Impact of the Social Environment on Occupational Experience and Performance Among Persons With Unilateral Neglect

Kerstin Tham, Gary Kielhofner

OBJECTIVE. The purpose of this study was to gain an understanding of social environmental influences on occupational experience and performance over the course of rehabilitation of four persons with unilateral neglect.

METHODS. The Phenomenological Psychological Method (Karlsson, 1993) was used to gather and analyze qualitative data on four women over a 4-month period. Four women were interviewed five to seven times each and observed during their rehabilitation process. Analysis focused on how these persons with unilateral neglect experienced and responded to their interactions with others in their everyday lives.

FINDINGS. As perceived by the study participants, rehabilitation professionals and relatives demonstrated a sequence of strategies for dealing with and helping the women perform despite their unilateral neglect. The sequence of strategies reflects the changing experience of neglect over time. The strategies used by professionals and family members during the rehabilitation process enabled these women to reclaim and occupy the neglected half of the world. Moreover, the women with neglect learned to incorporate others as extensions of their bodies in order to compensate for their ongoing inability to directly experience the left half of the world.

CONCLUSION. The results suggest that it is important for others (e.g., therapists, nurses, or relatives) to understand the client's changing experience of neglect and adjust their support and collaboration accordingly. Occupational therapy intervention for persons with neglect could potentially become more effective by systematically incorporating the kinds of strategies identified in this study. Moreover, therapists could consult with others to increase their understanding and effectiveness in interacting with persons who have unilateral neglect.


Occupational therapy literature acknowledges the importance of the environment for occupational performance and for therapy (Dunn, Brown, & McGuigan, 1994; Law, 1991; Law et al., 1996; Nelson, 1988). Occupational therapy consists primarily of using and creating conditions in the environment to support the client's occupational engagement (Kielhofner & Forsyth, 2002). While the field has generated substantial knowledge about physical barriers and supports in the environment, there is limited empirical data about how the social context influences occupational performance among persons with disabilities. Even less has been published about how the social environment influences change in clients during therapy.

The objective of this study was to understand how the social context had an impact on persons with unilateral neglect following cerebrovascular accidents (CVA) in the right hemisphere during 4 months of rehabilitation. The term, impact, is used to denote how opportunities, supports, demands, and constraints posed by the environment resonate with and influence a person given his or her unique characteristics (Kielhofner, 2002). In this case, our focus was on how the actions of others res-
onated with and influenced persons with unilateral neglect as they engaged in their everyday occupations.

Unilateral Neglect

Unilateral neglect is most common and severe after right CVA and "when the neglect is severe, the patient may behave almost as if one half of the universe had abruptly ceased to exist in any meaningful form" (Mesulam, 1985, pp. 140–142). Persons with unilateral neglect may be inattentive to stimuli in space (i.e., extrapersonal neglect) or may be inattentive to one half of their own body (i.e., personal neglect) (Bisiach & Vallar, 1988). Our specific focus in this study was on extrapersonal neglect. Such neglect severely influences the person's interaction with the environment during the performance of such daily tasks as eating and reading, since the person is not aware of the impairment and does not act with reference to half of the external world (Tham & Borell, 1996).

Phenomenology and the Lived Body

The theoretical basis for this study is phenomenological philosophy as it has been incorporated into the model of human occupation concept of the lived body (Kielhofner, Tham, Baz, & Hutson, 2002). The concept of the lived body emanates from the work of phenomenological philosophers (Husserl, 1970; Leder, 1990; Merleau-Ponty, 1945/1962), who criticize the mechanistic view of the body as a complex machine producing perception and action. Husserl (1970) originally called attention to the life-world (i.e., how the self and the world are experienced) as fundamental for understanding how humans learn and perform.

The life-world refers, then, to the most basic way in which we apprehend ourselves as situated in a practical and intersubjective world. As Husserl (1970) points out, the life world is ordinarily taken for granted and unquestioned. It is the starting place from which we act and create meaning. Building on the life-world premise, other philosophers have focused on how embodiment shapes experience and action. Merleau-Ponty (1945/1962) and Leder (1990) both emphasize how experience is given and shaped by the body and they argue that this experience also plays a central role in performance. One cannot, therefore, conceive of action as separate from experience since all action implies a way of apprehending self and the world. Unlike approaches that examine bodily mechanisms and processes to describe and explain performance from a detached, objective perspective, phenomenology focuses on how subjective experience shapes action.

