RESEARCH PAPER

To regain participation in occupations through human encounters – narratives from women with spinal cord injury

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Abstract
Purpose. To gain an understanding of how women with spinal cord injury (SCI) experienced human encounters in occupations and how these influenced their participation.
Method. The data were collected through two or three in-depth interviews with 13 women (age 25 – 61 years) with SCI. Data analysis was carried out by using a paradigmatic analysis of narrative data, followed by an interpretation based on a narrative theory.
Results. The results showed a complexity where the women's experiences and acting in human encounters changed over time. In these human encounters the women struggled with conflicts, supported other persons that were insecure and revaluated their apprehension about persons in their social network. These multidimensional human encounters thereby enabled them to regain participation in occupations.
Conclusions. This shows that human encounters are important for persons with disabilities so they can restructure their occupational identity and their needs for participation in occupations. The study also showed that the use of narratives as a tool within rehabilitation could lead to an increased understanding of the subjective changes that occur over time for a person with a disability.

Keywords: Occupational therapy, rehabilitation, spinal cord injury, relations

Introduction

To be disabled can influence a person’s identity and acceptance from others [1]. It has been argued that this stems from how western society historically has viewed persons with disabilities. The traditional view during the 20th century was that a disability is a personal tragedy for the person where the individual had to depend on others for support [2]. An increasing criticism was raised against this view, and as a result a social approach to disability was developed. According to this approach, disability is described as all the things in society that impose restrictions on persons with disabilities [3]. Health professionals have also been criticized for defining the needs of persons with disabilities without taking into account their subjective experiences [4 – 6]. Furthermore, earlier studies [7 – 9] have shown the importance of looking at the timing, setting and individual biographies in order to understand the complex ways in which people experience illness and disability.

Persons with disabilities sometimes have to change their performance in daily occupations and may require social support from persons in their social network to be able to participate in occupations that are purposeful and meaningful [10 – 12]. Attitudes from persons in the social network and the availability of social support are therefore important for persons with disabilities to facilitate participation in occupation [13]. McColl [14] points out that support from persons in the informal network, such as family members, friends and colleagues at work, are most important. However, it has been shown that some people have an ambivalence towards persons with disabilities and how they should treat them.
[9,10]. This can result in attitudes and treatment of betrayal and discomfort from people in the social network and therefore the social groups where persons with disabilities do things can change profoundly [10]. The timing of social support in occupations is also of importance since the needs of persons with disabilities change over time [14–16]. Furthermore, it has been shown that changes and losses of daily occupations can lead to a changed identity for the person [3,8,14].

Identity can be described as an active and changing process that is both shaped by and shapes one’s social environment, and also involve person–environment interactions [17,18]. A person’s life develops over time and can be seen as a series of changing thoughts, feelings and actions. The identity is therefore best conceptualized as a process of change [19]. Bruner [20] uses the term “turning points” when he describes how people go through changes in their life. These turning points are linked to happenings in the person’s life and can lead to changes within the person. Example of a turning point in a person’s life could be an injury or a disease.

Focus within occupational therapy is to enhance participation in occupation for persons with an injury or a disease. A person’s participation can be described as involving performance and subjective experiences [10,13]. As stated earlier, participation in daily occupations can also serve as an important way to enable persons to experience or create their personal identity. A disability that interferes with the ability to participate in occupations can therefore be a threat to the identity [1]. Kielhofner [10] and Unruh [21] describe occupational identity as a composition of one’s occupations over time and that occupational identity has components based on the person’s subjective experience. Therefore, it is of interest for occupational therapists to consider not only the doing aspects of occupations used in treatment, but also the meaning the person has assigned to his or her occupations from the persons perspective [22].

