The Discovery of Disability: A Phenomenological Study of Unilateral Neglect

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Key Words: cerebrovascular disorders • occupational therapy (treatment)

Objective. Clients with right brain damage and unilateral neglect often lack awareness of their disabilities. This study examined how 4 participants with neglect experienced, discovered, and handled their disabilities in the context of their everyday life.

Method. The 4 participants were interviewed five to seven times during their rehabilitation process. The data were collected and analyzed using the EPP (empirical, phenomenological, psychological) method.

Findings. Findings revealed seven features that described a discovery process for the 4 participants. During this process, each participant began to discover and understand the consequences of her unilateral neglect in the performance of everyday tasks. This increased understanding was a prerequisite to being able to use compensatory strategies.

Conclusion. By experiencing meaningful occupational situations, the participants gradually discovered and began to compensate for their disabilities in everyday life.

Unilateral neglect (UN) is common after right hemisphere brain damage and has been found to be an important predictor of functional ability after injury (Chen-Sean, Henderson, & Cermak, 1993). Persons with UN are unable to orient their attention toward the left hemispace when performing everyday tasks such as eating or reading (extrapersonal neglect) and often are not aware of the left half of their body when performing tasks such as grooming or dressing (personal neglect) (Bisiach & Vallar, 1988). Many persons with UN are not aware of their bodily impairments such as hemiplegia or hemianopia (McGlynn & Schacter, 1989) or the consequences of those impairments in the performance of everyday tasks (Tham & Borell, 1996). Accordingly, they often are not motivated to learn strategies to compensate for their disabilities in everyday life (Diller & Riley, 1993; McGlynn & Schacter, 1989; Tham & Borell, 1996).

Levine, Calvanio, and Rinn (1991) presented a theory of unawareness—the discovery theory—which is based on the premise that sensory loss must be discovered by the person and that this discovery often requires self-observation. Generally, persons with sensory loss continue to believe that a sensation is intact until the discovery of loss takes place as they interpret the evidence of their problems in everyday life. Persons who cannot make observations and who cannot correctly interpret cues about their everyday function fail to experience the gradual process of discovery of sensory losses (Levine et al., 1991).
Research in the area of UN has not yet focused on how persons experience living with UN or how they discover their disabilities. There is a lack of knowledge about how persons with UN become aware of their disabilities and how they learn to use compensatory strategies to overcome their disabilities in everyday life (Diller & Riley, 1993).

If occupational therapists can better understand how persons experience their disability in the context of occupational life, they may be better prepared to plan interventions and to work with persons in their unique life situations (Clark, 1993; Helfrich & Kielhofner, 1994; Mattingly, 1994). Mattingly (1994) and Kielhofner (1995a) have emphasized the importance of treating the lived body or the phenomenological body in occupational therapy. The concept of the lived body derives from phenomenology, particularly the work of the French philosopher Merleau-Ponty (1962/1945). In the work of Merleau-Ponty, the body is viewed (a) as the intentional subject that is always present in the occupational life of a person, and (b) as the starting point from which people act and grasp their life-world. The body “inhabits space and time” (p. 139) and is “our general medium for having a world” (p. 146).

The phenomenological philosophy, which is based on the work of Husserl (1970), includes the concept of the life-world. The life-world is our subjective and culturally meaningful world, which we take for granted and whose existence we never question. The time and space to which we refer in the life-world are experienced and lived through (Husserl, 1970), and the life-world experience is a practical and nonreflective way of being in the world (Karlsson, 1993). By critically examining life experiences, the phenomenologist seeks to describe the essence, structure, and character of the life-world (Karlsson, 1993).

In their biographies, Murphy (1987) and Sachs (1993) described their experiences of living with disability. Sachs (1993) gave examples, in the context of his occupational life, of the emotional and existential feelings that surrounded the experience of losing his leg. Both Murphy (1987) and Sachs (1993) described the experience of disabilities that affect IADL ability as one of becoming disembodied and alienated from one’s own body.

The purpose of this study was to describe and understand, from a phenomenological, occupational perspective, how persons with UN experience, discover, and learn to handle their disabilities in daily life during rehabilitation.