These ideas have been recently incorporated into the model of human occupation to conceptualize performance capacity (Kielhofner, 1995; Kielhofner et al., 2002). This perspective employs the concept of the lived body to refer to the experience of being and knowing the world through a particular body. This concept is proposed as being particularly relevant to understanding how alterations or impairments of the body are also represented in transformations of experience. It also follows from this that both difficulties of performance and enhancement of performance should be understood and addressed in terms of the specific life-world experience that is involved. A central idea of the lived body that guided this study was the assertion that subjective experience of performance is not simply an artifact of performing. Instead, we view experience as fundamental to how we perform. This means, then, that how people with impairments do things and how they will learn better ways to do things cannot be understood without careful attention to their life-world experiences.

A previous study (Tham, Borell, & Gustavsson, 2000) focused on how persons with unilateral neglect experienced, discovered, and learned to handle their disabilities in everyday life. The study demonstrated that the participants needed to experience and ultimately come to a practical recognition of their own impairments and their consequences in order to improve their performance. However, persons who had unilateral neglect did not directly experience the neglect (i.e., the left half of the world is not "felt" to be absent from perception). Consequently, they had to engage in a process of discovering and understanding that there exists a half of the world that is not part of their life-world. Once they were able to comprehend the existence of a part of the world that was outside their experience, they could begin to manage the consequences of their own unilateral neglect during occupational performance.

Study Design

In this study, we examined how the actions of others influenced the process by which persons with unilateral neglect come to comprehend and manage their neglect and its consequences. In order to be faithful to a phenomenological perspective (Karlsson, 1993), we examined this process from the point of view of the women who had neglect. We wanted, specifically, to understand how these women experienced others’ actions and how those actions appeared to contribute to the transformation of these women’s occupational performance over time.

Methods

Participants

The study participants were four women in an inpatient neurological rehabilitation clinic in Sweden. The partici-
pants were consecutively recruited based on the following inclusion criteria: right CVA of less than 10 weeks duration with left hemiparesis and severe extrapersonal unilateral neglect, as verified by the Letter Cancellation Task (Mesulam, 1985), and physical, psychological, and intellectual capacities, which allowed active participation in the study. See Table 1 for further information about the participants (all names are pseudonyms). The Ethical Committee at the Karolinska Institutet approved the study. The participants received both written and verbal information as part of their informed consent.

**Data Collection**

The participants were interviewed five to seven times each, over 16 weeks during which they received occupational therapy and other rehabilitation services, such as daily physical therapy. From the third to the seventh week of the study, the four women also received specialized occupational therapy intervention (1–2 hours, 5 days a week) focused on improving awareness of their unilateral neglect (Tham, Ginsburg, Fisher, & Tegnér, 2001). The rationale for the specific awareness-training program was to use meaningful everyday occupations as the therapeutic media to improve awareness of disability. Interviews with the participants lasted between 30–75 minutes and were tape recorded and transcribed verbatim. Questions were informal and open-ended and focused on the participants’ experiences of everyday occupation. They were asked to concretely and spontaneously describe their recent experiences with a focus on how they did the things they did in everyday life, and to tell about how they experienced and managed the situations they chose to describe. In asking participants about their perceptions of how others actions affected them, no distinction was made between professionals and other persons. Also, the focus on data collection and analysis was specifically on how the women with neglect experienced others’ actions and not on the intentions or clinical reasoning behind those actions.

The interviews were supplemented with observations of the participants as they carried out their daily occupations in the rehabilitation setting and in their home settings. Field notes were written after each interview and following observations. The field notes helped us to better understand the participants’ experiences, described in the interviews, during the phenomenological analysis.

**Data Analysis**

A modified form of the Empirical, Phenomenological, Psychological method (EPP method) (Karlsson, 1993) was used to analyze data. Specifically, the psychological focus of the method was replaced with a focus on the daily occupational experiences of the participants. The EPP method is based on the philosophy of Husserl and to a lesser extent Heidegger (Karlsson, 1993). It aims to critically examine persons’ life-world experiences in order to describe the essence, structure, and character of those experiences.

