Meaning of Context in Recapturing Self-Care After Stroke or Spinal Cord Injury

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KEY WORDS
activities of daily living
environment
self care
spinal cord injuries
stroke

This study identifies the meaning of context in recapturing self-care after a stroke or spinal cord injury (SCI). Recapturing denotes the process of engaging in self-care to regain the ability to participate in self-care activities. Five people who had had a stroke and 6 people with SCI were interviewed 1–3 months after onset. The interviews were open ended and transcribed verbatim. They were analyzed by using the empirical, phenomenological, psychological method, which identified 6 main characteristics describing the role of context in recapturing self-care: (1) support from others, (2) an air of expectation, (3) extended time, (4) new daily structure, (5) therapeutic relationship as enabling possibility, and (6) gradual change in challenge. These findings showed that rehabilitation professionals play an important role in creating a context that contributes to recapturing self-care by allowing extended time, enabling patients to see possibilities, and creating expectations for them to do things on their own.


People who have had a stroke or a spinal cord injury (SCI) often experience their bodies as limited and have difficulties in performing daily activities (Kvigne & Kirkevold, 2003). They often find activities that were once taken for granted, such as eating breakfast or taking a shower, difficult to perform. To enable performance, it is necessary to consider changes within the person's context (Kielhofner, 2008). Our aim in this study was to identify the meaning of context in recapturing self-care after a stroke or SCI. Recapturing denotes a process of engaging in self-care to regain the ability to participate in self-care activities. This process is closely linked to the body, and one must understand both bodily and contextual experiences (Guidetti, Asaba, & Tham, 2007).

In this study, the notion of context is closely aligned with concepts from the International Classification of Functioning, Disability and Health (ICF; WHO, 2001) and a phenomenological life-world perspective, which adds an important dimension needed to understand the complex and many-faceted meaning of context (i.e., the living space in which the person acts). The life-world is viewed as the subjective, historical, cultural, social, concrete, and practical world in which people live, which is taken for granted and not questioned in their daily life (Husserl, 1925/1977). By critically examining people's experiences in daily activities, the meaning of context can be identified and described (Tham & Kielhofner, 2003). Moreover, it is often necessary to consider changes in the person's context (Kielhofner, 2008), such as providing technical devices in the home setting or supporting significant others in handling new situations in daily activities.

According to the ICF (WHO, 2001), a person's functioning and disability is understood as a dynamic interaction between health conditions (e.g., injuries, traumas) and contextual factors. The contextual factors in a person's life encompass
environmental factors (e.g., physical, social, attitudinal) and personal factors (background).

In this study, we draw on a phenomenological tradition (Husserl, 1925/1977; Merleau-Ponty, 2002) to capture this dynamic interaction between health condition and context. According to this tradition, the body is the starting point for how people are in the world, relate to the world, and interact with the world in daily life (Merleau-Ponty, 2002). The life-world is intersubjective, which means that people can, on the basis of their own perceptions and experiences, understand the experiences of other people. The body inhabits space and time in the life-world.

After a stroke or SCI, the person’s lived body often changes; according to Merleau-Ponty (2002), every change of the body leads to a change in the person’s life-world because the person’s life-world is experienced through the body’s perspective of the world. When studying the meaning of context in the recapturing of self-care, one cannot overlook the experiences of body, space, and time. A person’s way of understanding a new situation involves not just his or her own perceptions about what occurred, for example, after a stroke or SCI; it also involves the ideas and perceptions infused in the occupations that are part of the social contexts in which people’s everyday lives are carried out (Asaba, 2005). Context therefore represents more than merely a generic social milieu or physical environment; here we use the term context to refer to physical and social environments as well as the entire life-world that the person inhabits.

Researchers engaged in phenomenological work (Erikson, Karlsson, Borell, & Tham, 2007; Lampinen & Tham, 2003; Tham & Kielhofner, 2003) have identified characteristics in the environment that may influence occupational performance during the rehabilitation process after stroke. Those researchers, however, did not identify the role of context in the recapturing of self-care.