Method

Participants

The participants comprised a consecutive series of 4 inpatients with cerebrovascular lesions (CVL) at a neurological rehabilitation clinic in Sweden. Criteria for participation were (a) right CVL of less than 10 weeks’ duration; (b) severe extrapersonal UN verified by the Letter Cancellation Task (Mesulam, 1985); and (c) physical, psychological, and intellectual capacities that allowed active participation in the study. Four women with left hemiparesis were selected (see Table 1 for more information about the participants). The participants received written and verbal information regarding their participation, and they gave their verbal agreement to participate. The Ethical Committee at the Karolinska Institutet approved the study.

Data Collection

During 4 weeks (weeks 3 to 7) of the 16-week period of data collection, the four women participated in an occupational therapy intervention program focused on improving awareness of disabilities in everyday life (Tham, Ginsburg, Fisher, & Tegnér, in press). During the rest of the period, they received occupational therapy focused on training in self-care activities both by using the clients’ available abilities and by adapting task demands and contexts (1 to 2 hr a day, 5 days a week). Participants also received other individualized rehabilitation services, such as daily physical therapy. The rationale for the specific awareness-training program was to use meaningful everyday occupations as the therapeutic media to improve awareness of disabilities. On a daily basis, the therapists enabled the participants to gain experiences from task performances to confront them.

Table 1

<table>
<thead>
<tr>
<th>Participants’ Characteristics</th>
<th>Alice</th>
<th>Ellen</th>
<th>Ruth</th>
<th>Sally</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>64</td>
<td>73</td>
<td>76</td>
<td>58</td>
</tr>
<tr>
<td>Days after CVL</td>
<td>21</td>
<td>70</td>
<td>19</td>
<td>17**</td>
</tr>
<tr>
<td>Sensory loss</td>
<td>Severe</td>
<td>Severe</td>
<td>Severe</td>
<td>Severe</td>
</tr>
<tr>
<td>Visual field deficit</td>
<td>Hemianopia*</td>
<td>Lower field deficit</td>
<td>Lower field deficit</td>
<td>Hemianopia</td>
</tr>
<tr>
<td>ADL motor ability</td>
<td>−0.1</td>
<td>0.00</td>
<td>0.0</td>
<td>0.8</td>
</tr>
<tr>
<td>ADL process ability</td>
<td>−1.8</td>
<td>−1.6</td>
<td>−0.6</td>
<td>−0.5</td>
</tr>
<tr>
<td>MMSE (score)</td>
<td>22</td>
<td>26</td>
<td>24</td>
<td>27</td>
</tr>
</tbody>
</table>

*Sally had had a right cerebrovascular lesion 8 years earlier, with no residual effects.

Note: CVL = cerebrovascular lesions; ADL = activities of daily living; MMSE = Mini Mental State Examination (Folstein, Folstein, & McHugh, 1975).

*Mild sensory loss: can identify not more than two of five single stimuli in arm and leg.

Hemianopia: Cannot identify any of the five single stimuli in the upper and in the lower visual field.

Lower field deficit: Can identify not more than two of five single stimuli in the lower visual field.

ADL motor ability, in 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.

ADL process ability, in AMPS: Persons with ability measure scores below 1.0 are likely to have skill deficits that affect IADL ability.

MMSE: Cut-off score is 24.
with their difficulties and to encourage them to describe
and solve problems that occurred during performance.
Video feedback (Tham & Tegnérr, 1997) was also used to
support the participants in becoming more aware of their
difficulties during task performances.

The first author interviewed the participants five to
seven times each, over 16 weeks. Most of the interviews
took place in the clinic, but the last interview with partici-
pants Ellen and Sally took place in their homes. Each interview
lasted between 30 min and 75 min, and was tape-
recorded and transcribed verbatim. Questions were inform-
al and open-ended and focused on experiences from actual
daily life situations. The interviewer invited the partici-
pants to describe their recent occupational experiences (i.e.,
what they had been doing since the last interview) and how
they managed the occupational situations they chose to
describe. After each interview, the researcher recorded her
observations and reflections related to the participant's occu-
pational performances and descriptions of experiences,
noting any discrepancies. These field notes facilitated an
understanding of the participants' experiences during analy-
ysis of the interviews.

Data Analysis
A modified form of the empirical, phenomenological, psy-
cho logical (EPP) method (Karlsson, 1993) was used to
analyze data. The psychological perspective was, in the
analysis, replaced with an occupational perspective, which
focused on the daily occupational experiences of the par-
ticipants and which was guided by the purpose of the study.
The EPP method is a qualitative, interpretative, and
descriptive analysis, based on the philosophy of Husserl
and, to a lesser extent, Heidegger (Karlsson, 1993).