Thus, the EPP method strives to comprehend a person’s experience and to represent it faithfully. This means that any theory, which would already explain or account for the phenomenon under investigation, is bracketed during the phenomenological analysis. Consequently, our previous knowledge of unilateral neglect based on medical, neuropsychological and occupational therapy cognitive-perceptual concepts had to be put aside. Instead, we approached the women’s experience as an unknown phenomenon that had to be understood in its own right.

The analysis was done in five steps that make up the EPP method. The first four steps were completed separately for each participant. In the final step, data from all the participants were synthesized together. First, all the interviews of one participant were examined to generate an empathetic understanding of the participant’s experiences without any interpretation. Second, the data in each participant’s interview transcripts were divided into meaning units (i.e., unique ideas, themes, topics, or experiences). Division of the transcript into meaning units is done by noting when a shift in meaning (i.e., the sense or significance of what is being said) occurs in the interview. Third, meaning units in each participant’s interview transcripts were interpreted in light of all the data in the interview. During this step themes were identified by moving back

<table>
<thead>
<tr>
<th>Table 1. Participants’ Clinical Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Days post CVA</td>
</tr>
<tr>
<td>Sensory loss</td>
</tr>
<tr>
<td>Visual field deficit</td>
</tr>
<tr>
<td>I-ADL motor ability</td>
</tr>
<tr>
<td>I-ADL process ability</td>
</tr>
<tr>
<td>MMSE</td>
</tr>
</tbody>
</table>

*Sally had also had a previous right CVA 8 years earlier, with no residual effects.

CVA = Cerebrovascular Accident
Sensory loss: Can identify less than 2 of 5 single stimuli, in arm and leg (severe)
Visual field deficit: Can not identify any of the 5 single stimuli, in the upper and in the lower visual field (hemianopia); Can identify less than 2 of 5 single stimuli in the lower visual field (lower field deficit)
I-ADL motor ability: Measured by the Assessment of Motor and Process Skills (AMPS) (Fisher, 1997): Persons with ability measure scores below 2.0 logits, are likely to have skill deficits that affect IADL ability.
I-ADL process ability: Measured by the AMPS (Fisher, 1997): Persons with ability measure scores below 1.0, are likely to have skill deficits that affect IADL ability.
MMSE = Mini Mental State Examination (Folstein, Folstein & McHugh, 1975).
I-ADL = Instrumental activities of daily living.
and forth between concrete facts (e.g., events, actions) and the meanings that permeated facts. For example, when a participant described an everyday situation in which another person did something that she found helpful, we sought to understand exactly how the participant experienced the action as helpful (i.e., the meaning of the experience). During the fourth step, the themes that emerged from the previous step were synthesized into what Karlsson, (1993) refers to as a “situated structure of meanings” (p. 106). This process involved characterizing each participant’s life-world experiences. Finally, we synthesized the information from each participant into an account that described features common to all four participants. In producing this account, we sought to assure credibility by moving back and forth between the arguments we were creating and the data from each participant. We discussed and refined our interpretations multiple times between ourselves and with others to clarify our ultimate presentation of the findings.

Findings

As expected, the participants did not perceive and, therefore, were unable to intentionally interact with other people or objects located in the left half of their environment. Their neglect was such that the “left half” of their worlds, which they did not apprehend, always shifted according to where they focused their attention. We will refer to this region to the left, that they did not perceive, as the left-world. Importantly, the right half of the world that they perceived was for them complete, natural, and unquestioned. It was their life-world. This is not to say that the life-world was unproblematic for them. Indeed, these women experienced many things about the world that were new and strange after their CVAs.

In what follows we will present the strategies that other persons used and that were perceived as positive and helpful by the participants. It is important to note that these strategies were not necessarily those that professionals were consciously using to provide therapy related to the participants’ unilateral neglect. In fact, many of the most useful things were done by nonprofessionals or by professionals outside their therapeutic role. Participants perceived strategies as helpful and positive when they resonated with how they were experiencing their neglect at the time. Consequently, as the participants’ experiences of neglect changed, the strategies that they found helpful changed. There was a natural history both to how the participant’s experienced and adjusted to unilateral neglect and what actions of others facilitated this process.

We grouped the strategies we found according to the general sequence in which they appeared and the strategic significance they appeared to have for the women with neglect. These groupings, in order of appearance, are:

- Bringing order to a chaotic life-world
- Providing access to the left-world
- Permitting encounters with the left-world
- Supporting occupation in the left-world
- Adjusting collaboration for occupying the left-world

While these groups of strategies generally occurred in sequence, they did not constitute discrete stages. Rather, the groups overlapped, and complemented the unique unfolding of each woman’s experience.

