The Lived Experience of Recapturing Self-Care

Susanne Guidetti, Eric Asaba, Kerstin Tham

KEY WORDS
- life-world
- recapturing
- self-care
- spinal cord injury (SCI)
- stroke

This study sought to identify the characteristics of the lived experience of recapturing self-care after a stroke or a spinal cord injury (SCI). Five people who had had a stroke and six with SCI who were in the midst of recapturing self-care (1–3 months after onset) were interviewed. All interviews were analyzed using the Empirical, Phenomenological, and Psychological method. Four main characteristics were present among all of the participants’ lived experiences: (a) becoming familiar with the new body, (b) recapturing self-care through trying, (c) reclaiming control, and (d) feeling uncertainty in the continued recapturing process.

The findings indicate that a prerequisite for recapturing self-care was to get experience from doing to become familiar with the new body, which makes explicit the importance of enabling self-care in the rehabilitation process after stroke or SCI. The findings can be used in clinical practice to improve the understanding of how to better plan individualized self-care intervention.


After a stroke or spinal cord injury (SCI), taken-for-granted activities such as eating breakfast or taking a shower can suddenly become great challenges for independence (Tham, Borell, & Gustavsson, 2000). Consequently, many people often participate in self-care training programs as part of rehabilitation (Fowler & Hardaway, 1995; Neistadt & Seymour, 1995). Recapturing daily self-care activities after such conditions as stroke or SCI can be a long and demanding process (Mayo et al., 1999). In this article, we use the term recapturing to denote a process of engaging in self-care to regain abilities to participate in self-care activities.

Occupational therapists must better understand the lived experience of recapturing self-care (Söderhamn, 2000) and must understand experiences contributing to changes in the self-care training process among people living with the aftereffects of a stroke or SCI. This thinking is in keeping with the present study, which has a phenomenological perspective and focuses on the life-world experience of people who have had a stroke or SCI who commonly participate in self-care training and who experience a wide variety of activity limitations as well as participation restrictions (World Health Organization, 2001).

Several empirical studies have explored the experience of recovering from a stroke (Hafsteinsdóttir & Grypdonck, 1997; Tham et al., 2000) or SCI (Asaba, 2005; Cole, 2004). These studies identify personal consequences of disability in new life situations after injury or explore the reconstruction of self from the perspective of the person with a disability. Thus, although literature is sparse concerning the lived experience or meaning of recapturing self-care after a stroke or SCI, grounds exist on which to build and explore this process.

Although some studies have claimed that independence in self-care after a stroke or SCI is important for people and their close relatives (Bendz, 2000;
Lysack, Zafonte, Neufeld, & Dijkers, 2001), such ideas are not universally supported. According to a study by Pentland and colleagues (1999), men with SCI needed to spend 1.5 hours more time with self-care compared to a group without disabilities. Moreover, Weingarden & Martin (1989) showed that people with SCI who were able to dress themselves did not routinely do so when discharged from the clinic, owing to effort and strain. There is an ongoing critical discussion about the concept of independence within occupational therapy (Christiansen & Townsend, 2004), emphasizing the importance of how activities are valued by individuals. Other studies have shown that people who had a stroke perceived a loss of control of their bodies (Burton, 2000) as well as of their worlds (Nilsson, Jansson, & Norberg, 1997), which seemed related to feelings of being dependent on others. Moreover, Nilsson and colleagues described a change in identity when people who had had a stroke were faced with contemplating who they were in the future. This understanding is important for the development of therapeutic strategies for self-care training, whereas for the participants who had had a stroke, occupational therapy included only a few isolated sessions of self-care training, whereas for the participants who had had a stroke, occupational therapy included daily self-care training and because the characteristics of the impairments and disabilities vary widely, which can give rich and varied data representing 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 participants’ criteria for selection were (a) age ≤ 65 years; (b) inability to perform self-care activities and in need of self-care training several times a week in their continued rehabilitation, according to their occupational therapist’s clinical assessment; and (c) ability to understand interview questions and to share their experiences, according to their occupational therapist’s clinical assessment. Participants received written and verbal information about the study, and informed consent was obtained with 11 participants. The ethical committee at the first author’s affiliations approved the study. To protect the privacy of participants in this study, detailed individual demographic data were withheld. Collectively, however, it can be noted that all of the participants were employed (e.g., cook, construction worker, personal secretary, computer seller, student) at the time of injury (see Table 1).