Narratives are a useful way to obtain experiences from person with disabilities, by listening to what they present as the narrative of their disability and their lives [23]. Mattingly has argued that narrative reasoning has a central role in providing coherence to the confusions and chaos that injuries or diseases create, since narratives are more than reflections on experiences, but also words that give appropriate responses to deal with a disability [24,25]. Polkinghorne [18] describes that narratives can also provide identity for persons with a disability because they enable constructions of meaning to their lives which provide purpose and direction for their actions. Furthermore, narratives can be used as a method to come closer to a “true” representation and mirror a person’s reality; from another position, narratives can be used to explore possible understandings rather than fixed representations [26]. A narrative approach can therefore be described as an adequate theoretical framework to understand and describe the life processes of persons with disabilities, as one of the properties of narratives is to retain the temporal and sequential relationship among life event processes [18,27,28].

Persons with a spinal cord injury (SCI) are confronted with a changed life situation and with difficulties to perform and participate independently in daily occupations, something that can lead to a changed identity [4]. Earlier studies have shown that social support is important for a successful rehabilitation of persons with SCI, as well as other disabilities [12,29–31] and that social support seems to be more important for women with SCI than for men [32]. Furthermore, results from our earlier studies of women with SCI [15,16] showed that social support was important for the women’s ability to participate in daily occupations and that their needs of social support changed over time. Our findings also showed that the women needed to receive social support soon after the injury and to have reciprocal support some time after the injury [15]. Previous research of people with SCI has focused mostly on men [33] and their needs of support from persons in their social network from an objective perspective. There is also a lack of knowledge about women with SCI and their subjective experiences about how their social network influences their participation in occupation. We therefore considered it worthwhile to use narratives to study women with SCI in order to gain an understanding of how they experienced their human encounters in occupations and how these encounters influenced their participation.

Method

This study emerged from findings in an earlier study designed to describe how women with SCI perceived changes in the social network and how these changes affected their ability to participate in occupation [16]. The data collection in this earlier study involved two in-depth interviews and field notes. When analysing the data, we found that along with the description of changes in the social network the participants also described experiences of how they had been treated by persons in their social network. In order to get a deeper understanding of how they perceived this in a time perspective from soon after the injury until today, a third interview was carried out. The present study includes an analysis from the interviews in the former study and the third complementary interviews.
Participants

A total of 13 women, 25–61 years of age, with SCI participated in the study. They were recruited from the regional Spinal Cord Injury Unit in the Department of Rehabilitation, Lund University Hospital. The women were selected from the Spinal Cord Injury Unit database through a purposeful sampling to get information-rich cases [34], based on the following inclusion criteria and information from their medical records:

1. Sudden onset traumatic or non-traumatic cervical or thoracic SCI;
2. A minimum of 1 year and a maximum of 10 years post-SCI;
3. In need of social support in occupations in everyday life, such as self-care, leisure and productivity;
4. Medically and psychologically stable with no other diseases that significantly influenced their participation (e.g., major depression, substance abuse);
5. Age between 20 and 65 years;
6. Cognitive and mental ability to understand both verbal and written information and the capacity to respond to questions during an interview;
7. Discharged from interdisciplinary rehabilitation services but part of the follow-up programme since the time of their SCI.

This purposeful sampling was done by a physician (third author, not primarily involved in the SCI rehabilitation) and one of the occupational therapists in the SCI Unit, who had detailed knowledge of the women and their needs. Four women were initially contacted by the occupational therapist in the SCI unit. To guarantee the women's confidentiality the occupational therapist mailed a letter to the women describing the aim of the study and asking if they were willing to participate. When the women had given their written consent to participate, the first author contacted the women to schedule the interviews. Further selection of women continued according to the same procedure until the data reached saturation. The Research Ethics Committee of Lund University, Sweden approved the study.

Data collection

In the former study [16], the two interviews consisted of open-ended questions and field notes were taken after the interview [34]. The two interviews with each woman were separated by two to five days (during the period of March to June 2003) and took place in a setting chosen by the women. Both interviews focused on the women's ability to participate in occupation and relations with persons within their social network, such as family members, relatives and friends, colleagues at work and neighbours.