Bringing Order to a Chaotic Life-World

The strategies that others used and how they were perceived by the women must be understood in terms of the experiential ground of the women. So, we begin by describing what the participants’ initial experiences were. Moreover, as we discuss the evolving strategies we will link them to the women's evolving experiences.

For these women, the left-world did not reveal itself as an ordinary presence. Rather, the women encountered things in the left-world in extraordinary or strange ways. For example, the four women experienced objects and people as disappearing and reappearing as they passed in and out of the left-world. Such experiences were quite bewildering and unsettling; as Sally noted, “It is very unpleasant when [new] things suddenly materialize despite your thinking you knew what was there.” Also, when the women went about doing things as they were accustomed to do them, they often made mistakes when they unknowingly encountered the left-world. For example, when maneuvering their wheelchairs, the women sometimes bumped into furniture that did not exist for them (i.e., that was in their left-world). Moreover, when they made such mistakes they did not experience or recognize them as ordinary mistakes. That is, instead of noticing an object into which they accidentally bumped, they heard a banging sound that “came from nowhere” and felt their chair jar or stop suddenly “for no reason.”

Because in this early stage they did not yet experience themselves as having neglect, the participants could not interpret the strange things that happened to them as being due to their neglect. Consequently, they were not able to make sense of their problematic actions by recognition of personal errors. Rather, the consequences of errors emanating from their neglect were bewildering to them. Having experienced a host of such unfamiliar and unfathomable events, they felt that their worlds were in chaos. To an extent, their life-worlds had lost their familiar order in that their actions frequently had inexplicable consequences. The chaotic life-world they now encountered left them, quite understandably, anxious.
Compounding the women’s confusion and anxiety about the external world was their sense of estrangement from the left half of their own bodies. These women all felt as though the left half of their bodies did not belong to them. In the same way the left-world was no longer part of their life-world, the left half of the body also seemed not to be part of the self (Tham, Borell, & Gustavsson, 2000).

Initially, the group of strategies used by others served to bring some kind of order into the women’s new and unfamiliar life-worlds. For these women, experiencing some semblance of order was important to stabilize them in a life-world that was not utterly strange and confusing. When they talked about what others did, the women acknowledged that these strategies by others (described below) served to bring order to their everyday world.

Preventing Failures and Strange Experiences

During the early phase of rehabilitation, others in the social environment prevented the women from having failures and strange experiences by adjusting things in the left-world or by adjusting the women’s relationship to the left-world. For example, one common preventative measure was moving objects to the right side, where the women would find them. Referring to instances when someone had purposefully placed her glass on the right side of the table, Ellen noted, “Sometimes I can easily find the lingonberry drink on the table and I like that because I don’t need to look and look, and then finally ask for help to find it.” Another example was correcting the trajectory of the women’s wheelchairs to avoid a doorpost or corner, thus allowing the women to continue their journeys without incident.

Such interventions reduced the women’s experience of the world as chaotic and helped alleviate their anxiety during this early phase when they did not comprehend what was going on. Notably, these strategies did not help the women learn about their neglect, but rather reduced the bewildering consequences of neglect.

Framing the Body

Others took on a significant role in helping the participants deal with the estranged left half of their bodies. Sometimes this meant locating where the left half was. One woman described, for example, how she needed others to help her to find her left arm, which she would “lose” when lying in her bed. “When I can’t find my bad arm in the bed I call for the nurses and ask them if they can find my arm and I am so satisfied because they always can find it in the bed. Usually, they find it on the pillow, otherwise we continue our search together.”

The participants often had difficulty knowing where their bodies “started” and “ended.” Ellen described, for example, that she couldn’t tell where her mouth started and ended. She explained: “I need help to use my lipstick. I feel very uncertain because I worry that I’ll paint outside my lips and it will look very strange.” Consequently, she received physical assistance to trace her mouth when putting on her lipstick. Such strategies helped the women feel more at ease with their own bodies, bringing some order into their life-worlds.