The EPP method attempts to be as open and presup-
positionless as possible; the researchers' pre-existing theoret-
ical understanding, such as bio-medical knowledge of UN,
was therefore bracketed. The analysis was faithful to the
phenomenological view of consciousness as intentional, as
meaning–bestowing. The data were analyzed and interpret-
ed in five steps.

In the first step, the first and second authors read all the
interviews of one participant until they had a “good grasp”
of the material, (i.e., when a sufficient understanding had
been reached in order to continue the analysis in step 2.) In
this first step, the researcher tried to have an empathetic
understanding of the participant's original experiences.

In the second step, the first author divided the data in
each participant's interview transcription into smaller units,
called meaning units (MU); the divisions indicated each
time a shift of meaning occurred.

In the third step, the researcher tried to move from the
explicit facts of the transcripts to their implicit meanings.
Each MU was transformed into the researcher’s language
and understood in light of the whole interview. To avoid
theory-laden language, it is preferable for the researcher
using the EPP method to use everyday language, avoiding
words that are too vague.

In the fourth step, the transformed MUs were synthe-
sized into a so-called “situated structure of meanings”
(Karlsson, 1993, p. 106) for each transcript. The researcher
tried to arrange the constituents (i.e., the features of the phe-
nonomenon) into a form that was most suitable for revealing the
phenomenon. In this study, the presentation of the meaning
structure included the process dimension of the phenome-
non. The process describes how the phenomenon is lived, and
the structure focuses on what the phenomenon is. The
process and the structure are dependent on each other.

In the fifth step, the situated structure of meaning for
each participant was synthesized into a general structure for
all four participant interviews. This general structure incor-
porated the constituents of the phenomenon across all situ-
tated structures (i.e., the main constituents). Some typolog-
ical structures (the subconstituents) representative of one
or more of the 4 participants were also described to
give examples of the different variations of the phenome-
on across participants. Seven main constituents were
identified (see Figure 1) and arranged in the order in which
they occurred over time, the first constituent representing
the first phase of the discovery process and the last con-
stituent representing the last phase. The order in which the
constituents appeared was not the same for all participants,
and sometimes a participant’s constituents overlapped.

To establish credibility, we examined the horizontal con-
sistency of the interpretations as suggested by Karlsson (1993),
who made it clear that “a horizontally consistent interpreta-
tion is an interpretation consistent with all constituents in the
protocol” (p. 131). To establish trustworthiness and limit bias,
each step of the analysis and each interpretation was also sub-
ject to peer examination (Gliner, 1994).

Findings
The meaning structure of the discovery process—that is,
the process in which the participants experienced, discov-

Figure 1. The main constituents in the discovery process

Experiencing the new and unfamiliar

Comparing the new with the old

Searching for explanations

Understanding the disabilities

Learning to handle disabilities in daily life

Incorporating the new strategies
ered, and learned to handle their disabilities—is described in the main constituents (see Figure 1) and subconstituents of the process. During the discovery process the participants gradually became more aware of their disabilities.

Experiencing the New and Unfamiliar

In the beginning of the discovery process, the four women had a limited ability to interact with the left space of their environment. The borderline between the left and the right half of their environment seemed to shift, depending on where the women focused their attention. It seemed as though the left half of their worlds did not exist for them and that they, therefore, lived and acted in only the remaining right half of the surrounding world. From the interviews, we could understand that the women did not seem to miss their loss of interaction with the left half of the world; they experienced their surrounding world as if it were complete.

In the beginning of the discovery process, before the women had started to regularly perform everyday tasks, they told only about experiencing “something” new and unfamiliar. They found that their perceptions of their bodies and their perceptions of space and time felt new and strange. They had not yet started to know and understand their disabilities, and they did not know how to handle them in everyday life.

Experiencing the left body parts as objects. Early in the discovery process, the participants described how the left half of the body felt unfamiliar, as if it did not belong to them. They expressed a sense of distance between themselves and their body half and stated that the left arm and leg felt like objects, outside themselves. “I feel like my left hand and foot are objects. I have to go up to my shoulder to call the girls and ask them, “Can you find my bad arm?,” and of course they always can. When referring to her hand, Sally stated, “For me, it’s five sausages that lie there.” The left half of the body was talked about in the third person, as though it had its own life, a life that could not be controlled. “The hand is cold and strange. This right arm is kind, warm, and nice, but the left one is always cold and it wants to reject people. It is not generous. It will just give chilliness” (Sally). If one views the body as our medium for having a world (Merleau-Ponty, 1962/1945), one could say that Sally had lost half of her medium for having a world and for inhabiting the world.