In spring 2004, a new letter was sent to the women asking if they were willing to participate in a third interview. About a week later the women were contacted by the first author and new interviews were scheduled with 11 of the 13 women; two women declined to participate. The third interview was made by telephone, lasted between 20–40 min, had a narrative character and complemented and expanded on the first two interviews. All questions were open-ended aiming to capture the participants own stories [34] about how they experienced their human encounters in occupations and how these encounters influenced their participation over time. Follow-up questions were asked to ensure that the time perspective was covered or to encourage the women to tell their stories. By using these open-ended interviews, the women could bring up issues they thought relevant. Through the repeated interviews, a closer contact was achieved with each woman which gave them the confidence to reply to more personal questions and served to enhance the understanding of the phenomena under investigation and the comprehensiveness of the data [35]. All interviews were tape-recorded and transcribed verbatim.

Data analysis

The data analysis was carried out by using a paradigmatic analysis of narratives, described by Polkinghorne, to identify aspects of the data in order to locate common themes among the collected stories. The paradigmatic analysis provides a method where concepts can be inductively derived from the data to uncover commonalities that exist across different stories [36]. To gain a deeper understanding of the women's narratives the analysis was followed by an interpretation based on a narrative theory [25]. This is a theoretical approach that can be helpful to understand and describe life processes of persons with disabilities over time in relation to meaning, contradictions, suspense and interactions in their stories [18,25,27].

To obtain an overall sense of the data, the transcribed interviews were first read independently by the first and the last author. The process of analysis started by reading and coding the transcripts to define plots that described changes or turning-points in the women's stories about how they experienced human encounters in their social network. All defined plots were then sorted and in order to get an overview of the plots, the plots were organized in seven categories. The categories were discussed by the first, second and last authors and
this resulted in four categories related to the purpose of the study. In the first category – “I was treated in an insecure way” – the women experienced that people in their network were frightened and shocked and did not know how they should treat them in occupations. In the second category – “I was treated in a strengthening way” – the women gave a picture of how people treated them positively, something that was inspiring and made them feel the strength to participate in occupations. In the third category – “I was treated in a supporting way” – the women perceived that people in their network were willing to find solutions for them, something that made the women feel confidence when they participated in occupations together with others. In the fourth category – “I was treated in an insulting way” – the women talked about how people did not show them respect in human encounters.

The analysis then continued with an interpretation built upon narrative theory to get a deeper understanding of why the women experienced human encounters in the way the results from the paradigmatic analysis showed, and how they acted in these situations. To gain a deeper understanding the first, second and last authors searched for changes over time and formulated interpretations in relation to meanings, contradictions, suspense and interaction in the women’s stories, in a back and forth altering to each woman’s story. The interpretations were controlled and rejected until the “best fit” of interpretation emerged [37]. The interpretation gave an understanding about how and why the women acted toward persons in their social network according to how they experienced human encounters in occupations. The analysis showed that the women went through an individual process, but that the women’s stories also had similarities. In this part of the analysis, a complexity emerged regarding how the women became actors in their everyday life and interplayed with persons in their social network. The rest of the narrative analysis gave a picture of the women’s action in their social network, in line with Mattingly’s [24] reasoning that narratives can be seen as intimately tied with one another because of the nature of social actions and human society. The analysis resulted in four themes and the authors found through discussions that one of the themes unified the other themes and was abstract enough to encompass everything described. Based on this new understanding, data were organized into one main theme and three sub-themes.

Results

The results comprised one main theme “Regain participation in occupation through human encounters”. This theme included three sub-themes (i) “Conflicts made me change my acting”, (ii) “Insecure treatment made me act”, and (iii) “Unexpected encounters created a new way of acting”.

Main theme: Regain participation in occupation through human encounters

We found a complexity in the women’s stories of human encounters in occupations with others. They experienced over time that human encounters were different in similar occupations and therefore acted differently against persons in their social network in similar occupations. Soon after the injury the women could be seen as passive in human encounters, and we interpreted that the encounters often became unidimensional. It seemed like the women became insecure about how encounters with persons in their social network should be shaped in the new situation after the injury and thereby became passive. Furthermore, their insecurity and changed needs of support influenced how other persons in their social network acted against them, for example insulting them, insecurely or unexpectedly. As a consequence, some women soon after the injury avoided these human encounters and did not participate in some occupations. One woman narrated:

I was sitting in the wheelchair and we were going to the boat. They (members in the boat club) came and said hello to my husband, but not to me. The same happened in the Clubhouse, so I said to my husband – I don’t want to come along any more.