Providing Security

Not surprisingly, the women felt quite insecure in doing even ordinary things. For example, Alice explained, “When I’m standing up I’m drawn to the left. It feels like something is pulling me. My body is being sucked to the left and also my head. So I try to hold against the force that’s pulling me off balance. Otherwise I will fall. However, I don’t feel so scared if someone that I can trust is standing beside me.”

Without the sense of security that others in the environment provided, the women often wouldn’t try to do things that they perceived as too challenging or uncertain. Sally felt, for example, that she could maneuver her wheelchair within the facility because staff would always find and redirect her when she got lost. She notes, “I am always asking others for help to lead me back to my room.” As this example illustrates, the women came to rely on others as guides to help them through their chaotic life-worlds. They came to recognize, refer to, and rely on nurses and therapists as “experts” on the world.

Providing Access to the Left-World: Coaching

As the women became more accustomed to their new life-worlds, others’ strategies began to shift toward helping these women begin to encounter and manage things in the left-world. The strategy which others used for providing this access to the left-world was coaching.

As they began to perform more and more daily tasks, the women increasingly needed to deal with the left-world. In order to facilitate this process, others routinely coached the women during their occupational performance. For example, therapists commonly reminded the women to look to the left when they were searching for objects or people. One of the women, Ruth, describes this strategy: “I was going to press down the button B in the elevator, but I couldn’t find it. ‘Look more to the left, look to the left, look to the left,’ she [nurse] said, and then I looked and could finally find it.” Such coaching allowed the women to “find” things in the left-world. Coaching not only served the practical purpose of revealing an unseen object, but also more
handling difficulties during occupational performance.

Because it was not part of their life worlds, the women could not simply be told, and thereby comprehend, that there was always something unseen to the left. Rather, the existence of the unperceived left-world was learned by degrees, as others repeatedly coached the women in specific situations as to the existence and implications of the left half of the world. Thus learning to deal with an unseen left-world was an entirely new enterprise that required coming to grips with the existence of something that did not present itself in ordinary ways to experience. The left-world slowly became for these women a new and extraordinary reality that had to be gradually incorporated into their life-worlds.

This incorporation of the left-world was initially a challenging and frustrating process. For example, Ruth described how she began to perceive the consequences of her unilateral neglect: “When I ask for coffee, juice, and milk for breakfast, they place the food nicely to my left, because they want to test me, and then they walk away, which makes me very irritated and angry. So I loudly ask them, again, if they can bring me the breakfast. They always answer me that I shall look to the left, and when I do, I finally can find the three cups on the left side. It is very difficult to remember to look to the left because I don’t know that the cups are there.”

As noted, the women at first did not experience coaching as helpful. Rather, for the most part they felt constantly reprimanded and interrupted by frequent and persistent reminders about the left-world. It was hard for the women to understand and accept that they needed to be coached about something that for them didn’t exist. In a very real sense, others had to help the women achieve kind of “paradigm shift” in which the practical world consisted of more than what was directly experienced as “the world.” They had to slowly habituate to the reality that there was always something to the left outside their perception.

Permitting Encounters With the Left-World

With time, the participants learned to reframe their strange experiences and mistakes. One frequently mentioned mistake that occurred when the nurses and therapists began to allow the women to independently propel their wheelchairs on the ward unit is illustrated by Sally: “I commonly drive into door posts, tables, and chairs standing in the corridor. I cannot see my mistakes because I am just looking straight ahead.” Making and learning about mistakes made in the left-world was a prerequisite for understanding and better handling difficulties during occupational performance.

Alice noted, “I am now more aware of my left-problem because of all the reminders from others, but also because of my failures during eating or hygiene when I try to find my things.”

Consequently, whereas others in the social environment initially sought to structure objects and situations to avoid strange experiences and mistakes, nurses and therapists increasingly began to allow the women to encounter the left-world as they became more active in daily occupations. In doing so, these others had to be careful about how much to allow the left-world to intrude upon the women’s performance. A delicate balance was needed to allow the left-world to assert itself in the women’s experience without allowing the women to become too confused or overwhelmed. An equilibrium between preventing and permitting failures had to be maintained. Two strategies supported permitting encounters with the left world. They are discussed below.

Providing Feedback About Failures in the Left-World

In addition to allowing the women to encounter the left-world, others also gave them feedback about how they were failing to deal with the left-world in performance. Such feedback helped the women become increasingly aware that they were neglecting a left-world. Mostly, others gave verbal feedback although they also gave feedback by visually guiding them over to the left side to see the “neglected” half of tasks.

