# Living With Bodily Strangeness: Women's Experiences of Their Changing and Unpredictable Body Following a Stroke

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The authors' aim in this phenomenologial and feminist study was to gain a deeper understanding of how female stroke survivors experienced their body after a stroke. They recruited 25 women in a rural area in eastern Norway who had suffered a first-time stroke and interviewed them in depth three times each during the first  $1\frac{1}{2}$  to 2 years following the stroke. The data analysis was inspired by phenomenological method. The stroke survivors' experiences of their bodies were characterized by profound, disturbing, and, in part, unintelligible changes during the onset and the process of recovery from the stroke. Their experiences can be summarized under three major themes: The Unpredictable Body, The Demanding Body, and The Extended Body.

**Keywords:** female stroke survivors; feminist perspective; body experiences; phenomenology

Stroke is a major cause of disability in the Western world. It brings about great changes in the survivor's body and life (Doolittle, 1994; National Stroke Association, 2001; Nilsson, Jansson, & Nordberg, 1997; Nolan & Nolan, 1998; Norsk Offentlig Utredning [NOU] 1999: 13 Women's health in Norway). Understanding the patient's perspective is a valued goal in nursing practice and depends on the ability to listen to patients and imagine changes in their life worlds (Benner & Wrubel, 1989; Carpenter, 1995; Oiler, 1982; Omery, 1983; Walton & Majdar, 1999).

Several qualitative researchers have presented insights into the world of stroke patients. In their studies, they have documented that a stroke leads to comprehensive changes in the lives of individuals (Backe, Larsson, & Fridlund, 1997; Doolittle, 1988, 1992; Folden, 1994; Hafsteinsdöttir & Grypdonck, 1997; Häggström, Axelsson, & Nordberg, 1994; Kirkevold, 2002; Mumma, 1986; Nolan & Nolan, 1998). Stroke survivors report experiences of extensive physical, psychological, and social changes; crisis; loss; and changing roles. They describe experiences of a

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personal catastrophe and lengthy struggles to grasp the impact of these changes and to accept that life will always be different.

Few researchers have explored the long-term experiences of stroke survivors. Secrest and Thomas (1999), in an existential-phenomenological study of 14 stroke survivors with a 2-year median length of time since stroke, found that the world of the stroke survivor is grounded in a life of loss and effort. They described three interrelated themes: Independence/Dependence, In Control/Out of Control, and Connection With/Disconnection From Others. These changes greatly influenced the participants' sense of self. Burton's (2000) phenomenological study, following 6 informants for at least 12 months, highlighted stroke as an intensely personal experience, involving the rebuilding and restructuring of the individual's world. The social context of recovery was very important, as the focus of recovery was on participation in the social world through adaptation and development of coping skills rather than on improvement in discrete physical functions alone.

Kirkevold (2002), following 9 stroke survivors closely during the first year, found that the adjustment process moves through different phases and encompasses extensive adjustment work on the part of the individuals. Understanding the ramifications of a stroke is a demanding and lengthy interpretive process, focusing on recreating an understanding of oneself and one's life.

There is a close connection between the human body and the human life world, as emphasized by phenomenological theorists (de Beauvoir, 1974; Bengtsson, 1993; Heinämaa, 2000/2001; Merleau-Ponty, 1945/1994; Moi, 1999). The French philosopher Merleau-Ponty claimed that the body's experience in interaction and communication with other people and things is fundamental for the constitution of the human life-world (Bengtsson, 1993; Merleau-Ponty, 1945/1994). Feminist phenomenological theorists have discussed thoroughly how the female body's interaction with its surroundings leads to experiences and expectations that are different from those of men. These experiences might have consequences when an individual is suffering from illnesses such as a stroke, in which the body is changed in relation to both functional abilities and appearance.