Several empirical studies have illustrated the importance of contextual factors related to social interaction; that is, the client–therapist relationship and the significance of establishing shared goals for intervention to achieve successful outcomes in self-care training (Gagne & Hoppes, 2003; Guidetti & Tham, 2002; Lucke, 1997). Some studies have shown that many clients with stroke do not participate in the goal-setting process, and those clients and their therapists do not share goals for the intervention (Bendz, 2000; Wohlin-Wottrich, Stenström, Engardt, Tham, & Von Koch, 2004).

Guidetti and Tham (2002) identified therapeutic strategies used by occupational therapists during the self-care training process with patients who had stroke or SCI. The strategies primarily had to do with creating a relationship of trust with patients, which seemed to be a precondition for developing the self-care training process. Other strategies consisted of finding ways to motivate the patient, enabling meaningful therapeutic experiences, and adjusting the training situation to the patient’s needs. The therapists had very little focus on teaching patients how to use technical and compensatory strategies. This finding was in keeping with other studies in which a self-care learning process was described as a partnership between nurses and therapists (Lucke, 1999). Previous studies (Guidetti & Tham, 2002; Guidetti et al., 2007) have indicated the importance of context with a focus on client–therapist relationship in the self-care training process, but there is little documented knowledge of the meaning of context in a wider sense, that is, which characteristics in the context may support or hinder the recapturing of self-care. By critically examining experiences of recapturing self-care early in rehabilitation, one can also identify and better understand the meaning of context. This process is of importance for the development of rehabilitation intended to support the recapturing of self-care among clients with stroke or SCI who commonly participate in self-care intervention.

**Method**

**Design**

To identify and understand the meaning of context, we used the Empirical, Phenomenological, and Psychological method (EPP; Karlsson, 1993). Interview data were collected and analyzed using the EPP, which aims to describe the essence, structure, and character of the studied phenomenon (i.e., the meaning of context in recapturing self-care) by examining how meaning is expressed in the life-world experiences of people with stroke or SCI (Karlsson, 1993). Data consisted of interviews conducted 1 to 3 months after stroke or SCI. We used the same data in a previous study examining the lived experience of recapturing self-care (Guidetti et al., 2007).

**Participants**

The study group consisted of 5 participants who had experienced a stroke and 6 who had experienced a SCI. We selected these two diagnostic groups because self-care training is a common therapeutic intervention in the early phases of rehabilitation for patients with these conditions. The characteristics of the impairments and disabilities vary widely, which can provide rich and varied data on different characteristics of the phenomenon under investigation (Karlsson, 1993). Participants were consecutively recruited from one hospital in Stockholm, Sweden, where they received acute care. The criteria for selection were...
• Age ≤ 65 years;
• Inability to perform self-care activities and in need of self-care training in their continued rehabilitation, according to their occupational therapists’ clinical assessment; and
• Ability to understand interview questions and to share their experiences according to their occupational therapists’ clinical assessment.

The participants received written and verbal information about the study, and we obtained informed consent from all 11 participants. All participants were in the beginning phase of rehabilitation (1–3 months after the stroke or SCI) and were still hospitalized in a rehabilitation setting when they were interviewed. Because our purpose was to identify characteristics related to recapturing self-care, it was critical that the participants be in the process of recapturing self-care and participating in training. The ethical committee at Susanne Guidetti’s affiliations approved the study. To protect the participants’ privacy, detailed individual demographic data were withheld. Collectively, however, we note that the participants were all employed (their vocations included cook, construction worker, personal secretary, computer seller, or student) at the time of the injury. See Table 1 for the participants’ demographics and clinical characteristics.

Study Context

All participants were patients in an inpatient rehabilitation hospital and were receiving occupational therapy 1 to 2 times per day. For the participants with SCI, occupational therapy included daily self-care training, whereas for the participants who had had a stroke, occupational therapy included only a few isolated sessions of self-care training.