A common example of feedback occurred when the women mistakenly entered the wrong room because their own room was located in the left-world. As Alice described, when the room was on the left, she was prone to mistake the room opposite her room (on the right) as her own: “Yesterday I drove into another patient’s room but I thought it was my room and I didn’t understand it was his room before he told me that I was in the wrong room. I felt so stupid!” As this example illustrates, feedback sometimes came from other patients.

Initially, feedback focused on the neglect of the left-world and the problems associated with it. With time, feedback increasingly pertained to the women’s success in recognizing and dealing with the presence of the left-world despite the fact they still did not directly encounter it as an ordinary presence. The women were thus learning through feedback in specific occupational situations to habitually incorporate the left-world into their new life-worlds.

Creating Significant and Familiar Situations

As the women began to have a cognitive understanding of their neglect of the left-world, there were certain situations
that they could better manage. These situations involved doing things that were both meaningful and familiar to the women. When engaged in familiar and meaningful occupations, the women were able to more readily incorporate the left-world.

Others played an important role in creating familiar and meaningful situations. For example, all four women stated that eating was important for them to be able to do. They remarked that this situation was easier than some others to handle because they were familiar with the situation and the objects that were used. For example, Alice described how when she was doing familiar daily routines such as eating, “I am telling myself that I must look to the left to find more food.”

The women also described that it was easier to find things in the left-world if someone gave them prior knowledge of their placement. For example, when the occupational therapist had informed Ellen about where the objects were placed in the training kitchen, it helped her to better know where to search for them. About this Ellen noted, “I can now find things in certain situations only when I know where the things are located. In these situations I am thinking that I must search to the left. For example, today in the training kitchen I knew where the things were in the refrigerator and therefore I remembered to look to the left when I first could not find them.” In unfamiliar circumstances, others played a significant role in creating situations in which the women could more easily encounter the left-world during occupational performance and therefore better handle the situation.

**Supporting Occupation in the Left-World**

As the participants gained a more habitual awareness of the existence of the left-world they began to develop their own approaches to dealing with the left-world’s existence despite its lack of ordinary presence. That is, the women increasingly learned to gather information about circumstances in the left-world from others in their social environment. Consequently, the participants began to use others as guides for occupying the left-world. Being a guide meant both pointing out things that the women would not otherwise be aware of, and also allowing the women to independently explore and encounter the left-world as discussed below.

**Providing Cues During Performance**

As the women began to have increasing awareness of their neglect, they more readily used cues from others to explore the physical world to the left. At this point, the interaction changed from “coaching” by others to a form of collaboration between the women and others in their social world. The participants began to actively use others as a means of navigating the unseen world to the left. They found it helpful to be cued by others as to the approximate location of things hidden in the left-world, before they began to search for or interact with them. As a consequence, the women actively attended to how other people informed them about the left-world. For example, Alice, noted, “Other patients help me when I can’t find the napkins on the table. They tell me where the napkins are and that feels very good.”

Consequently, others in the social environment learned to serve as collaborators, providing information as the women appeared to want it. In a very real way, the others became a kind of “sensory conduit” through which the women gathered ongoing information about the left-world so as to incorporate it into what they did. At this point, the women also began to make use of other sensory cues from the left. For example, they began to attend to sound coming from the left-world such as a knock on the table or a squeak. Sometimes, just the sounds of others’ movements or voices alerted the women to search for people located in the left-world. For example, Sally noted, “Sometimes when we are having dinner it is difficult for me to know who is talking on my left side and I really need to concentrate on looking to the left.”

**Stepping Aside**

While it was important for others to be available as sources of information about the left-world, it was equally important that they knew when and how to stay out of the way as the women began to interact with the left-world on their own. Once the women had begun to understand that there was an unperceived world to the left and to deal with its existence in their performance, others began to step aside, allowing the women to practice managing the left-world on their own. This provided the women with the time and opportunity to solve the problems they faced on their own and through trial and error.