Doolittle's (1992) is the only published study focusing particularly on the stroke survivors' experiences of living with an impaired body. The experiences were characterized by the loss of the automatically smoothly functioning body and a body that was objectified. The stroke survivors reported having to control their body and its movement using their minds. In a study focusing on patients' suffering from traumatic injuries or life-threatening illnesses, Morse, Bottorff, and Hutchinson (1995) identified eight themes of bodily experiences that were associated with discomfort. These were The Dis-Eased Body, The Disobedient Body, The Deceiving Body, The Vulnerable Body, The Violated Body, The Resigned Body, The Enduring Body, and The Betraying Body. They concluded that illness and injury place patients' bodies in the foreground, dominating their attention and disrupting their accustomed orientation to the world. Studying children with disabilities, Bleeker and Mulderij (1992) identified eight themes related to bodily experiences: The Vital Body, The Rebellious Body, The Unreliable Body, The Sensitive Body, The Exercise Body, The Dependent Body, The Conspicuous Body, and The Incomprehensible Body. Seymour (1998) explored bodily experiences and the process of reembodiment among 12 young men and 12 young women suffering different kinds of paralyses (but not stroke patients). She found that although the informants lived with a continual threat of danger and fear of bodily betrayal and were constantly reminded of the impaired parts of their bodies, they still experienced their bodies as a resource with which they could explore new possibilities and that created opportunities of reembodiment. Seymour found that many informants seemed to be reproducing, rather than challenging or transcending, conventional forms of masculine and feminine bodily expressions. Female informants in her study described the double burden of being a disabled woman in a wheelchair.

Given the body's fundamental position in creating one's life world, there is a need to explore women's experiences of their bodies after a stroke. The purpose of this article is to present and discuss from a phenomenological and feminist perspective findings from a qualitative study of how female stroke survivors experience their body and life after a stroke. In a separate article, we will present how a stroke led to struggles to maintain a sense of self and maintain valued female roles.

#### THEORETICAL FRAMEWORK

The view of the body in modern Western culture is complex. The body is rather invisible and taboo, but, on the other hand, we are very preoccupied with exhibiting and perfecting the body (Leder, 1990; Lomborg, 1994). In science, particularly in medical science, the body is considered from an objectivist and reductionist perspective, as an object of investigation. From a phenomenological perspective, the body is considered ambivalent, because, although it exists at a purely physical level, it is at the same time more: It is the person. It is an object, but not a real object, which can disappear from and return to "me." The body is also a subject; it is "me." One can never escape one's own body (Bengtsson, 1993; Merleau-Ponty,1945/1994). Leder (1990), who is greatly influenced by Merleau-Ponty but who has sought to go beyond the latter's work, uses the concepts of Leib and Körper in his description of the body. Körper refers to the body as an object (the physical body) as experienced by others, from the outside, whereas Leib refers to the lived body (the phenomenal body), which is experienced "from the inside" by the subject. Similarly to Merleau-Ponty, Leder points to the ambiguity of the body, as both an object and as something more: as a living subject. He has emphasized that Leib and Körper are not two different bodies. Körper is itself an aspect of Leib, one manner in which the lived body shows itself. A kind of new dualism will be developed if we do not take that into account. Leder has pointed out that even if the body is characterized by its presence for "me," it is also characterized by its absence. The body has different ways of being absent and present in health and illness (Leder, 1990). When we are trying to learn a new skill such as swimming, we need to be very conscious and focused on our body, on our hands, feet, and breathing. Then, the body is present. When we have learned to swim and the body "can" swim, we forget our body. It disappears from selfawareness. Instead, we focus on the object or the goal for our action and, in that way, are able to reach out in the world. During action, the body is absent from direct experience. In unproblematic and healthy conditions, the body "dis-appears" and becomes recessive. When the body manifests itself as a problematic or disharmonious thing, or in situations such as embodied distaste, dissatisfaction, ungracefulness, illness, and loss of embodied ability, the body might be experienced as strange. In this strangeness and alienation, the body is experienced as present in our consciousness, it "dys-appears." "Dys" signifies "bad," "hard," "ill," or "dysfunctional" (Leder, 1990). The dys-appeared body is marked by being away, apart, and asunder along several dimensions. Dys-appearance tends to arise when the body deviates from its ideal and normal state. There is the sense of privation, which provokes a bodily "thematization," meaning a conscious experience of and attention to the body (Duesund, 1993; Leder, 1990). Surfacing in times of illness, dysfunction, or the threat of death, the body can emerge as an alien "thing," a painful prison or "tomb" in which one is trapped. The body can no longer be taken for granted (Leder, 1990).