Study Context

All of the participants were in the beginning phase of rehabilitation (1–3 months after the stroke or SCI) and at a rehabilitation clinic setting when they were interviewed. Because the purpose of this study was to find characteristics related to recapturing self-care, it was critical that the participants be in the process of recapturing self-care through training. To schedule interviews, the first author contacted the participants through their occupational therapists.

At the rehabilitation clinic, all participants received occupational therapy 1–2 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. All participants underwent an activities of daily living (ADLs) assessment.

Methods

Design

The interview data were collected and analyzed using the EPP (Empirical, Phenomenological, Psychological) method (Karlsson, 1993). This method has previously been used in occupational therapy research (Erikson, Karlsson, Borell, & Tham, in press; Guidetti & Tham, 2003; Tham et al., 2000).

Participants

The study group consisted of 5 participants who had had a stroke and 6 who had SCI. These two diagnostic groups were selected because they commonly participate in self-care training and because the characteristics of the impairments and disabilities vary widely, which can give rich and varied data representing 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 participants’ criteria for selection were (a) age ≤ 65 years; (b) inability to perform self-care activities and in need of self-care training several times a week in their continued rehabilitation, according to their occupational therapist’s clinical assessment; and (c) ability to understand interview questions and to share their experiences, according to their occupational therapist’s clinical assessment. Participants received written and verbal information about the study, and informed consent was obtained with 11 participants. The ethical committee at the first author’s affiliations approved the study. To protect the privacy of participants in this study, detailed individual demographic data were withheld. Collectively, however, it can be noted that all of the participants were employed (e.g., cook, construction worker, personal secretary, computer seller, student) at the time of injury (see Table 1).

Study Context

All of the participants were in the beginning phase of rehabilitation (1–3 months after the stroke or SCI) and at a rehabilitation clinic setting when they were interviewed. Because the purpose of this study was to find characteristics related to recapturing self-care, it was critical that the participants be in the process of recapturing self-care through training. To schedule interviews, the first author contacted the participants through their occupational therapists.

At the rehabilitation clinic, all participants received occupational therapy 1–2 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. All participants underwent an activities of daily living (ADLs) assessment.

Data Collection

The first author interviewed each participant once for approximately 1 hour 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 and how they experienced these 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 is a qualitative, interpretative, and descriptive analysis that aims to describe the essence, structure, and character of the studied phenomenon based on participants’ life-world experiences (Karlsson, 1993); therefore, the EPP method seeks to comprehend a person's experience and to represent it faithfully. Any theory outside phenomenology that explains or accounts for the phenomenon under investigation is bracketed during the phenomenological analysis. In the present study, the data were analyzed and interpreted in five steps. The first author was responsible for design, data collection, and analysis (Steps 1–5). The second author contributed to the study from the fifth step of the analysis. The third author was the senior researcher during the whole process. Steps 1–4 were completed separately for each participant during the analysis to discover how the phenomenon was presented and described within life-world experiences. In the first step of the analysis, the first and third authors read the interview of one participant (the protocol) until a good grasp of the material was achieved. In this step, the authors tried to have an empathetic understanding of participants’ original experiences of recapturing self-care.

In the second step of analysis, the first author divided the participant’s interview protocols into smaller units, called meaning units. The text was divided each time the author found a shift of meaning in the data. The aim was to help the author concentrate and focus on each shift of meaning in the text.