Data Collection

To schedule interviews, Susanne Guidetti contacted the participants through their occupational therapists. She interviewed each participant once for approximately 1 hr in his or her rehabilitation setting. Interview questions were informal and open ended, albeit based on an interview guide. The participants were asked to describe, as concretely and with as much detail as possible, their experiences in performing self-care activities; moreover, they were asked how they experienced those activities immediately after onset and at present (main focus). They were asked to describe self-care situations and, more concretely, how they handled the situations. The interviews were audiotaped and transcribed verbatim.

Data Analysis

The EPP method encompasses a qualitative, interpretative, and descriptive analysis. To understand the participants’ life-world experiences and how the phenomena presented in their experiences (Karlsson, 1993), we bracketed during the analysis any theory outside of phenomenology or knowledge derived from clinical practice within a medical context that explains or accounts for the phenomenon under investigation. We analyzed and interpreted the data in five steps. Steps 1–4 were completed separately for each participant to discover how the characteristics of the phenomenon (i.e., meaning of context in recapturing of self-care) were presented and expressed within each participant’s life-world experiences as described in the interviews. In Step 5, we identified and interpreted the characteristics that ran across all participants (i.e., general characteristics) to describe the meaning structure of the phenomenon encompassing main characteristics and subcharacteristics. Susanne Guidetti was responsible for design, data collection, and analysis (Steps 1–5). Eric Asaba contributed to the study during the fifth step of the analysis. Kerstin Tham was the senior researcher during the whole process.

In the first step of the analysis, we read the interview of 1 participant (the protocol) until an understanding of the

Table 1. Participant Demographics

<table>
<thead>
<tr>
<th>Participant Group</th>
<th>Age</th>
<th>Gender</th>
<th>Living Conditions</th>
<th>Wheelchair</th>
<th>Location of Brain Lesion</th>
<th>Paraplegic or Tetraplegic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke</td>
<td>40</td>
<td>Man</td>
<td>Married</td>
<td>No; crutches</td>
<td>Right hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke</td>
<td>57</td>
<td>Woman</td>
<td>Married</td>
<td>No</td>
<td>Right hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke</td>
<td>60</td>
<td>Woman</td>
<td>Married</td>
<td>No</td>
<td>Left hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke</td>
<td>65</td>
<td>Man</td>
<td>Widower</td>
<td>No</td>
<td>Left hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke</td>
<td>50</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>Right hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>SCI</td>
<td>28</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>—</td>
<td>Paraplegic</td>
</tr>
<tr>
<td>SCI</td>
<td>65</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>—</td>
<td>Tetraplegic</td>
</tr>
<tr>
<td>SCI</td>
<td>53</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>—</td>
<td>Tetraplegic</td>
</tr>
<tr>
<td>SCI</td>
<td>30</td>
<td>Man</td>
<td>Living together</td>
<td>Yes</td>
<td>—</td>
<td>Paraplegic</td>
</tr>
<tr>
<td>SCI</td>
<td>21</td>
<td>Man</td>
<td>Single</td>
<td>Yes</td>
<td>—</td>
<td>Tetraplegic</td>
</tr>
<tr>
<td>SCI</td>
<td>38</td>
<td>Man</td>
<td>Living together</td>
<td>Yes</td>
<td>—</td>
<td>Tetraplegic</td>
</tr>
</tbody>
</table>

Note. — = not applicable. SCI = spinal cord injury.

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material had been achieved. In this step, we tried to have an empathetic understanding of the participant’s original experiences of the meaning of context in recapturing self-care expressed in the interview.

In the second step of analysis, Susanne Guidetti divided the participant’s interview protocols into smaller units called meaning units. The text was divided each time Guidetti found a shift of meaning in the data (i.e., when the participants described a new aspect or experience), which helped her to concentrate the data.

In the third step, each meaning unit was understood and interpreted in light of all data from the interview protocol and the phenomenon under study. The focus was on the meaning imbued in the facts and events that were described by the participant.

In the fourth step, we synthesized and summarized the interpretations from Step 3 (summary formats) and arranged the features of the phenomenon (i.e., characteristics) in a way that best described different aspects of the context and their meanings in the recapture of self-care for this person. In this step, we went back to the interviews to confirm the interpretations and synthesis and to identify quotations and examples that reflected the meaning of context for this person.