Through the analysis it became clear that the women’s acting changed over time, from being passive to taking part and interplaying in human encounters. We found that the women were dissatisfied being passive and started to search for how they could interplay with others and regain participation in occupations. For example, they started to give support and advice to others regarding how they could act against them, explained their own feelings and created the power to interplay in human encounters. The women’s acting changed the human encounters from being unidimensional to multi-dimensional. This shows that the women over time, in an active manner, began to accept or reject how persons in their social network treated them, something that one woman illustrated in the following citation:

I have been a little, how should I say, aggressive. Earlier, when people helped me, for example when a man opened the door for me, I felt a little – O that’s nice that someone still does that. Later, when I was sitting in a wheelchair the change came and if someone opened a door for me, man or woman doesn’t matter, I snapped
they over time had to handle conflicts with persons were meaningful for them. The women also felt that possibilities to resume control over occupations that with persons in their social network, they had Through the women’s capacity to handle conflicts mobilized power so they could handle conflicts. We found that the women after some time created and human encounters changed over time. We found presented in the following citation:

"ally they had these conflicts. One example of this is should act, which implies that it was only occasion-

soon after the injury were insecure about how they meeting some persons since they were afraid to end up in a conflict. We understood this as the women’s acting and how they wanted to act. Our interpreta-
tion was that this discrepancy was the reason for the women’s change over time from being passive to being active in human encounters, and that they thereby created multidimensional encounters in occupations were they could regain participation. The complexity of these changes will be presented from three perspectives in the following sub themes.

Sub-theme 1: Conflicts made me change my acting

When the women experienced that they were treated in an insulting and depreciated way from persons in their social network the encounters often ended up in a conflict. We found that soon after the injury it was emotionally difficult for the women to have these conflicts. As a consequence, the women avoided meeting some persons since they were afraid to end up in a conflict. We understood this as the women soon after the injury were insecure about how they should act, which implies that it was only occasional-
y they had these conflicts. One example of this is presented in the following citation:

"She was a social worker and she came to me and left an application to send to a traffic accident foundation, where I could apply for grants. – You can have 5000 SEK directly, that was the first thing she said to me. I answered her – You can go away, I don’t need money, I don’t care about money, it is not important. I don’t want to see her anymore, although I think she was the only social worker in the hospital.

Still, the women’s experiences of conflicts in human encounters changed over time. We found that the women after some time created and mobilized power so they could handle conflicts. Through the women’s capacity to handle conflicts with persons in their social network, they had possibilities to resume control over occupations that were meaningful for them. The women also felt that they over time had to handle conflicts with persons they met in the society when they felt treated in an insulting and depreciated way. This indicates that the women’s acting over time changed and thereby the human encounters also changed and became multi-dimensional. Through their capacity to handle conflicts we were led to the interpretation that the discrepancy between how persons interplayed with the women and how the women wanted to interplay in occupations decreased.

A similar pattern was seen in the encounters with professionals. Some women started to confront professionals when they felt insulted. These situations could occur when professionals did not ask the women about their needs and what support they required in daily occupations, but instead presumed what needs the women had. This was, for example, how their home should be adapted and when they could have help from professionals. We found that the women over time did not accept they had to be treated as a person unable to make their own decisions about daily occupations. This gave an understanding of how conflicts between the women and professionals altered the women so they could start to act in these human encounters and thereby participate in occupations they found meaningful. One woman narrated:

"It was December 19 and I had made a decision to go home, but at the same time they were having a Christmas lunch in the hospital. I said to the . . . – I like to take part in the lunch before I go home and she answered very irritated – Shall we never get rid of you. I don’t like the way she talked to me, I have been in the hospital so long so why shouldn’t I eat the Christmas lunch before I went home. I said to her – I eat the lunch before you order the taxi for me.