Unpleasant bodily experiences. The four women described some new, unfamiliar, and unpleasant bodily experiences that were not directly linked to their feelings of unfamiliarity in relation to the left side of the body, but that probably contributed to these feelings. Alice said, for example, that her leg felt like ice during the night, which made her think about losing her leg. Ellen described how scared she became when she could not find her arm in the bed: “When I am going to bed I think that I need a pillow for my arm and if the arm is not lying there, I get scared to death. I think something is wrong because I must always have my arm with me. If I don’t have that, it will become swollen. If I can’t find my arm, I use the alarm to call the girls and ask them, “Can you find my bad arm?,” and of course they always can.

Disorganization in daily life. Participants seemed to have a diffuse feeling of not being able to orient in their life-worlds, both in relation to their body, and to space and time. In the beginning of the discovery process, these perceptual experiences seemed to contribute to a feeling of disorganization and insecurity.

The women came to recognize that, quite often, they did not know where they were in the physical environment of the clinic. Many times they described situations when they could not orient themselves in space. Sally said, “The other day I went out with my wheelchair and, God, I didn’t know where I went. I couldn’t recognize the doors or anything.” The women also described many situations in which they felt insecure in their collaboration with the social and physical environment; for example, when both people and objects suddenly disappeared from their view. “When I had dinner, I suddenly didn’t know where my husband went. He just disappeared” (Alice). Alice also described an unpleasant perceptual experience of an “attraction to the right.” She said: “When I am lying in my bed and the lamp is on, I can’t avoid looking to the light. I also have a curiosity when something is happening on the right side, so I have to look. I would need to have eye-blinkers.”

New behavior in the social environment. The women discovered that other persons such as the staff or relatives perpetually reminded them to look to the left in different occupational situations. However, at this stage of discovery, the women did not understand why persons in their environment had begun to act in this new way. Often, the participants believed that these reminders were reprimands.

Comparing the New With the Old

After the beginning discovery of the new and unfamiliar, the women progressed to the next phase in the discovery process. By having experiences in different occupational situations, they began comparing their new experiences with the old; that is, what they could do now compared with what they could usually do before the stroke. They started to discover and describe their limitations as they encountered them in the performance of daily living tasks.

The experience of not being able to do things they had previously done spontaneously and routinely was something that the participants emphasized in their comparison between the new and old. Previously, they had taken their bodies for granted but now they could no longer depend on “automatic” competence in daily habits and routines. For example, as described by Ellen, “Today I wanted to crack the eggs for making pancakes, but it was so difficult, because they didn’t break in the way I wanted, as I used to do at home.”
The women gradually discovered new disabilities when confronted with their limitations during occupational situations:

You can see your limitations all the time, for example, when you can’t come and go whenever you want or when we are eating and I want to have more food. Usually, I should move the chair backwards, stand up from the table, and take the plate with me to fetch some more food. But now I need to ask for help. (Sally)

Experiencing the consequences of neglect. The interviews verified that the women essentially lived and acted in one half of the surrounding world, which contributed to practical problems in daily life. Usually the women were not aware of what was happening on their left side and could therefore not discover their limitations in their neglected half of the space. Consequently, they could not find objects located to their left, for example, or find words on the left side of the page in a written text. Although the women noticed that things did not work as they had before the stroke, it seemed as though the women could not yet understand why they had problems in performing certain tasks. The women discovered that they could no longer read or understand what they were reading, but they did not understand why they had these difficulties.

Another incident that frequently demonstrated the consequences of their neglect was when they bumped into things with their wheelchairs. Despite the women’s inability to perceive what was happening on their left side, the collision provided sensory feedback about the incident. “Then I can hear a crashing sound. Oh yes, it was a door. I can feel that the wheelchair stops, and I can also hear it.” (Sally)

Feelings of failure. The problems of interacting with objects, people, and space to the left often contributed to a sense of failure and anger in daily occupations. “It can be a problem when I am in a new and unfamiliar place. Often I crash into the walls with the wheelchair and become very, very angry” (Sally). Whereas these feelings of failure and anger arose from the participants’ difficulties in the performance of certain tasks, they also seemed to contribute to the discovery of disability.