In the fifth step, we moved from how the phenomenon was characterized within each participant’s interview (described in a summary format) to a general meaning structure that ran across all the participant interviews. In this step, we described and characterized from participant perspectives aspects of meaning of context in the recapturing of self-care. We discussed and refined the analyses several times by using a horizontally consistent interpretation among ourselves, making sure that each characteristic fit well with the other characteristics from the analyses and in that way clarifying the most valid interpretation (Karlsson, 1993). In this fifth step, Susanne Guidetti translated the meaning structure from Swedish to English. To ensure accuracy, Eric Asaba independently translated all selected quotations from Swedish to English and also translated Guidetti’s English translations back into Swedish.

Through this step-by-step process, we generated a meaning structure consisting of six main characteristics that were general for the 11 participants (Figure 1). We identified typological subcharacteristics representing typical features of the main characteristics and subcharacteristics that differed between participants. We used examples and quotations to illustrate the characteristics and the variations in individual experiences. The results were also presented to, and discussed with, experienced occupational therapists and researchers in the neurological rehabilitation field as a method of validating the findings.

Findings

The phenomenological analysis identified essential characteristics of the meaning of context in the participants’ lived experiences of recapturing self-care during the early rehabilitation process. We conducted all interviews while participants were still in a rehabilitation setting, where the environment was modified and accessible. We use the term meaning to denote the different roles and aspects played by context, as experienced by the person. Meaning is applied to the phenomena we focus on here to thus relate them to the different roles that context plays in the process of recapturing self-care. We present the findings as main characteristics, followed by subcharacteristics. The characteristics of recapturing self-care overlapped, drawn from each participant’s unique experiences. The last main characteristic, gradual change in challenge, subsumed and made visible the gradual change in meaning of context in the process of recapturing self-care. All of the participants shared common experiences with regard to self-care while attributing different meanings to their therapeutic relationship with rehabilitation professionals.

Support From Others

The participants expressed that immediately after their stroke or SCI, they needed support from others because of fatigue and feeling challenged by performing tasks. In the beginning, support entailed having someone else perform self-care for them; this gradually shifted to wanting support in performing self-care more independently. Later in the process, support began to mean having someone else in proximity who could provide support just by being nearby. The participants described that after the stroke or SCI, they first required physical support and felt comfortable having other people available to assist them with self-care activities. Receiving support and assistance during the performance of self-care was an important aspect of feeling secure and safe.
during the early phase of rehabilitation. One participant (recovering from stroke) said, "There is a lot one has forgotten, one’s movements feel dull, everything is difficult, the body feels heavy and it’s comforting to have people around who help." As time progressed, participants increasingly felt that the need for emotional support from others was of greater importance. “Others” in this case meant occupational therapists and rehabilitation staff members as well as relatives. One participant (with SCI) felt that his brother and parents were better at verbally nudging him to keep trying because they knew him: “They tried to explain why I had to . . . ehh, they understand me at least.” To be in an environment in which there were opportunities to meet and interact with other patients also provided social support for some participants, as one man (recovering from stroke) described: “It is positive for me to see others returning home; it is positive that they are doing well. Another patient was also impressed how quickly I did everything and that was also motivating.” Patients found that both seeing others and being seen by others motivated them to see the possibility of recapturing self-care. Being in a supportive context and having fruitful opportunities for social interaction with other patients, relatives, and rehabilitation staff were conditions necessary for recapturing self-care.

An Air of Expectation

Unspoken expectations were an aspect of context in which a culture of assuming responsibility for one’s own self-care emerged. This expectation was considered intangible, as an unspoken anticipation of people’s acting in particular ways even though the particularities were often perceived to be unclear. One participant asserted that “one should take care of oneself as one” of the daily routines in the rehabilitation wards. The atmosphere at the rehabilitation clinic signaled that participants should perform activities on their own; for example, in an SCI ward, breakfasts were placed at a level so that it was possible for patients to prepare and take it by themselves. These unspoken expectations could sometimes be explicit verbal expressions, or they could be something that participants sensed implicitly, which is exemplified by the following subcharacteristic. By verbally asking how self-care worked in the morning, occupational therapists created a sense that there were certain expectations.