In the third step, each meaning unit was identified and interpreted in light of all data from the participant and the phenomenon under study. The focus was on the meaning imbued in the facts described by the participant. The authors traced and interpreted the meaning of recapturing self-care that was explicitly and implicitly expressed by the participants.

In the fourth step, the authors synthesized the interpreted meaning units into a “situated structure of meaning” (summary format) for each protocol. The authors arranged the characteristics (i.e., the features of the phenomenon) in a phenomenologically significant way by identifying and interpreting the self-care situation and process, with a focus on the experiences expressed in the doing and thinking described by the participants.

In the fifth step, the authors moved from the situated structure of meaning within each participant's interview to a general meaning structure that ran across all the participant interviews describing and characterizing the recapturing of self-care from their perspective. The analyses were discussed and refined several times by using a horizontally consistent interpretation between the authors, making sure that each characteristic fit well with the other characteristics in the analysis, and in that way clarifying the most valid interpretation (Karlsson, 1993). In this fifth step, the first author translated the meaning structure from Swedish into English. To assure accuracy, the second author translated each of the quotations into English, independently of the first author. The translations were compared and then rechecked against the raw data by all authors. No further action was taken when there was agreement; where translations did not agree, the authors deliberated further to achieve accuracy.

Through this step-by-step process, a meaning-structure was generated consisting of four main characteristics that were general for the 11 participants (Figure 1). Typological

### 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 40</td>
<td>40</td>
<td>Man</td>
<td>Married</td>
<td>No; crutches</td>
<td>Right hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke 57</td>
<td>57</td>
<td>Woman</td>
<td>Married</td>
<td>No</td>
<td>Right hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke 60</td>
<td>60</td>
<td>Woman</td>
<td>Married</td>
<td>No</td>
<td>Left hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke 65</td>
<td>65</td>
<td>Man</td>
<td>Widowder</td>
<td>No</td>
<td>Left hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>Stroke 50</td>
<td>50</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>Right hemisphere</td>
<td>—</td>
</tr>
<tr>
<td>SCI 28</td>
<td>28</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>Paraplegic</td>
<td>—</td>
</tr>
<tr>
<td>SCI 65</td>
<td>65</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>Tetraplegic</td>
<td>—</td>
</tr>
<tr>
<td>SCI 53</td>
<td>53</td>
<td>Man</td>
<td>Married</td>
<td>Yes</td>
<td>Paraplegic</td>
<td>—</td>
</tr>
<tr>
<td>SCI 30</td>
<td>30</td>
<td>Man</td>
<td>Living together</td>
<td>Yes</td>
<td>Paraplegic</td>
<td>—</td>
</tr>
<tr>
<td>SCI 21</td>
<td>21</td>
<td>Man</td>
<td>Single</td>
<td>Yes</td>
<td>Tetraplegic</td>
<td>—</td>
</tr>
<tr>
<td>SCI 38</td>
<td>38</td>
<td>Man</td>
<td>Living together</td>
<td>Yes</td>
<td>Tetraplegic</td>
<td>—</td>
</tr>
</tbody>
</table>

Note. SCI = spinal cord injury.
subcharacteristics of the main characteristics, which differed between participants, also were identified. As a method of validation, the results were presented to and discussed with experienced occupational therapists and researchers in the neurological rehabilitation field.

Findings

The findings from the phenomenological analysis identify essential characteristics of the participants’ lived experience of self-care during the beginning of their rehabilitation process. (It is important to note that interviews were conducted while participants were still in a rehabilitation setting where the environment was modified and accessible.) The findings are presented with main characteristics followed by sub-characteristics. Moreover, the characteristics of recapturing self-care occurred as an overlapping process, drawn from the unique experiences unfolding for each participant. Participants who had had a stroke or SCI shared common experiences with regard to self-care while also attributing different meanings to the process of recapturing self-care.