We found that the women over time struggled with conflicts in human encounters to create possibilities to regain participation in occupations. That led us to the interpretation that even though their conflicts were difficult for the women, they could, through these human encounters, participate in occupations they found meaningful.

Sub-theme 2: Insecurity from others made me act

Insecurity from persons in human encounters was a common experience among the women soon after the injury. They experienced insecurity when persons in their social network helped them too much with occupations they didn’t want help with. For example, help with cleaning, washing and shopping restricted the women’s opportunity to participate in these occupations. We found that the women, fairly soon after the injury, explained to these persons what kind of help and support they needed to participate in occupations. This acting from the women led over
time to less insecurity from others. This indicates that the women’s acting against insecurity from others increased their opportunities to participate in occupations. One woman narrated:

They made it because they wanted to take care of me, I thought that was bothersome. I talked to them, they didn’t let me do anything by myself; at last I was both sad and angry and said – Let me for God’s sake try, I have to try since I have to manage this again. Then they realized that their mother was very stubborn, but it was perhaps because of my stubbornness that I have got as far as I have.

The women also met people in the community who treated them insecurely. These human encounters could be seen as unidimensional because people did not ask the women if they needed or wanted any help. Instead the women were helped too much in occupations that they didn’t need help with or asked for. This was common soon after the injury but also occurred later in some occupations. A consequence of this was that the women became restricted in their occupations. Thus, over time the women started to support these persons and taught them to act differently so they could have multidimensional human encounters where the women could participate. These findings gave an understanding of how the women acted to reduce the insecurity from these persons and thereby created multidimensional encounters. One example of this is presented in the following citation:

Some people have tried to take my wheelchair and push me away, like I was an old lady. For example, if you are at the X-ray department they will try to drive you into the room. I said – walk in front of me and show me where it is, then I will come after you. Then, when you came in and were going to sit close to the screen they will start to pull the wheelchair to get me right in front of the screen. I said to them – Tell me were I should sit; I can fix it much easier than you because I know to handle my wheelchair much better than you. You have to tell them very clearly.

Furthermore, the analysis showed that the women wanted to find solutions to reduce the insecurity from others so they could build a joint resolution about participation in occupations. The women struggled to reach an active engagement together with persons in their social network so they could encourage and support the women in occupations. The joint resolution with persons made the women feel inspiration and happiness. We interpreted such joint resolution as a form of multidimensional human encounter where the women acted and participated in occupations.

When the insecurity from others decreased the women could participate in occupations and the human encounters became multidimensional. We realize that the women’s understanding of the other person’s insecurity against them had grown from the women’s own experiences and feelings of not being injured. We interpreted this as, even though the women soon after the injury were insecure about how they should interplay with others in encounters, they soon came to support persons they perceived insecure.

Sub-theme 3: Unexpected encounters created a new way of acting

The analysis showed that the women soon after the injury had experiences of unexpected human encounters with persons in their social network. Some relatives, friends and colleagues at work were more engaged in the women than they expected, and the women therefore came to re-evaluate their apprehension about these persons. That changed the women’s acting against these persons and they came to be more close to each other than before the injury. We interpreted that the women because of these unexpected encounters created a new way of acting with these persons.

Another experience of unexpected human encounters soon after the injury was that some friends and colleagues at work could not handle the women’s new situation and thereby the women also came to re-evaluate their apprehension about these persons. This was seen when some persons avoided them or treated them in a way they never expected. This unexpected treatment was difficult to understand for the women and influenced them so they avoided these persons or ended the relationship, something they never thought should happen. The following citation is an example of how one woman was treated:

He (the chief) talked about how he had ended the distribution of work. We are sitting there and I always have some commissions in my service. So I just say – what plans do you have for me? He answered – What use could I have of you?

