally, the focus has been on education, injury level and independence, and on age and work prior to injury [1,3,11–15].

Expectations on future working life are an important factor for successful integration to work [16]. However, experience concerning these expectations has not yet been explored in depth. The purpose of this study was, thus, to explore experience and expectations concerning paid work among young adults on sick leave after SCI.

Method

Participants

Participants were recruited using purposive sampling, including a diversity of participants to obtain
information that would facilitate a broad understanding of the research area [17]. Inclusion criteria were the following: traumatic SCI, 1–5 years post injury, age 20–34 years and not yet returned to work. Persons of different genders and different levels of injury were sought, as was diversity in vocational background or education. Excluded were the following: persons receiving clinical occupational therapy from the researcher, persons who did not speak or understand Swedish (due to the qualitative nature of the data collection) and persons with a psychiatric diagnosis as defined by axis I and axis II in Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV.

Eight participants (two women and six men) were included. Four participants were diagnosed with paraplegia and four with tetraplegia. The neurological level ranged between C4-L1, AIS (American Spinal Injury Association Impairment Scale) A–C. The participants ranged in age between 20 and 34 years. At the time of the interviews, two were on sick leave, and six had time-limited sickness benefit. Before the injury, six of the participants were in paid work or civic duty. To maintain confidentiality, no specific employment information for each participant can be given. One participant was in upper-secondary school, and one was unemployed. None were university graduates. Prior to the interview, the participants gave informed consent to participate. The study was approved by the Ethics Committee at Karolinska Institutet.

Data collection

Data were collected using in-depth, semi-structured interviews and field notes after each interview session. The interviews were conducted by the first author. An interview guide was developed based on the literature [5,18–22] with a focus on selected areas thought to influence experience of returning to work. These conceptual areas include the following: patterns of daily living, the meaning and value of work, expectations regarding return to work and future working life. Examples of questions asked were as follows: Is there something in your daily life that is an obstacle to your return to work? How would you describe your expectations of your own work performance? Can you describe how you envision yourself working?

Follow-up questions were asked to gain a deeper understanding of the individual’s experience and to allow for openness to experience that might not have been included in the interview guide. The guide was tested in a pilot interview, after which it was slightly revised. Each participant was interviewed once, at a place of their own choice: five at home and three at the rehabilitation centre. The interviews lasted 50–90 minutes; they were recorded digitally and transcribed verbatim by the interviewer.

Data analysis

Constant comparative method refers to a systematic process of analysis carried out together with continued data collection and review of literature studies [17]. Analysis of the interviews started with carefully reading through the text to discover patterns and emerging themes in the text, linked to the aim of the study. Phrases representing ideas and experience put forth by participants were coded using a word or a phrase. Initial codes were then repeatedly compared with the data. Through this back-and-forth process, codes were consolidated when referring to similar topics or experience. Field notes were used to supplement and deepen the understanding of interview text during this phase of analysis. The Open-Code software 3.4 [23] was used to code and organise the data. As codes were merged, categories began to emerge, around which the codes were linked. For example, the code time as a factor emerged from the data. The content of this code was the time needed to relearn activities and routines and to avoid feelings of pressure in this phase in rehabilitation. The code was exemplified by quotations such as ‘... it takes longer for people who get injured when young’, ‘time is important and it is not possible to force time ...’ or ‘every aspect in the process has its time ...’. A coding system developed with a final reduction to four themes consisting of 38 codes representing the analysis of the total data.

Interviews were conducted in Swedish, and Swedish was used during analysis. For the purpose of publication, quotations have been translated. The text of the interviews was translated from Swedish to English by two authors independently and compared for accuracy. When there were discrepancies, the authors discussed and proceeded with an agreement upon translation.

Settings for the study

This study was carried out in Sweden, thus experiences relating to work after SCI were influenced by the Swedish health-care context. The interviews were conducted during a period of change in social security benefits and insurance systems. Changes were established in July 2008; therefore, none of the participants were yet affected.

All participants were on (a) sick leave, (b) time-limited sickness benefit or (c) time-limited activity benefit (persons from 19–29 years of age). Until July...
2008, time-limited benefits (b and c) were payable if work capacity was affected by illness, injury or disability for more than 1 year. After July 2008, time-limited sickness benefit (b) was withdrawn, although previous decisions about this remained in operation until 2010. Persons on activity benefit (c) can, with retained benefit, participate in activities to support development and increase work capacity [24]. One of the present participants took part in such activities.

Results

The main findings were a strong conviction about the ability to work, but time was needed first, to create new routines in daily life. The major obstacles were described as lack of education, lack of work experience and perceived limitations due to the injury. Irrespective of expectations, definite solutions were for the majority yet to be found. Too many questions remained unanswered for a plan to be set.

The findings from the thematic analysis are presented in four themes: (1) finding your way to an everyday life where work is possible, (2) at the crossroads, expectations of work through education, (3) expectations of paid work as a part of a desired future life and (4) expectations of finding a solution within oneself or with help from others.