1. Becoming Familiar With the New Body

When participants shared their experiences from the first period after a stroke or SCI, they described their life-world as unfamiliar and their body as feeling different. During this period they needed to gradually take in and become familiar with their new body and with the new ingredients in their life-world, which was a prerequisite for recapturing self-care (i.e., regaining control over self-care). The earlier part of the recapturing process had been described as chaotic, and most participants felt that their bodies had been “in transit.” Although their bodies were in transit, participants reported that their lives continued, albeit with feelings of bodily tiredness. Participants believed that they were unable to influence this fatigue, and activities such as self-care were at times perceived as unreachable. One participant (recovering from stroke) said, “In the beginning it was exhausting for me to just think; that in itself was more than enough.” Another participant (recovering from stroke) said, “One could not move one’s arm, [could] not get dressed, and just the thought of putting on socks was tiring.” Being in-transit was characterized by passive receiving in the form of assistance with self-care, as opposed to being active actors in their own self-care. The participants allowed others to care for them so they could gain time to catch up with their bodies and lives. One interpretation is that the intense fatigue felt by the participants drained them of all their energy. Everything in daily life that they had earlier taken for granted felt as if it were impossible. They now needed to think and reflect on each and every action during performance because they could no longer take for granted their bodies or doing in self-care.

The participants felt like strangers to themselves in this new situation. When they tried to perform self-care activities, their body parts felt like objects or obstacles. One participant (with SCI) stated, “But it didn’t go so well at first, in the beginning, that’s a given, I have never in my life done this before,” and another participant (recovering from stroke) said, “In the beginning I didn’t have a clue where it [her hand] was, it was behind my back and like this, so the first night it could have been anybody’s hand, it could have been my neighbor’s hand [participant laughs].” The participants’ life-worlds were characterized by something “new and unknown,” and they were exposed to it without knowing the direction of their new life situation. The participants had experienced a sense of alienation—a disconnection between the self and the new body—and also a disconnection in the interaction between the body and the world in different kinds of activities. Merleau-Ponty (1945/2002) described the relationship between the body and the worlds: “I am conscious of the world through the medium of my body” (p. 94). One participant (recovering from stroke) felt as if she were someone else whose new body was not incorporated in hers, and she could not accept the new self when trying to perform activities previously taken for granted. She said, “I was in it [her body], but it wasn’t I, it wasn’t me.” Another participant (with SCI) explained her feeling of bodily alienation: “When I was lying down, I had two clumps by my side that were immobile; I felt so heavy in bed, couldn’t move.” Over time, the participants became more familiar with their bodies, first by being passive receivers during the “transit period,” followed by a more active period when they tried to perform and practice activities.

2. Recapturing Self-Care Through Trying

Through experiencing different daily activities, participants gradually became more familiar with their new bodies and

| 1. Becoming familiar with the new body |
| 2. Recapturing self-care through trying |
| 2.1 Everything you do is training (Spinal Cord Injury) |
| 2.2 Self-care is not training—it is something you must do (Stroke) |
| 3. Reclaiming control |
| 3.1 Taking control over the new body (Spinal Cord Injury) |
| 3.2 Reclaiming body part (Stroke) |
| 3.3 Taking control over activities linked to the old identities (Stroke) |
| 4. Feeling uncertainty in the continued recapturing process |

Figure 1. Meaning structure, consisting of main characteristics and subcharacteristics.
abilities. All of the participants expressed “recapturing” through doing activities. One participant (with SCI) described the feeling of trying self-care activities with a new body: “It was like starting over from the beginning.” The recapturing of self-care comprised both trying and regaining competence through doing activities. One participant (recovering from stroke) described taking back competence as, “I am trying to learn as quickly as possible, and it can take as much time as it takes. I cannot get away from that, it’s just got to be done, and it’s so damn much.” One participant (with SCI) used a strategy to develop these self-care skills: “Before I ask for help I try by myself, and then maybe I develop something.” To fully comprehend the feeling of the new body and to be able to incorporate self-care, the participants needed to try the body in an activity.