Unexpected human encounters in occupations were also illustrated in the women’s stories about professionals soon after the injury. The women perceived that they had been treated unprofessionally, something they found unexpected. Some professionals had, for example, treated them as objects instead of treating them as a person in need of help and support in occupation. It was also unexpected for the women that some professionals did not provide the interventions that the women found important. The women became passive in these encounters as they felt insulted and hurt.
However, some time after the injury the women started to struggle against professionals when they experienced that they were treated unprofessionally so they could get help and support to participate in occupations. We found that the women created a new way of acting and thereby the encounters with professionals became multidimensional. One woman described her new way of acting like this:

I tried to get help from the community assistance with weekly shopping, but they couldn’t help me. I got no assistance at all since the person responsible for the community assistance told me that I wasn’t injured enough for assistance. So I had to fight and struggle and by that time you give up. I went to my occupational therapist instead and she had great ideas how I could do it myself.

We found that the women over time created a new way of acting in human encounters in occupations they found unexpected. This new acting was built upon a re-evaluation of their apprehension about persons in their social network and their own capacity to act in encounters. This is essential for our understanding of how the women changed their acting and how they created a new way of acting to reach multidimensional encounters in occupations. When they created a new way of acting they could also interplay and regain participation in occupations.

Discussion

This study showed a complexity about how women over time experienced human encounters differently in similar occupations and also acted differently which influenced their participation. Over time, there was a gap between how people acted against them in occupations and how the women wanted them to act. There was also a gap between the women’s acting in occupations and how they wanted to act. To change these gaps the women struggled with conflicts, supported persons who were insecure and revaluated their apprehension about persons in their social network. Through the women’s acting these human encounters gradually changed and the women could regain participation in occupations.

The results indicated that the women had to struggle with the sudden injury. We found that soon after the injury it was difficult for the women to imagine how their own values and the treatment from others could change, and they became insecure and passive in their human encounters in occupations. Similar results have been described in earlier studies [8,9,38,39]. Our results also showed that the women over time created a new way of acting in human encounters that was built upon their intention to regain participation in occupations. These changes can be understood as a disability that may force time to reflect and reassess and present opportunities where persons with disabilities restructure old relationships, reassess priorities, discard old habits, and develop new ones [11]. Charmaz further describes that when a person has a disability, not only do their habits change over time, but also their ways of thinking, feeling and acting towards themselves. This sudden injury can also be described as a “turning point” in the women’s lives that influenced them to get new beliefs and courage [20]. Our results also showed that other people’s acting in these human encounters caused the women’s changed acting. This is in line with Charmaz’s [11] opinion and our earlier study [15] that habits are social and arise in everyday occupations and are patterned through relationships. Furthermore, the women’s acting to regain participation in occupations showed how they over time were trying to challenge the idea of normality and refused to be categorized on the basis of bodily differences, or as Watson [40] states, a person with impairment.

How the women’s experiences and acting in human encounters changed over time is of interest in relation to their identity. These changes can be seen through Cochran’s and Laub’s [38] description of how persons after an injury or disease go from a victimic to an agentic life, through a cycle of progression and retrogression that consists of four phases. It has also been argued that identity is influenced by the larger social world in which the person finds himself or herself [1,20]. Our results showed that the women soon after the injury were insecure about how they should act in human encounters, something that is described as feelings of entrapment or a sense of incompleteness in the first phase or as concerns of acceptance from others [1]. After a while the women felt dissatisfied being passive and started to search for how they could regain participation in occupations. According to the second phase, this can be seen as the women began to prepare themselves for a return to a life of active engagement in occupation. Furthermore, the gap between how persons acted against the women and how the women wanted them to act changed the women’s acting. From this they began to focus on the life skills needed to live as independent and self-directed persons, according to the third phase. In line with Christiansen’s arguments [1], it also showed that others in the social network influenced these changes in the women’s acting. Finally, the women found solutions to handle conflicts, insecurity from others and unexpected treatment and could participate in occupations that were meaningful for them. That can be seen as the women became authors of their lives and took control of their existence, something that both Cochran and Laub [38] and Magnus [39] describe. The results also
showed that human encounters in occupations, which the women found difficult to handle, influenced the women’s acting and shaping of identity.