Searching for Explanations

With increasing engagement in everyday activities, participants began to reflect on their occupational experiences. They began to search for explanations for their difficulties in performing certain familiar everyday tasks at the neurological clinic, and they expressed a desire to understand their occupational experiences. The explanations they found were based on their experiences of living in half of a world. They often attributed their inability to find objects to limitations in the physical environment and began to imagine how they would face difficulties at home. “It’s much easier to find objects at home. I will find them much faster, everything will go faster at home because I don’t need to search for anything at home” (Ellen).

The women’s explanations as to why they could not read, find objects, or orient themselves in their environment were understandable, considering their occupational experiences in a world where the difficulties in the left half of space were only dimly perceived.

Becoming More Familiar With the New

After some time (6 to 10 weeks), the participants indicated that they were becoming more familiar with their new lifeworlds and were beginning to be conscious of situations in which they had problems in orientation and interaction with the left half of the surrounding world. Cognitively, they began to be aware that they had this problem during certain occupations, but they still could not consciously use any strategies to compensate for the inability. The left half of the surrounding world still did not exist for them.

As the women became more familiar with their disabilities, it seemed, paradoxically, as though it was more difficult for them to experience any improvements in daily life. The women described how difficult it was to see their own improvements and that they felt more and more uncertain about their abilities.

In this phase, the participants also told about how they sometimes believed that they could use their left arm or leg, even if they could not.

Suddenly I forget that I can’t use my left hand, especially when I am eating. For example, if I find some crumbs at the table, beside my plate, I want to clean them up and to put them together. So I try to put the crumbs in my left hand, even if I know that I can’t use it. Suddenly, I have forgotten that I can’t use the hand. (Alice)

Despite the participants’ descriptions of not experiencing improvements and that they sometimes forgot the inability to use the left body parts, they also expressed that they had begun to incorporate the left body parts in their daily life.

Becoming more familiar with the left body parts in daily life. Because of improvements in mobility, the 4 participants now primarily believed that their left legs belonged to them. The feelings of alienation toward the left arm remained during the whole discovery process; however, the women described how they slowly got used to the left arm and how they began to incorporate it into their daily lives. Despite the continuing feelings of strangeness, they seemed to feel a responsibility to the arm.

I have to accept it, because it is sitting here on my body. All the time when I am doing something, I have to think of it and to bring it with me. It is like I am carrying a baby all the time, a baby you can’t leave on a table and then go your way. You have to bring it with you. You can’t forget your hand because everything can go wrong if you do that. Instead, you bring your baby; and it is the same with your hand, you can’t ignore the hand, because you have it, and in the future you will need it. (Sally)

Understanding the Disabilities

During the next phase, the participants began to understand that they had a limited ability to interact with the left
half of the environment in everyday life. The understanding was cognitive in nature, and the women said that they still did not have any intuitive feeling of their limitations. However, they described how they wanted to improve their ability to find objects and to orient in the left half of the environment. They explained how they tried to cognitively find and use strategies to overcome this inability. Understanding of the disabilities seemed to be an important prerequisite for being able to consciously search for new strategies to handle the disabilities in daily life.

Learning to Handle Disabilities in Daily Life

By first experiencing and finally achieving an understanding of the disabilities, the four women gradually became more and more able to use various strategies to better handle different occupational situations in a more conscious way. They were able to describe many situations in which they tried to adapt to their limited ability and to environmental demands. It seemed as though their attempts to adjust were part of a natural adaptation process that had started soon after onset of the stroke. However, the participants’ inability to interact with the left half of the surrounding world seemed to be a big obstacle in this natural adaptation process. When they slowly began to discover and understand these perceptual limitations in certain occupational situations, they also began to consciously use compensatory strategies for their UN.

Handling occupational situations that are meaningful and well known. In the interviews, we found evidence that some occupational situations more than others supported the conscious use of compensatory strategies. In these occupational situations, the women were able to more easily compensate for the difficulties related to their neglect. For example, it was easier to learn the use of compensatory strategies in occupations that were particularly important to the person. It seemed easier for them to find an object to the left if they were very interested in finding it. While Sally worked in the training kitchen, she suddenly noticed the toaster on her left side when she discovered that the electrical cord was hanging over the sink: “I could see the electrical cord to the left because I know it is unsafe to have it over the sink. The electricity can short, and that is dangerous. I can see things if I am interested in seeing them.”