It appeared that once the women began to be aware of their neglect and to actively seek to solve problems related to the neglect, others had to be careful not to be too quick to intervene. Sally described one example, “I need to sit and scan and memorize the furniture and other things located on the left side of the corridor, before I start to drive the wheelchair. This takes time and very often other people come and interrupt me and talk with me and I become very irritated because I need to memorize before driving, otherwise I will bump into the furniture with the wheelchair. Sometimes they disturb me and will help me with the wheelchair, but I want to do it on my own. Of course it is hard to think and plan all the time but it is the only way to improve and to be discharged from hospital.” Such stepping aside was an important strategy that needed
to be implemented by others during the women’s performance.

**Collaborating To Support Occupation of the Left-World**

Near the end of the studied rehabilitation process, the women still did not have direct access to the left-world as an ordinary experience. However, the women had learned to understand that the left-world existed and that they had to factor its existence into most things they did. Because of their lack of direct access to the left-world, collaboration with the social world was essential to how they went about their occupational performance. Consequently, much of what they did, they did in cooperation with others.

This meant that almost everyone with whom the women regularly interacted had to be comfortable with this collaborative process and know what it entailed. It also meant that, increasingly, family members and friends became part of how these women navigated everyday life. Ruth noted, “I feel that I can manage better and I am also fortunate that I have so many persons reminding me both here and in my home. Especially when my sons come here and remind me, ‘Look to the left, what do you see, Mother?’ They are so helpful.”

**Practicing Neglect Empathy**

In order to effectively collaborate with the participants, the others in the social environment had to enter into the participants’ life-worlds to an extent. According to the participants, this meant that others understood their needs while at the same time respecting their integrity during collaboration. Consequently, effective collaboration in doing things with the women required that others develop “neglect empathy,” (i.e., an appreciation of the women’s experiences and what kind of cooperation they needed in order to perform). Neglect empathy involved understanding not only that the participants did not perceive the left-world, but also that the women knew about its existence. Moreover, the participants had to understand and come to rely on the fact that others in their social environment were empathetic to their experiences. Thus, the women and others in their social world together created a shared life-world.

Others, particularly family members, developed a ready comprehension of the women’s experience and how to best assist their relative during performance. For example, Ellen noted, “Yesterday, when we were sitting watching TV together, my grandchildren told me several times, what was happening on the screen. They are so aware of my need of support to attend to the left. If the younger children give me certain objects my granddaughter, who is 10, says to her younger brother, “You must put it more to the right so that grandmother is able to find it.” As the example illustrates, family members often share information relevant to neglect empathy amongst themselves.

**Serving As Instruments for Managing the World**

At this point, others in the social environment no longer orchestrated the occupational performance of the participants. Instead, to a larger extent the participants initiated and used the social environment as a part of their occupational performance. They had learned how to use other people as instruments for managing the world. Ellen gave, for example, instructions to the nurses who served her food. She said, “Please, display the food so it is possible for me to see it, because I cannot see the food on the left side of the plate.”

Those who became collaborating partners for the women had to become comfortable with being used as “instruments” for these women’s performance. They had to allow themselves to be incorporated as a kind of unique sensory organ that enabled perception of the left-world, providing information about the left world. They also served as instruments when they rearranged objects in the left world at the request of the participants.

**Becoming Incorporated As an Extension of the Body**

Sometimes other persons allowed themselves to be incorporated as an extension of the participants’ bodies in order to manage doing things. The following is an example of how one participant incorporated another’s hands during performance: “I am always cutting the Christmas ham steak, and this year I first had to stick the fork in it and then my daughter put her left hand on my weak left hand, and finally I was ready to cut the ham with my right hand.”

By the end of the rehabilitation process the women had begun “doing with” or incorporating the social environment in certain occupational situations. They could, in these situations, better manage the “problematic” physical world.

**Discussion**

In this study, we identified a number of unfolding strategies that others in the social environment employed with reference to four women with unilateral neglect. The women characterized these strategies as helping them come to understand and manage their unilateral neglect. Importantly, these strategies are not discussed in the literature on, when they have been touched upon, are only partly understood. In this discussion we will examine the findings in light of existing literature and their implications for intervention.

Initially, others in the social environment employed strategies of preventing failures, framing the body and pro-
viding security to bring order to the participants’ chaotic and unfamiliar everyday worlds. These strategies have not previously been mentioned in the literature on unilateral neglect. However, the present study findings suggest that more attention should be paid to bringing order in the chaotic worlds of clients with cognitive or perceptual impairments following stroke.