An interesting point is that our findings are built upon the women’s stories from soon after the injury until today. There is always a temporal situatedness between past and future in a narrative story [25]. Through the use of narratives we found complex changes over time in how the women experienced human encounters in similar occupations. Williams [7] describes that in confronting the experience of chronic illness, a person’s narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has. Thereby, Williams suggest that narrative reconstructions can be seen as an attempt to reconstitute and repair ruptures between body, self and life by linking and interpreting different aspects of biography in order to realign present, past and self with society. Our results showed a complexity of how the women over time experienced and acted in human encounters, which can be seen as they started to reconstitute and repair their ruptures. These narratives of complexity can also be understood in relation to Mattingly’s [25] explanation that most stories that a person chooses to tell include difficult passages which could have significant gaps between where the person is and where the person wanted to be. These results are built upon difficult passages in the women’s stories that contain conflicts, insecurity and unexpected treatment in human encounters. However, emergent narratives can be seen as they do not mirror life, instead they are built upon the person’s capacity to transform lived experiences and are useful when a person needs to find new solutions in a situation where they experience a gap [24]. Through these narratives we found a complexity in the women’s stories over time, something that showed that narratives are very useful to reach the subjective experiences by persons with disabilities.

We consider that the women’s changed acting in human encounters influenced occupations so they could participate. We therefore interpreted that the encounters changed from being unidimensional to multidimensional. The women’s changed acting over time came both from the gap between how people acted against them in occupations and how the women wanted them to act, and from the women’s acting in occupations and how they wanted to act. Through the women’s new acting in human encounters they constructed a changed occupational identity and thereby could regain participation in occupations. Our results are in agreement with the theoretical framework of occupational therapy: That a person’s identity is built through occupations that provide the person with the context necessary for creating meaningful lives [1]. Building an occupational identity starts with self-knowledge of one’s personal capacity and interests from past experiences and constructions of a value-based vision for the future [10]. Occupations can also be used to promote self-knowledge because limitations in occupation can restrict how one perceives himself or herself, and thereby manage social identity [17]. However, our results indicated that the way others acted in encounters influenced the women’s changed occupational identity after the SCI. These findings showed, in agreement with Mattingly [25], how persons constrained by a physical body tell stories that deal with how they, but also other persons, respond to their disability. This gave us a deeper understanding about how other persons influenced the women’s participation in occupations. Our results showed how important it is, within rehabilitation of persons with a sudden injury or disease, to have knowledge of the changing process a person goes through after an injury and how that influences their participation in occupation. It is also important to consider that persons in the social network influence how persons with disabilities participate in occupations over time. Persons in the social network can both be seen as disabling or enabling opportunities to participate in occupations [10]. With knowledge of the changing process, professionals within rehabilitation can adapt the interventions but also give support to persons in the social network so they can enable them to participate in occupations.

Methodological considerations

To strengthen the study we used a purposeful sampling built upon inclusion criteria that would give information-rich stories, and three in-depth interviews to minimize the weaknesses of emotional interviews [34]. To enhance the trustworthiness and improve the credibility, the first and last authors had a constant dialogue with the second author, who is experienced in narrative analysis, during the analysis process and in discussion with the third author who is an experienced rehabilitation medicine specialist [35]. Furthermore, the first author kept field notes to be aware of and reflect on the research process and personal feelings that may have influenced the findings [41]. Another methodological consideration is whether the use of narrative theory to interpret the final analysis might have put some parts of the material out of focus. It should also be noted that the focus of this study – the individual perspective – might have put societal and cultural aspects that are also of importance for a person’s identity, out of focus. Thus, further research based on other theoretical approaches such as coping or adaptation,
or other perspectives, might add to the understanding of the complex changes in stories from persons with disabilities about their experiences and acting in human encounters.

Conclusions

The conclusions of this study are that women with SCI went through complex changes over time that influenced their participation in occupation. These complex changes also altered the women’s identity over time and influenced how persons in the social network acted against them after the injury. Through their changed acting in human encounters, the women could regain participation in occupations that were multidimensional. This implies that human encounters are important for persons with disabilities to restructure their occupational identity and their needs for participation in occupations. Finally, the use of narratives as a tool within rehabilitation can lead to an increased understanding of the subjective changes that occur over time when a person has a disability.

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