Frequency of performance was another characteristic of occupational situations that seemed to facilitate the use of compensatory strategies. Occupations that were performed often or on a daily basis were usually already familiar; obviously it was easier to handle well-known occupational situations that the women had already learned through frequent practice. The participants also reported that it was easier to use compensatory strategies in activities that involved objects that they knew well:

I used to sit and look for my things in my dressing-case, for example, lotion and toothpaste. I look and I look. At first, I can’t see the things, but I know that they should be there. Then I move my eyes and I turn my head so I really can see everything because I know that the things should be there. (Alice)

The women stated that some occupational situations could be too demanding for them (e.g., driving the wheelchair in new environments, making a salad with several ingredients); the high demand made it more difficult to interact with the left half of the environment. Typically, these complex situations gave no clear feedback about failures or problems on the left side, and usually demanded very high levels of attention and concentration. Video feedback proved to be an effective therapeutic strategy in these types of situations. The women said that they experienced difficulty in perceiving their own performance problems during the actual doing, but could suddenly see and understand their own disabilities when they had the opportunity to watch their performances on video. As Alice described it: “When I saw the film, I suddenly could see what I didn’t feel when I drove the wheelchair.” By watching the film, she could understand her difficulties in performance of the activity.

Finding and using strategies. The participants often described how they tried to solve the problems that occurred when they performed tasks in daily life. After much trial and error, they began to successfully find their own strategies to solve problems. The women reported that they needed time to think and also the opportunity to practice on their own. Sometimes such opportunities did not seem to be made available because staff members often assisted them in daily tasks.

Conscious reflection during performance was one type of strategy. To use that strategy, the participants needed a “motive” for seeking something on the left side. Commonly, the women reasoned with themselves during a task performance in order to solve the problem of not being able to find an object or person:

Sometimes when I am eating, I think:…God, didn’t I get the fish? They told us that we should be served fish today. But of course, it is placed on the left side of the plate, I think, and I begin to search to the left, and then I can see it and reflect upon finding the fish that I first thought was mashed potatoes. (Ellen)

Reflection before the performance was another type of strategy that was used. The participants concentrated their thoughts on remembering to look to the left when they started to do an occupation. This strategy seemed to be more demanding than reflection during the performance when the problem already had occurred. Sally described her strategy of memorizing the environment before she began to drive around with the wheelchair:

If somebody wants to speak with me when I am searching to the left, before I start to drive, I become very irritated because I am concentrating on memorizing the environment. You need an inner picture of it, to be able to manage the unfamiliar setting.

To compensate for the limited attention given to the left, the four women each used different strategies to explore or “screen” the left side of the body or the environ-
ment. Sometimes the participants described how they searched for an anchor on the left side, to better know where they should start or stop screening the environment on the left side.

From the interviews, we could understand that it was always necessary for the participants to experience the meaning or the benefit of using a compensatory strategy. Our conclusion was that to be useful tools in handling different occupational situations, the strategies must be based on the person’s own occupational experiences and understanding.

Incorporating the New Strategies

At the end of the discovery process (i.e., 16 weeks), when the four women had a lot of experience using compensatory strategies in a conscious way, their understanding and awareness seemed to become deeper, and they began to incorporate the new strategies into their daily habits. The women described how they spontaneously began to remember to look to the left and think in a new way:

Look to the left, look to the left, I tell myself, and then when I look to the left, I can find the thing that I am looking for. If I can’t find what I am looking for, it is now engraved in my head to look to the left. (Ruth)

However, at the end of the 16 weeks, the four women, especially Ellen and Sally, still had problems in several occupational situations remembering to use the strategies they had learned. It seemed as though they needed to continue their discovery process over a longer period of time to recapture the left half of their surrounding world.

Discussion

This study demonstrated how persons with UN experienced, discovered, and gradually began to understand and handle their disabilities in the context of their everyday life at the rehabilitation clinic. The features of a discovery process, represented by seven constituents that were general for the 4 participants, emerged during the phenomenological analysis. The participants’ occupational performances and experiences of doing seemed to facilitate the discovery process. Their active engagement in the rehabilitation program contributed to their discovery process, implying that the evolving process would have been less successful if the participants had not had the opportunity to engage in meaningful occupations in the program. This conclusion is consistent with the ongoing discussion in the occupational therapy literature about the therapeutic use of occupation (Kielhofner, 1995b; Nelson, 1996; Trombly, 1995) as a therapeutic tool to successively build up new self-knowledge and positive adaptation to disability.