When the women felt more secure with their new life-worlds, others coached the women to comprehend that there was a left-world outside their perception during occupational performance. Previously published intervention studies have focused on improving the clients’ scanning behavior in the left hemispace by training visual scanning in different contrived training tasks (see Robertson, Halligan, & Marshall, 1993, for a review). Studies of these interventions indicate that they do not demonstrate any generalization effects to everyday life. The lack of carryover may be because the intervention was not related to clients’ familiar life-worlds and, thereby, failed to support clients’ learning about the existence of the unperceived left-world.

When the women had become more aware of the existence of the left-world, others used the strategy of permitting encounters with the left-world. The strategy of creating a balance between preventing and permitting failures has been discussed by Seron, Deloche, and Coyette (1989) as well as Toglia (1991). They emphasize that attentional demands of tasks may influence the clients’ abilities to compensate for their unilateral neglect during occupational performance. Authors have also noted that developing awareness of one’s unilateral neglect requires that clients confront the consequences of this impairment (Diller & Riley, 1993; McGlynn & Schacter, 1989; Tham et al., 2000; Tham & Tegnér, 1997).

The strategy of supporting occupation of the left-world by providing information or cues during performance is commonly used in rehabilitation. Nonetheless, more research to elucidate and evaluate strategies for increasing clients’ occupation in the left-world are needed. For example, several studies have shown that activating the left arm or leg encouraged attention to the neglected left half of the world during task performance (Robertson & North, 1992; Robertson, Tegnér, Goodrich, & Wilson, 1994), but the participants in the present study did not describe this as a strategy they found helpful. It would be useful to explore such techniques from a phenomenological perspective to see if they are perceived as useful at some point in the rehabilitation process.

When the women had began to understand that there was an unseen world to the left, others began to step aside, which allowed the women to practice managing the left-world on their own, to occupy the left-world on their own. The strategy of stepping aside has not been described in the literature. Future research could examine more closely how to balance the strategy of providing information and cues with stepping aside to develop clearer guidelines for practitioners.

In the end of the studied rehabilitation process, others no longer orchestrated the occupational performance of the four women. Instead the women used the social environment as a part of their occupational performance. Both the women and others (primarily family members) had gradually created a shared life-world based on others’ neglect empathy and the women’s understanding of their neglect and how to incorporate others as extensions of their own perception and action in order to perform. These findings resonate with Merleau-Ponty’s (1962/1945) observation that objects outside oneself can be incorporated as an extensions of the body and with concepts of the family as a dynamic and adaptive system (Larson, 1996). Moreover these findings suggest that the final stage of rehabilitation could profit from active involvement of family members. Such an approach would require additional knowledge about the process by which others become incorporated as an extension of the disabled person’s body in their collaboration during occupational performance.

Overall, the findings suggest that therapy for persons with unilateral neglect could be improved by more careful attention to the lived body and the life-world of such persons. From this perspective, therapists and others could more systematically adapt the social environment to enable persons with neglect to develop a comprehension of the left world and achieve effective ways of performing despite the ongoing perceptual absence of the left-world. Current rehabilitation approaches are based on a framework that views neglect from an outsider perspective, focused on the errors persons with unilateral neglect make in performance. This approach also focuses rather narrowly on interventions for improving the individual’s scanning behavior to correct the neglect problem and compensation for the errors persons with neglect typically make. As noted earlier these approaches have not been shown to generalize to everyday performance.

The findings of this study suggest that the limitation of the standard approaches for unilateral neglect described in the literature is that they fail to appreciate the experience of neglect and how that experience unfolds over time. Additionally, the findings of this study provide a rationale for the strategies used by professionals and lay persons based on their commonsense appreciation of the person with neglect. While these strategies were found in the present study, they were not part of a coherent and conceptually based rehabilitation approach. The phenomenological
framework and findings of this study indicate that the concept of the lived-body (Kielhofner et al., 2002) has potential as a complementary approach to existing ways of addressing impairments. This approach is based on the assertion that “transformation in performance capacity depends on a transformation in experience” (p. 97). The present study affirms this assertion since the women's neglect remained constant although their ability to perform depended on a transformation of how they experienced that neglect. The present study is a first step in identifying the kinds of strategies that could make up a coherent, phenomenological-based approach to intervention for persons with unilateral neglect. Future research will be needed to refine such an approach and to test its effectiveness.

References