Asking Questions. All the participants declared that when they were asked a question, they felt as though they needed to answer. By telling their stories to the therapist, they could understand and realize the importance of performing self-care independently. The implicit expectations that occurred through this questioning and answering could also imply to the participant that he or she could actually perform the task. One participant (recovering from stroke) stated that the therapist constantly asked questions about the participant’s progress in performing specific self-care activities: “She asked if I could tie my shoes; ‘No,’ I answered; ‘Have you tried?’ ‘No,’ I said. Then I tried and it worked.” Frequent queries made the participants more attentive to their own difficulties and more inclined to try doing things on their own. These questions exemplify the mechanism through which an air of expectation was created and also served as a feedback mechanism through which participants were able to see their own progress. The participants expressed that in the process of asking questions, they began to see the occupational therapists as people to whom they wanted to look good. Thus, expectations were experienced as demands to train and attempt to perform tasks on their own. One participant interpreted the process in the following way:

In the beginning, it was more that she [the occupational therapist] was there and [she] observed in order to later give advice; later we had some contact when we met and then she asked, “How did it go this morning, can you do it now?”

Participants with stroke more than participants with SCI described the occupational therapist as asking questions that produced unspoken expectations that contributed to the participants’ trying to perform the activities by themselves.

Extended Time

The participants mentioned a context of extended time (i.e., a feeling of an increased amount of time) as something important in the recapturing of self-care. Participants’ lived time was no longer in synchrony with clock time as before their injury, and they felt a need for time extended beyond clock time. In contrast to immediately after the stroke or the SCI, when participants just felt the need to rest, during the early rehabilitation phase, they needed more time to catch up and become acquainted with the new situation and their new body. An increased amount of time allowed participants to actually engage in self-care activities and get back on the right track. One participant described it the following way: “Nothing should have to take a certain amount of time so that one has to look at a clock, so that you feel rushed; rather, one keeps going until one succeed[s] or not.” Time and the use of time were necessary tools for enabling self-care activities and sometimes for just doing nothing.

Moreover, participants needed downtime and time to think about their bodies and about what they were doing. They also felt that they needed extended time to perform activities such as self-care. They valued being able to take the time they needed when they physically needed more time than before to manage different tasks. Participants described the importance of timing in the performance of self-care activities—of having someone to provide support when
needed but also of having an occupational therapist present to guide their development in performing self-care activities at the right moment.

**Down Time.** Immediately after their stroke or SCI, participants described needing to be in a context in which time was not filled with anything. We define this as *down time.* Participants’ interpretation was that they needed that time to think, and they expressed the idea that rest was important to allow the brain time to recover. One participant (with SCI) said, “The first 2 weeks, I only thought everything was strenuous when I couldn’t do anything.” One participant (recovering from stroke) stated, “It is really important to listen, and even that is tiring; after only half an hour, it is tiring.” The participants wanted to be in a context in which they were granted the extra time they needed to recapture self-care. One person (recovering from stroke) said, “Now I have been here for some time, and now I feel like things are slowly settling down, and when things settle down more and more, then I can move on.” Participants faced the sudden necessity of accepting a new life situation in which once taken-for-granted activities were now challenging. Moreover, one participant (recovering from stroke) felt that she was someone else immediately after her stroke. She also reported that she could not manage to perform the activities. She felt isolated and could not really accept her new life situation. She needed time to become familiar with her new situation and extended time. Another participant (recovering from stroke) stated, “There has been a full in a way; I think one needs that time in some way to catch up to oneself again. That is what I think most people experience as down time.” Down time seemed to give participants time to personally catch up, think, and reflect.

**Taking the Time It Takes.** Because they could not use their old routines and habits anymore, participants expressed the need for time to pass more slowly so that they could take the time they needed to perform self-care activities at their own speed. One participant (with SCI) said, “She [the occupational therapist] gives me time, and rightly so as it’s going to take the time it takes.” Participants were concerned about allowing time for themselves to carry out activities. As one participant (with SCI) explained,

> I have looked at my time here as something that my body needed for 3 months in order to heal, and at the same time I have 3 months to practice things—and this cannot be separated but must happen together. I cannot train more than my body can take.