Finding your way to an everyday life where work is possible

During the first phase of acute care and rehabilitation and immediately thereafter, getting to know one’s body in daily activities was described as being of utmost importance and a prerequisite to working life. One consequence of the SCI was a lack of bodily control. Initially, the focus was to understand bodily alterations and to regain control of functions. Life after injury was described as lacking spontaneity: managing everyday life required detailed planning, and prioritising became a necessity. This shift was described by one participant:

Before, if something came up, one could just hit the road. Now one has to think of all the things one needs for going to the toilet and so on. One has to know that it takes extra time to get the wheelchair into the car and to get to the car and get dressed and whatever else. These are probably the main things that are different.

Relearning activities and finding new routines were described as time consuming, estimated to a period of 2–3 years. Participants emphasised the need not be forced to proceed faster than what they perceived to be possible. To reinvent routines that would allow spontaneous activities despite changes in body or environment seemed crucial to some. To manage everyday life, the participants described a need to construct a foundation from which they would be able to take the next step. Not until then would work be possible. One participant said:

Right now one feels the need for more stability and a calmer daily life in general, and a feeling of simply being able to connect all the different pieces of everyday life. Not through temporary solutions in some way, but actually managing to get things together for a day by oneself. This is what is needed; I think this is what it takes for me to be able to take the next step in life.

Most participants tried to keep to a regular everyday routine and fill the day with varied activities. The activities aimed at meaningful occupation during the day as well as preparing for working life. Work preparation included trying to follow a type of work schedule in daily life, being able to sit for a longer time in the wheelchair, having the physical strength, techniques and also mental energy to manage activities similar to one’s work tasks. One participant described preparation for future working life in these words:

Still trying to keep a, still trying to keep up my physical training, and so on, fairly regularly, so as to maintain all these small things that one has to consider anyway when one goes to work or school, a type of schedule for an ordinary day.

The ability to maintain routines with regularity was described as a challenge. The participants were convinced that they would manage work for a fairly short period, but were uncertain whether they could maintain it for a longer period considering the daily challenges they experienced at the moment.

At the crossroads: expectations of work through education

None of the participants had an employment to return to after their injury. Some had no previous work experience, others had worked with odd jobs of a physically intense character, and a few had been trained in manual labour. All lacked a formal academic training.

All participants pointed to the same factors of importance for future employment: choices previously made, the potential – but at that point unknown – limitations posed by the injury and the necessity for a suitable job rather than an adapted one. Education was described as the main avenue towards future employment. The participants who had made an active choice of manual labour expressed regret at not being able to work in an area...
of their interest and competence. Some of them also expressed hesitance over studies. One participant described his thoughts:

I wanted to work with something physical. Where I could use my body, see, I worked-out a lot so I think it suited me quite well. I have never had much of a head for studying and never liked reading and such.

The participants who had envisaged an academic career and had confidence in their ability to complete a formal training described other obstacles. Their worries were mainly financial and whether it would be possible to follow a full-time schedule. Formal training often requires full-time studies. Part-time studies would take much longer, as well as involving a prolonged period with a difficult financial situation. Anxiety connected to anticipated injury-related medical consequences such as pain, sleeping problems, pressure sores or recurrent urinary tract infections could mean periods of interruption, and therefore, poor study performance. The current economic situation, although not good, was described as better than an alternative student’s economy would be. To study or to work would mean giving up financial security. A possible failure to perform would add a study debt to existing financial strains. One participant described his view on managing full-time studies:

... to be able to follow through, week after week. That is what it’s about. It’s those things you don’t think about; it might work really well, to have a part-time job or something five days a week for two weeks, but then you are totally worn out.

Some participants had tried shorter periods of study and had found it difficult to balance studies with other tasks of daily life. Only one participant was pursuing full-time academic studies when interviewed.

Expectations of paid work as a part of a desired future life

The participants described their expectations about wanting, and being able, to make a relevant contribution through work. The desire to work was grounded in different perspectives among the participants, but emerged in the analysis from their description of the value of work. This was not only economic but also had to do with being productive in a profession. For the participants, work meant participation, regularity and a way to express creativity, as well as being good at something.

Most participants expected to obtain paid employment in free competition on the open labour market. One described how he saw his ability to get, and do, a job post injury:

I don’t think there would be any major problems, as an xx you are not tied to your body in that way ... I think I would do a good job, simply because ... I have a passion for it and, yes, simply I think I would be of great use.

However, not all the participants expected to obtain employment on the open labour market despite their desire to work. Considering disability, lack of formal training and limited work experience, they could not imagine themselves finding employment on the open labour market without support. Instead, they expressed a wish for a secure income through permanent sickness benefit.