When participants tried performing activities, they found it helpful to start with a “harmless activity” (one in which the participant felt safe and that could be okay to fail). For example, activities performed together with other clients in the training kitchen were perceived as purposeful and at the same time less threatening than self-care. One participant (with SCI) said, “I had never baked before but I thought it was quite fun,” and another participant (with SCI) described the kitchen activity as follows:

When we got to make cakes, which involved making a cake bottom, I got to decorate and everyone does their own part and that works. Someone makes coffee, and someone was too tired and could stay in their room and it was no problem. There was nothing that was important, actually; okay, one does what one can and everyone does their best.

By performing these harmless activities, the participants experienced doing, which seemed to help them dare to try self-care activities. By trying and feeling that they were able to do something with the body, the participants expressed a sense of possible development and a potential future.

2.1. Everything You Do Is Training (SCI)

The participants who had SCI described self-care activities as training, starting in the morning by rising from bed, performing personal care, making breakfast, and then continuing until bedtime. Moreover, self-care was seen as part of rehabilitation. One participant expressed his days in the rehabilitation clinic as, “It was one big training session from morning ’til night.” Another participant spent much time thinking about how to manage a particular activity, which he then needed to try. The participants with SCI said that they needed to start from the beginning with their “new” body, and needed to find new experiences that could lead them to independence. The possible routines and habits that the participants had perceived as having earlier no longer existed with this new body.

2.2. Self-Care Is Not Training—It Is Something You Must Do (Stroke)

The participants who had a stroke said that self-care activities were something that they had to do, “a must,” and therefore they did not experience self-care as training. They saw self-care as common sense or something ordinary that they had to do in their daily life, such as dressing and washing. Moreover, the participants stated that the goal was to perform self-care as opposed to training an affected body part; therefore, the affected body part often was not incorporated when they performed self-care activities. The participants described an inherent drive to do an activity with or without arms in order to become independent (managing to perform the self-care). One woman talked about how her hand didn’t function as it used to when brushing her hair before her stroke: “To brush my hair is a little difficult, but that is nothing compared to how it used to be . . . I can handle that, and it is bound to get better, I hope.” Participants expressed recapturing self-care as something that would fall into place with time. For the participants who had a stroke, training was more about arranged activities (such as picking up pegs and fitting them into Peg-Boards) at the occupational therapy department, which focused on body functions. Another participant said, “They [occupational therapists] are giving me things to do for the arm and the leg to get better.” During this early phase of recovery, participants still did not understand the future consequences of their strokes in their everyday activities and focused on how their lives would return to the way they were before the stroke.

3. Reclaiming Control

All participants expressed the desire to become less dependent on others and to have more opportunities to make choices for their actions in daily life at the clinic. They described how they sought to reclaim control of their bodies and doing in their daily life. In particular, they expressed that becoming independent in self-care was important for their self-perceived sense of agency (i.e., the sense that they are the owner of their own actions). In this way, the participants made a connection between their sense of independence and their ability to make choices, express intentions, and thereby affect their own situation through doing. One participant (recovering from a stroke) stated, “It’s important to manage to do something on your own so that you will not feel so entirely dependent on others.” Through experiences of doing, participants shifted from being passive receivers to people who could see new possibilities for making their own activity choices. One interpretation is that the participants had lost a certain degree of agency after their
stroke or SCI and now had regained this feeling through their experiences of being able to act on their intentions. However, participants who lived with the aftereffects of a stroke versus SCI differed in how they attributed meaning to this reclamation process of taking control.

3.1. Taking Control Over the New Body (SCI)

Participants living with SCI talked about control in terms of taking control of their new body—that is, the whole body or the body below the waist. One person said, “One tries things one doesn’t really know and before one can, and feel [through the body] how it is to do [them] . . . .” To develop independence, the participants needed to learn and to feel through bodily engagement what activities worked well. Another person said, “You need to notice what is needed, what it is that triggers, what works, and what is cumbersome [to manage to do]!” After a more passive period of transportation, the participants realized that they were responsible for their choices; thus, through striving for better control over the body, they could reach agency.