Having time to independently decide how and when to perform self-care provided participants with a source of motivation to continue training. One participant (with SCI) said, “You need to focus on yourself and that is the only energy you have, time for yourself and your training.” Having time to do activities seemed to help participants get things working, and they continued getting on with their new life situations.

**Timing.** Participants described performing self-care activities at the right point in time (timing) as important. Timing was not only about getting the right kind of support at the right moment but also about trying an activity just when the participant felt ready to manage or to practice the activity. One participant (with SCI) stated, “I needed that little push; perhaps it also was the timing, it was exactly then when I succeeded, 1 week earlier I wouldn’t have been able to do it.” Another participant (with SCI) described good timing in this way: “The occupational therapist saw what I could manage and we used that as a starting point.” The participants expressed that the occupational therapists supported them in self-care activities when they felt they needed it. One participant (recovering from stroke) described a situation in which the occupational therapist arrived in the morning and showed him how to put on his shirt. The participant explained that this was important because someone gave him a nudge to start performing his self-care; he then continued on his own.

**New Daily Structure**

Before the stroke or SCI, self-care had been a part of everyday life that the participants took for granted. They described needing help in organizing their day and obtaining routines and structure in their daily activities. One participant (with SCI) said, “It was like starting over from the beginning.” Participants described daily schedules as helpful in planning activities and expressed that having structure in daily life was a prerequisite to being able to perform self-care activities. Setting self-care goals provided a concrete plan and structure for what to do and also served as a mechanism for feedback. A participant (recovering from stroke) stated, “The occupational therapist helps me by telling me what kind of activities I should do; one shouldn’t do too much because the brain, no, the brain has to get some rest.” A concrete structure allowed the therapists to challenge the participants to meet their present ability. The participants who had SCI described how they commonly participated in self-care training and formulated goals together with the occupational therapists, whereas participants who had stroke were more frequently on their own. Therapists and the participants who had SCI discussed the training schedule together. Participants expressed that this made them feel more involved in their own training situations and that creating a new structure with concrete goals contributed to furthering their self-care training. Yet, they also experienced the weekends as a non-organized span of waiting because they were used to doing activities with the occupational therapist. The participants who had stroke did not share this experience because they continued as they did during weekdays.
Therapeutic Relationship as an Enabling Possibility

Participants described the therapeutic relation with the occupational therapist as a possible means of recapturing self-care. The therapist was seen as one of the people who served this function of demonstrating and explaining activities. Participants who had stroke or SCI shared common experiences with regard to the therapeutic relationship while also attributing different meanings to their relationship with the therapists. On the one hand, the participants with SCI felt close to their occupational therapist and often referred to their relationship using the term we as though they had formed a union. On the other hand, the participants who had stroke experienced the therapist’s role as that of a nonpresent organizer. Participants also expressed a need to have activities explained or demonstrated in a practical manner. One participant (with SCI) described,

"The absolute first thing one has to do is to understand what to do now. It is, after all, the patient’s will that has to be included in the entire scheme, because if it isn’t there’s no point anyway, like it won’t work to train for something when one doesn’t know what to do, and that is how I understand it."

Another participant (recovering from stroke) mentioned when describing how others expressed themselves that “the most important aspect is how one says something to the patient and how one actually expresses it.” Collaboration and relationships with others were a prerequisite to and an enabling condition for recapturing self-care.

We as a Union (SCI). The participants with SCI, when talking about self-care training, included their occupational therapist as part of a we union. They described a very close relationship, near to a symbiosis, between themselves and their therapist. The participants’ contacts with the therapist might have been strong because of the close training situations. The therapist provided participants with feedback and was present at a bulk of the successes and failures during the rehabilitation process. One participant said, “And then one is swept up so that one can’t escape in some peculiar way. The occupational therapist catches you and sees to it that everything works out.” The occupational therapist was often described as one of the people who became close to the participants during the weeks after the accident, leading to the fostering of we thinking. For example, one participant elaborated on the success of his collaboration with the therapist:

"We discussed it, and this is what we are going to do, if there is something that I feel is a bit tough, is when we don’t do it right now. We do our exercises here, and that gives us the best results."