The findings have implications for how occupational therapists can support and guide clients in the different phases of the discovery process. The finding that the left halves of their bodies were not available to the participants—meaning that they had lost a part of their medium for having a world and for being in the world—has implications for therapy. For example, Bisiach and Vallar (1988) view extrapersonal neglect as more common and more severe than personal (i.e., body) neglect. Assessments and intervention strategies have been reported for remediating extrapersonal neglect (Robertson, Halligan, & Marshall, 1993) but not for personal neglect. The current literature tends to minimize the consequences of the feelings of alienation toward the left body half that was described by the 4 participants. If the body is our medium for having a world (Merleau-Ponty, 1962/1945), the intervention strategies for persons with UN should be based on the premise that the body and the environment is a unity in the life-world of a person. The interventions in occupational therapy, therefore, might include strategies for supporting persons to be more familiar with their new bodies in the context of doing. This need for attention to the clients’ experience of their bodies in therapy has also been stressed by Kielhofner (1995a; 1995b) and Mattingly (1994).

The participants’ need to reflect and search for explanations of their occupational experiences (the lack of awareness of disabilities) can be viewed, from a bio-medical perspective, as a symptom of brain damage (McGlynn & Schacter, 1989). However, from a phenomenological perspective, these strategies can be viewed as an attempt to understand and make sense of occupational experiences in a world that was only half there. This latter perspective is consistent with a phenomenological study of the illness experience of dementia (Nygard & Borell, 1998); compensatory behavior that is difficult for the observer to interpret as meaningful is often identified, from a bio-medical perspective, as disturbed behavior. However, by understanding the client’s life-world experiences, occupational therapists may be better prepared to plan individualized strategies for intervention, for example, enabling meaningful occupational experiences that may help the client discover and recapture the left half of space.

The findings presented here demonstrate the importance of an awareness of disability before a person can consciously use compensatory strategies and incorporate them in daily life. This finding supports earlier work by Crosson et al. (1989), Diller and Riley (1993), Tham and Borell (1996), and Toglia (1991). In the current study, we found phases of awareness during the discovery process that were present for all 4 participants. The final phase described in the last constituent could be characterized as an understanding or awareness that was incorporated into the person’s life-world. Awareness in this final phase resulted in a spontaneous use of compensatory strategies in certain occupational situations. By being confronted with an occupational problem, the participants began to solve the problem and learned to better handle the occupational situation. These findings are consistent with Crosson et al. (1989), who proposed that the level of awareness determines the types of compensations that can be used.
Our findings indicated that compensatory strategies must be built on the unique experiences and understanding of each person who has UN. The participants in our study began to use and incorporate strategies during occupations that were performed often (e.g., eating, hygiene) and that were well known and meaningful to the person. These findings suggest that occupational therapists should attend to how clients are experiencing their use of strategies in daily life. Instead of teaching new strategies, therapists can support clients in using their own strategies, but in a more structured way. Our findings also supported Toglia’s (1991) view that, after brain damage, persons need time to practice on their own and to become more active problem solvers.

Our goal in using the EPP method (Karlsson, 1993), a qualitative method based on phenomenology, was to discover the features of a process that described how persons with UN experience, discover, and handle their disabilities. We were not seeking to generalize the 4 participants’ experiences to a larger population of persons with UN. However, because all 4 participants demonstrated common patterns, we believe that the features of the discovery process probably could be considered as a useful hypothesis for a general discovery process in similar situations. Discovery is a process that might be viewed as a model to guide occupational therapy interventions for persons with UN.

We recommend that future studies further examine the different constituents of this discovery process. In addition, future studies are needed to analyze the discovery process from a long-term perspective.

Finally, findings indicate that occupational therapists can gain valuable information for intervention planning by asking clients about their experiences of living with UN. This method agrees with Spencer, Krefting, and Mattingly’s (1993) suggestions that therapists apply qualitative research methods in occupational therapy practice. By basing our practice on the understanding of the client’s occupational experiences, therapy can become an event of significance in a person’s unfolding life story (Clark, 1993; Helfrich & Kielhofner, 1994).

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