The participants were all aware that injury-related problems would probably affect their future work. However, given their limited working experience and the recent injury, they described this as mere speculation. Participants expressed insecurity about the type of work that would be suitable and how to plan their future work schedule. Due to their injury, they described a working life where they were more entangled by the circumstances. One woman tried to see how she could adjust her work in a compensatory manner:

I’m not as flexible as I used to be, but I think it is my obligation to compensate for this, I have to compensate in some other way, and I have to choose areas that work. Yes, it is my obligation to become as good as possible in those areas so that I can continue doing the job.

The participants emphasised their abilities in these descriptions. They described themselves as being good with children, being open-minded and social, having knowledge about computers or technology, or being good at leadership or writing. These abilities had not changed. Irrespective of how they would be met on the labour market, the participants themselves expected to do well at work.

Expectations of finding a solution within oneself or with help from others

Despite expectations and expressed desire for future paid employment, only one participant had as yet started her plans to change the current situation. Two different approaches to overcoming perceived obstacles were detected. Some participants described their situation in terms of creative solutions to the practical obstacles and expressed awareness of ways of thinking that would help them to overcome their worry or insecurity. Others
described problem-solving strategies as being out of their reach. One participant described his outlook on working life:

It doesn’t matter who I might have been or what ability I might have had, it’s completely out of my control. I don’t see it. There’s nothing I can do about it.

All participants described difficulties in designing a specific plan for the future. The unanswered questions were related to their new situation as disabled and their lack of work or study experience. Most described lack of support in creating a possible way forward towards working life. The participants who did not envisage formal training had expectations of support from the community to get employment. One participant described his expectations about obtaining employment:

There’s a possible solution to everything, it’s all about finding an employer that is willing to find the solution with me. As easy as that . . . maybe not that easy, but it is as simple as that according to me anyway.

The other participants, who were considering formal training, inquired support in terms of economic benefit until they were ready for the next step.

Discussion

Participants in this study not only described expectations to return to work but also expressed difficulties in bringing these expectations to fruition. It is this tension between high self-evaluation of ability to work and a need for guidance and support that participants were obliged to come to terms with.

Higher education is described in several studies as a main predictor of successful return to work after SCI [11,13–15]. Post-injury education is also described as important for work integration [11]. The present findings describe the difficulties to undergo formal training after SCI. The participants perceived difficulties to pursue full-time studies due to lack of endurance, a possibly added risk of medical complications and a strained financial situation as a student. Consequently, study plans were postponed for the majority of the participants. Since education is a main predictor of successful work integration, measures are suggested to enable people with SCI to access education possibilities post-injury.

Consideration of work in vocational rehabilitation follows getting to know one’s body, and relearning activities and occupational routines. This was emphasised by the participants in this study and is also pointed out in other studies [18,25,26]. Time to relearn occupational routines is described by Hammel [18] as crucial when taking the step towards work life. Hammel [18] reflects critically on the focus in early rehabilitation on the performance of separate activities rather than routines. She emphasises the need for early focus on supporting patients in recapturing activities and routines of everyday living.

The risks of long-term sick leave, like those of continued absence from work, have been emphasised [10,25,27]. In addition, important is an understanding of the difficulties for young, not-yet-established people on the labour market, or for those established in jobs no longer suitable after the disability. Timing seems to be even more important for this group with no employment to return to after injury. This conclusion is supported by other studies [3,28].

Limitations of a qualitative study always concern the subjective descriptions of a person’s experience given in interviews [29]. A further risk in the present case was that of bias since the interviewer (LB) worked at the rehabilitation centre where the participants were listed. There is here a possible risk that participants withhold information or give information showing them in a positive light [30]. The possible risks were all considered during data collection and analysis. To minimise this, people currently under treatment with the author were excluded from the study. The confidentiality of the participants’ answers was emphasised both verbally and in writing before the interviews. The analysis carefully kept presentation of the result closely to the participants’ descriptions. The group was constituted to represent a variety in age, gender, level of injury and education and/or professional background. This was achieved except for gender and educational level. That the group of participants was predominantly males by 4:1 is, however, in accordance with the population of traumatically injured persons with SCI [9]. Selection of the participants showed that all in this age group with a formal training had returned to work 1 year post-injury.

In conclusion, the present participants represent a vulnerable group in vocational rehabilitation, easily identified by their young age, recent injury and lack of work or study experience. Vocational rehabilitation and other supports after SCI have been highlighted as important in overcoming barriers to employment [3,11,12,25]. However, further studies of the implementation of vocational support in general rehabilitation are necessary. Longitudinal studies could give important information about timing, personal factors and vocational rehabilitation outcome.

A complex situation such as described above may well be handled following a coaching model. A form of apprenticeship as part of vocational training could also
be made part of rehabilitation. Experiencing a work routine would create possibilities to practice and evaluate work performance and may spark motivation for young injured individuals, when motivation is hard to find. In preparing for work, combining the participants’ demands of themselves in a future job with a perceived feeling of readiness is necessary. The feeling of being ready sometimes takes more psychological training than physical training.

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References