3.2. Reclaiming Body Part (Stroke)

Participants who had had a stroke focused on reclaiming one body part, such as one arm or leg, rather than taking control over the entire new body. Reclaiming the body part (arm) was perceived as a separate process that was disconnected from the process of recapturing self-care. For example, although the arm was disconnected from the taken-for-granted self-care, the participants strove to reclaim the body part. They said that it was difficult for them to understand the connection between individual body parts and body functions that were needed to make the self-care activities possible. One of the participants said, “I am trying to teach my arm to function again; it is the actual signal from the brain to the arm that has to go along this line.”

3.3. Taking Control Over Activities Linked to the Old Identities (Stroke)

The participants who had had a stroke described a loss of activities, routines, and habits in which they had previously been involved. It was not until the body did not function as it used to that participants first reflected on the difficulties involved in performing basic ADLs and how closely this aspect of their daily life was linked with their former identities, which they desired to resume. Getting dressed or putting on makeup, for example, was considered an important aspect of expressing who they were, which subsequently influenced possibilities for representing themselves at work. One woman described how her self-identity was related to how she dressed and how she looked at the workplace:

The occupational therapist said that I was independent in getting dressed, but I am stricter with [dressing for] work, so to speak; there, I wear high heels, and that is something that I cannot walk in now, that I cannot manage.

This notion finds support in the literature because Penny Richardson (an educator whose efforts to regain ability after having a stroke were described in the American Journal of Occupational Therapy) similarly believed that wearing certain clothes to work—in her case, high heels and a dress with buttons—was critical to her self-presentation (Clark, 1993). For the participant in the present study, self-care activities were strongly related to her identity as a personal secretary for a prominent company. The woman, who also dressed more casually in the rehabilitation setting, believed that it was impossible for her to wear this kind of “leisure” clothing at work. Participants felt a loss of identities as their abilities to perform self-care were challenged and as a result made attempts to reconnect with and express themselves through past identities.

4. Feeling Uncertainty in the Continued Recapturing Process

All of the participants in this study faced a certain need to cope with their new life situation and become active in the process of recapturing self-care. Some participants waited and wished for life to return to the way it was before; others began to incorporate their condition into thinking about a future independent life. The participants who had SCI often used previous experiences to find new ways of performing self-care, and they expressed a certain awareness of what strategies were needed: “I struggle [with self-care] and willingly laugh about [the fact] that I cannot manage it now, but I know that in a week it is going to [be better]. Let’s see if I can manage it then.” The participants who had had a stroke differed because they sought to be the way they had been before their stroke. They were striving to reclaim their old identities. The process of recapturing self-care did not end at the time of the interviews; rather, each of the participants expressed his or her future horizons as uncertain yet filled with desires and hope.

Discussion

The phenomenon of recapturing self-care has not previously been explored using a phenomenological approach (Karlsson, 1993). The findings explicate a meaning structure consisting of four main characteristics and five subcharacteristics. A common feature across these characteristics was the focus on the lived body experiences as the starting point from which the participants recaptured their self-care activities. However, participants who had had a
stroke versus those with SCI differed in their experiences of how they recaptured self-care. This bifurcation in the lived body experiences agrees with the phenomenology of Merleau-Ponty (1945/2002), who stated that the entrance to the world is through our bodies and that any altered bodily state (i.e., hemi-, para-, or tetra-paresis) will alter the entire life-world experience. The process of recapturing self-care was characterized by participants becoming familiar with a new life-world, which seemed to be a prerequisite for recapturing self-care through experiences of doing. A natural starting point for these participants was the body (Merleau-Ponty, 1945/2002), which has also been illustrated in previous studies focusing on the lived experience of stroke (Kvigne, Gjengedal, & Kirkevold, 2002; Tham et al., 2000). All participants seemed to experience their bodies as unfamiliar. However, the participants with stroke perceived their affected body parts as objects not integrated into their bodies, whereas the participants with SCI experienced their bodies as integrated. The objectification of body parts among people with stroke has been discussed in previous studies (Tham et al., 2000).