Dis-appearance and dys-appearance are complementary conditions or poles. Health and illness are examples of the two complementary conditions. Both exhibit an element of alienation from the body. In the case of health, the body is alien by virtue of its dis-appearance, as attention is directed primarily toward the world. With the onset of illness, this gives way to dys-appearance. The body is no longer alienas-forgotten but precisely as remembered.

A cerebral stroke can lead to considerable changes in the body. Parts of the body might lose their normal and effortless ability to function. This will change body language, in that gestures, the mobility of face, personal style, and appearance change (Brauer, Schmidt, & Pearson, 2001; Flick, 1999; Hafsteinsdöttir & Grypdonck, 1997; Häggström et al., 1994; Sisson, 1998), leading to changes in the interactions with the world (Overboe, 1999; Seymour, 1998). Moi (1999), a noted de Beauvoir scholar, has underscored the ambiguity of the body—as nature as well as a situation:

The body matters to Simone de Beauvoir. If I have to negotiate the world in a crippled body or a sick body I am not going to have the same experiences of the world or of myself as if I had a healthy or particularly athletic body. Nor will the world react to me in the way it would if I had a different body. To deny this is to be guilty of an idealist subjectivism. (p. 68)

Accordingly, to be in a female body disabled by a stroke might give particular experiences of the life world.

According to a feminist perspective, bodily changes must be understood from a gender perspective. Moi (1999) claimed that "no feminist has created a better theory of the bodily sexually differentiated person than has Simone de Beauvoir and that feminist theory has much to learn by returning to her ideas" (p. 23). de Beauvoir's ideas about the female body are grounded in the phenomenology of Merleau-Ponty, with whom Simone de Beauvoir worked closely. She maintained that biological gender is fundamental. The female body, with its particular biological characteristics and reproductive functions, places women in the world in a particular way. It creates distinct situations, challenges, and demands to which women must relate one way or another. de Beauvoir (1974) underlined, however, that biological facts alone give us no grounds for concluding anything about women's positions and value in society. The body is both a biological reality and a socially and historically constituted entity (de Beauvoir, 1974; Merleau-Ponty, 1945/1994; Moi, 1999). In de Beauvoir's analysis of how women became "the second sex," she maintained that for women, the body is considered as an important capital, which she has to make attractive. She also points out that the female body is very visible in that it is subjected to the gaze of others. Particularly in a patriarchal society, the female body is exposed to objectivation, alienation, and oppression. A stroke can affect these aspects significantly. The aim of the present study was an investigation of how a stroke can influence the lived body in women's life world.

#### **METHOD**

In phenomenological research, the everyday life, or life world, has to be taken as a point of departure (Bengtsson, 1993; Merleau-Ponty, 1945/1994). It is in the daily life and everyday practical tasks that the body is experienced.

# **Participants**

We recruited 25 women from three hospitals in a rural area in eastern Norway, based on the following inclusion criteria: (a) women who had been hospitalized due to a first-time stroke, (b) were able to participate in in-depth interviews (no serious mental and/or linguistic disorder), and (c) were not suffering from other serious disorders that might overshadow the experience of stroke. Initially, we planned to interview each participant three times. Three of the participants died between the first and the second interviews, 1 died between the second and the third interviews, and 1 withdrew from the study after the first interview. Consequently, 20 women completed the study. Ages ranged from 37 to 78 years at the time of recruitment. Five were employed at the time of stroke. Most participants had been employed after their children grew up. Seventeen participants were married or lived with a partner, 2 lived with adult children, 1 had moved to a nursing home after the stroke, and 7 lived alone.

The participants had a variety of educational and occupational backgrounds. Most had been occupied in typical female occupations (teacher, cleaner, office staff, saleswoman, nursing assistant, farmer's wife). Their educational backgrounds varied. One had university education, 2 had artist training, and 5 had vocational training. The others had no formal education. Twenty-two participants had adult children, 1 had small children, and 2 had no children. Twenty participants had grandchildren, and 4 had also great-grandchildren. Most of the participants had some degree of functional disability. Four used a wheelchair both indoors and outdoors. Three were dependent on aids such as a cane or a crutch when moving around. Some also suffered cognitive deficiency, such as concentration problems (when reading and in conversations), reduced memory, lack of initiative, or getting lost when outside the home. For most of the participants, cognitive functioning improved during the study. Two of the participants were not able to take care of themselves. One of those had moved to a nursing home, and the other received help from the community nurse several times a day. By the end of the study, three of the women had returned to almost the functional level they had before the stroke, but most still had persistent functional disabilities.