Participants described their relationship with the occupational therapist as “one,” or a whole, a unity.

Occupational Therapist as a Nonpresent Organizer (Stroke).

The participants recovering from stroke described their relationship with the occupational therapist (after one or two occasions) as that of a nonpresent organizer and advisor. The therapist supported them and was seen as expecting the participants to perform an activity on their own. In this way, the occupational therapists were perceived in an “as-if way,” as present even when they actually were not. All the participants mentioned that the occupational therapist had been present and observed them when performing the self-care activity at first. Initially, they felt that the therapist was there to organize the performance and structure the self-care training. One participant said, “Someone gives an impulse about how to do it and then one does it.” Another person said, “Then I got help to get going with it [self-care activities] and so it works really well.” The occupational therapist’s presence accentuated the importance of self-care; the occupational therapist was seen as someone organizing the training background. The participants experienced no need to have the occupational therapist present beyond this organizer role. One person stated, “The occupational therapist was really good at getting me to do things; [it] took a while for me to get going and then I learned very quickly.” Even though they were not present, the therapists and other staff infused participants with an air of expectation that encouraged them to feel and struggle for independence in self-care activities.

Gradual Change in Challenge

The meaning of context seemed to change in the process of recapturing self-care. Here we describe gradual change. Over time, the participants became more familiar with their bodies and with activities that they had previously taken for granted. Over time, others’ support changed from maximal to minimal. A gradual change in challenge was important in developing the performance of self-care activities. Another change in challenge was expressed in the participants’ need for extended time, which diminished during the process. The body and activities did not need as much time as in the beginning. By gradually developing new ways of doing, and new routines in which to embed self-care activities, participants began to incorporate self-care into their new lives and bodies. The participants began to accept the new challenges in performing self-care activities. One participant (recovering from stroke) stated, “Development is partly on your own and partly together with others.”

Discussion

The meaning of context in recapturing self-care has not previously been explored using a phenomenological approach. Our findings make visible the contextual aspects that play a
crucial role in the recapturing of self-care after stroke or SCI. There were many similarities in the participants’ lived experiences and in how context seemed to influence their recapturing process. However, we also noted differences between participants with stroke and participants with SCI in their experiences of the relations and interactions with their occupational therapists. Several clinical implications for rehabilitation can be drawn from this study’s findings.

The findings indicate the importance of being in a supportive social context, although the need for support seemed to change during the rehabilitation process. In the beginning, the participants needed more support and fewer challenges in self-care activities, which gradually changed as they developed their self-care skills. This finding is in keeping with those of other studies (Erikson et al., 2007; Tham & Kielhofner, 2003). The social interaction with the occupational therapists, rehabilitation staff, and relatives was important; moreover, other clients served as a mirror function for themselves as a type of feedback mechanism, which is in line with a study by Lampinen and Tham (2003). In accordance with the aspects of intersubjectivity as a part of the life-world (Merleau-Ponty, 2002), the participants seemed to understand one another, and by talking to one another, they also helped one another to shape reality. One clinical implication is that rehabilitation professionals can create a supportive context enabling social interactions between clients who can support each other in their recapturing of self-care. Another clinical implication is that occupational therapists need to give the right kind of support and understand when to alter the challenges during the self-care intervention process, which has been framed by Yerxa (1998, p. 370) as “giving just the right challenge.”