The participants in this study described a process of first being in chaos, then being in transit, and then slowly beginning to try activities. They expressed relief about being in a period of transition, which, in keeping with a previous phenomenological study, implied that they needed time to become familiar with the new life-world (Tham & Kielhofner, 2003). This finding indicates a need for more extensive social support in conducting self-care in the beginning of the process.

The experiences of trying activities were significant (Mattingly, 1998) and facilitated change in the recapturing process. Based on this study, enabling bodily experience through self-care training seems to be an important intervention early in the rehabilitation process. An interesting finding was that so-called harmless activities seemed to be important for the participants (especially those with SCI) before they were comfortable performing self-care. One way of understanding the meaning of harmless activities is that these activities were less threatening than self-care activities, which were connected to expectations rooted in past experiences. Activities associated with expectations were perceived as too risky because of a perceived possibility to fail in performing the activity as anticipated. This finding has implications for occupation-based therapy focusing on client-centered interventions and meaningful activities (Kielhofner, 2002). The present findings suggest that interventions sometimes could start with activities that are purposeful but less meaningful and therefore less threatening.

In this study, the participants who were recovering from a stroke described a lack of opportunity during self-care training to practice activities with personal significance, such as donning a bra, wearing high heels, or applying makeup. This finding is in keeping with Clark (1993), who highlighted the importance of using (in therapy) activities linked to the clients’ former identities and social roles. Activities such as picking up pegs were not experienced by study participants as familiar or linked to previous experiences or identities. On the basis of these findings, occupational therapists are encouraged to enable practices and activities that are important for the clients at present and future.

Another interesting finding was that the participants who had had a stroke still seemed to take self-care for granted; however, while simultaneously expressing a desire to reclaim body parts, they did not integrate these body parts into self-care activities. One clinical implication might be that occupational therapists should put more emphasis on guiding and supporting the clients to integrate the affected body parts into self-care training.

The aim of phenomenological research is not to generalize findings but to reveal the meaning structure of the participants’ life-world experiences related to the studied phenomenon to gain a deeper understanding. In this study, we chose to interview several people having varied experiences of recapturing self-care (after a stroke or SCI), and therefore the interviews were conducted only on one occasion, to limit the amount of data. This limitation could have influenced the richness of the data and credibility of the phenomenological analysis identifying the characteristics of the phenomenon under study (Dahlberg, Drew, & Nyström, 2001). The limitation of using the EPP method is that it aims to identify main characteristics that run across all interviews (e.g., despite differences in age), which could have limited the understanding of individual experiences. Therefore, we strove to give concrete examples and quotations, which reflect the individuals’ experiences.

By identifying the meaning structure with main and subcharacteristics, this study contributes to the future definitions of the self-care phenomenon. A future longitudinal study examining performance and experience over a longer period could add knowledge to develop this definition.

Overall, this study contributes to a better understanding of how people who had had a stroke or SCI experience the recapturing of self-care, which in turn can improve the implementation of client-centered rehabilitation interventions. The more specific clinical implication of the findings is that more extensive social support is needed during self-care training in the “transit” phase (i.e., in the beginning). When starting to practice self-care activities, it is important to allow for time during which clients can try to feel their bodies in the activity. If clients do not feel comfortable performing self-care, they can start with something purposeful.
but less meaningful and therefore not threatening. Moreover, rehabilitation interventions should enable bodily experiences, such as the integration of affected body parts in the performance of self-care, to enable recapturing and perceptions of autonomy.

Acknowledgments

We acknowledge the clients who gave their time to participate in the study. We also thank The Swedish Association of Persons with Neurological Disabilities; the Swedish Stroke Association; and the Centre for Health Care Science, Karolinska Institutet, for financial support.

References