# **Data Collection**

After obtaining approval by the regional research ethics committee, we recruited female stroke survivors assessed by the head nurse and the physician from the participating hospitals as physically and mentally fit to participate to take part in the study. Potential patients satisfying the inclusion criteria received written and oral information about the study from the head nurse of each participating unit. Following written consent obtained by the head nurse or the nurse responsible for the patients care, the participants were interviewed in depth three times. The first

interview took place in the hospital during the first 6 weeks after the stroke. The second and the third interview took place in the participants' homes 6 months and 1 year after they had returned home. The study is based on a total of 66 interviews, all of which were conducted by the first author. The interview was conducted as a dialog, focusing on the following topics: their everyday life before the stroke, thoughts and experiences connected with the acute stroke event, their experiences of the body and changes that occurred, experiences with the health care professionals, and thoughts about and wishes for the future. A great challenge in qualitative interviews is to create an atmosphere that allows participants to speak openly about their experiences. The interview often started by the researcher's asking the participants to tell about what happened when they were hit by stroke. Our experience is that this question opened the way for a good dialogue, because the stroke survivors were preoccupied by this remarkable change in life. People suffering from a stroke, particularly those with cognitive deficiencies, can have difficulties expressing themselves verbally. They need time and encouragement to get started. An interview also gives access to body language, which can be helpful for understanding what is said and can generate new questions to clarify or elaborate on particular points. The participants in this study were very willing to share their experiences, and rich data arose from the interviews. The rationale for interviewing three times during the first 1½ years was to gain knowledge about the women's experiences in three different phases of the rehabilitation process and to understand what happened to them over time. Each interview was tape-recorded and lasted approximately 1½ hours.

### **Data Analysis**

Most phenomenological researchers have been inspired by, rather than applying directly, any particular method (Dahlberg, Drew, & Nyström, 2001; Giorgi, 1985; Omery, 1983; Porter, 1998). Giorgi (1985) developed a phenomenological method, which he summarized in four steps: (a) initial reading of the data to get a sense of the whole, (b) discrimination of meaning units within the perspective of a particular sphere, (c) transformation of the subject's everyday expressions into a disciplinary language, and (d) synthesis of transformed meaning units into a consistent statement of the phenomenon investigated. Giorgi himself claimed that there is a great risk of misunderstanding in presenting the method in a schematic fashion. His method is very detailed and was initially developed for the purpose of analyzing relatively short narratives of 10 to 20 pages (Dahlberg et al., 2001). In this study, the transcribed interview text consisted of about 1,000 pages.

In the data analysis, we were strongly inspired by Giorgi (1985, 2000) but made adjustments to accommodate the method to our extensive data material, as accounted for below.

#### **Step 1: Initial Reading of the Interviews**

Initially, we read the informants' descriptions to get a sense of the whole. In this phase, we approached the material with the mind as open as possible, in that we attempted to "bracket" (Bengtsson, 1993; Dahlberg et al., 2001; Drew, 2001; Giorgi, 2000) preconceptions and previous theoretical understanding of the phenomenon

of suffering from stroke. A preliminary understanding from each interview and subsequently from the total interview material seen together was written down.

# **Step 2: Thoroughly Rereading the Interviews to Generate Meaning Units**

Following a preliminary understanding of the whole material, we reread each interview closely and broke them down into meaning units. We directed the following question to the text: In what ways do the female stroke survivors' experiences of their body emerge from the text, and how do they describe their bodily experiences? We found that the women described their body both directly and indirectly. We first read the interviews of each woman consecutively to identify meaning and changes of meaning in the text over time. Next, we read the interviews across the informants at each interview time to detect similarities and differences among the informants. Both steps generated meaning units, for example, the body experienced as strong, neglected, unfamiliar, failing, and unable.