The second important finding was the meaning of an air of expectation as a means of transmitting responsibility for the participants’ own rehabilitation, which, to our knowledge, has not been described within this research area. The participants stated that as soon as they could do more activities on their own, they sensed from their surroundings that they were expected to increasingly perform self-care on their own. That air of expectation, and especially the questions posed by other people, supported participants in using their time in the right way (i.e., timing). Hjelmblink and Holmstrom (2006) described the use of time for people with stroke as a structure that changed in their new situation, in how they both consciously and unconsciously related to time. In this study, the participants expressed how they were given the time they needed and were supported in using their time in the right way (i.e., timing). Hjelmblink and Holmstrom (2006) described the use of time for people with stroke as a structure that changed their present life and blurred their future. Their present and past experiences need to be transformed into a whole new context, which also tended to be the case for the participants in this study. One clinical implication is that rehabilitation settings and contexts need to consider a person’s need for time and use of time when, for example, planning the rehabilitation program. Considering that rehabilitation clinic stays are becoming shorter, one dilemma is that there is not enough time for the clients to experience the process of recapturing self-care.
Another main finding was that the participants who had stroke or SCI differed in their experiences and the meanings they attributed to their therapeutic relationship with rehabilitation professionals such as occupational therapists. Mattingly (1994) stressed that therapeutic efficiency depends more on what the clients and the therapists are able to do together in therapy than on what the therapists are doing. In this study, the participants with SCI had powerful experiences regarding their interaction with their therapist, a we symbiosis. Lysack, Zafonte, Neufeld, and Dijkers (2001) described self-care training as frequent and natural for people with SCI. The participants with SCI in this study came very close to a symbiosis with the occupational therapist and mentioned we in most of their sentences. In a study by Barclay (2002), the therapists used we and are most of the time, which was explained as the therapists seeing the goals as jointly owned, not as only the clients’ goals. The therapists felt that it was their responsibility. When working in a client-centered context, it is important that the therapist and the client have mutual goals, thus also motivating the use of we. Moreover, in this study participants perceived an air of expectation that motivated them to achieve independence in self-care. For the participants who had stroke, self-care training was not present in the same way as for the clients with SCI. The occupational therapists acted as nonpresent organizers—also illustrated in the study by Guidetti and Tham (2002)—a therapeutic strategy that therapists used to encourage clients to attempt to perform self-care activities by themselves. One clinical implication is that the occupational therapist could serve a backstage function, as a nonpresent organizer. At the same time, there could be a requirement to support clients in integrating their performance of self-care activities in a new daily structure that may demand a more present “we-occupational” therapist. Another clinical implication is that rehabilitation professionals need to be aware of the influences the relationship could have in the training situation.

Limitations

In this study, we chose to interview several people with varied experiences of recapturing self-care (after stroke or SCI), and we therefore conducted the interviews on one occasion to limit the amount of data. This may have influenced the richness of data and credibility of the phenomenological analysis (Dahlberg, Drew, & Nyström, 2001). With Susanne Guidetti’s clinical experiences and theoretical knowledge, there could be a risk of bias in the analysis of the interviews. However, with a conscious awareness of this problem in qualitative analysis, we discussed and refined the findings numerous times. As a validation, when new and unexpected characteristics emerged, we presented them to and discussed them with experienced rehabilitation staff and researchers in the field. Another limiting factor could be that the participants with stroke did not participate in self-care training in the same way as the clients who had SCI, which could have influenced the experiences and meaning of the therapeutic relationship. One follow-up should be to study what happens when the symbiosis between the participants who had SCI and their occupational therapists ends. It would be interesting to know whether this also occurs as a natural separation. There is a need for more phenomenological studies that can serve as a basis for the development of an individualized therapeutic core.

Conclusion

This study contributes to a better understanding of how people with stroke or SCI experience the meaning of context in the process of recapturing self-care. The findings show the importance of creating a context within the rehabilitation setting that enables support from others. Having other people available to assist clients with self-care activities in the early phases of rehabilitation and then shifting to a more emotional support might be a constructive way to plan occupational therapy.

Second, by creating an air of expectation, therapists may encourage clients to work toward their own goals of independence in self-care activities. Third, it is important to enable extended time for clients who need it to actually perform self-care activities with their new body and time for reflection on their new situation. Although the experiences of the therapeutic relationship differed for the participants with stroke and the participants with SCI, they described the relationship as having an influential impact on the recapturing of self-care.

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