# **Step 3: Generating Subthemes and Themes**

In this phase, we carefully scrutinized the meaning units of the text by reflecting on them using "free imaginative variations" and searched for patterns (Giorgi, 1985, 2000; Spiegelberg, 1982). To detect changes over time, we systematically compared the presence and change in meaning units between the first, second, and third interviews.

We identified subthemes encompassing several similar and related meaning units (e.g., The Unfamiliar Body, The Time-Consuming Body, The Limiting Body). In the next phase, we gathered cognate subthemes into themes (e.g., The Unpredictable Body, The Demanding Body, The Extended Body).

#### **FINDINGS**

The participants' descriptions of their bodies after a stroke wove together the past, the present, and the future. Their experiences of their current bodies were compared to experiences with their prestroke bodies as they interpreted it retrospectively, the events occurring at the time of the stroke, and their hopes and goals for the future.

The bodily experiences during the development of and recovery from the stroke were characterized by profound, disturbing, and, in part, unintelligible changes. There were periods of rapid changes and improvement, and periods of slow and almost undetectable changes. Improvements were expected. The informants hoped and struggled for such changes. Most also experienced negative or unexpected changes, such as pains, infections, fractures, or a new stroke. These changes were related to overload of both the healthy and the impaired parts of the body and were characterized by decreases in functional abilities. Over time, the informants gradually seemed to become more or less familiar with their unfamiliar body.

To understand the poststroke bodily experiences of the participants, it is necessary to understand both the women's prestroke experiences of their bodies and

their bodily experiences at the time of the stroke. We will give a short overview of these experiences as a starting point for our presentation.

Most participants in this study described their bodies as healthy and strong and themselves as hardworking. Expressions such as "strong as a bear" and "never been sick" were typical retrospective descriptions representing the participants' experiences and self-understanding of their bodies. Many participants described a life in which their bodies had been hard working and active in many ways, particularly in connection to rearing children and doing housework or working either on the farm or outside the home. Although many participants expressed satisfaction, happiness, and pride at being able to work so hard, they also complained that they had never paid attention to their own needs. They had always toiled and neglected their body and health, which had been possible to do with a strong, healthy, and smoothly functioning body.

During the development and onset of stroke, some participants experienced vague changes several days or weeks before the stroke, which gave rise to experiences of an "unfamiliar or strange body" and prompted them to ask themselves "What is wrong?" or "Is something wrong with me?" Other informants experienced body changes as a progressive process of a "failing body" over a period of hours and days. Lene<sup>1</sup> (age 57) was writing a letter when her right hand and fingers abruptly stopped functioning:

I could not understand what was wrong with my hand and I stopped writing. My hand became more and more powerless and I was not able to cook. After some hours I went to the doctor and said that is not *me*. After being examined by the doctor and when I had to put on my shoes again, I fell down. Then my right foot was affected.

One participant was struck down by the stroke under dramatic circumstances, whereas others experienced it dramatically, lying helpless for hours waiting for help. The experiences of their failing bodies in connection with dramatic circumstances obviously touch them very deeply. They talked about these experiences in all three interviews. Some participants experienced dramatic changes "overnight," which gave an experience of an "unreal body." Hedda (62) had gone to bed early because she felt tired. She had slept well during the night, but when she awoke in the morning, she was not able to turn around in bed. Her left side was paralyzed. She realized that she had suffered a stroke, but she would not accept that she was paralyzed. She got out of bed to go to the bathroom. It was only a few steps away, but it was a terrible toil, and she felt very dizzy. She thought, "I can't believe this is happening!"

# **Experiencing the Poststroke Body: Moving From Bodily Strangeness Toward Reembodiment**

The informants continued to experience their bodies as strange after hospitalization and the diagnosis of the stroke. In fact, the experience of strangeness lasted throughout the study. They expressed different dimensions, or themes, of bodily strangeness, which are not mutually exclusive but, rather, reflect different aspects of the participants' experiences. These changes will be presented in three main themes:

The Unpredictable Body, The Demanding Body, and The Extended Body. Gradually, during the recovery and rehabilitation period, the participants seemed to become more familiar with their changed body.

# The Unpredictable Body

The most fundamental characteristic and experience of the body after stroke seemed to be that the body had become unpredictable. The unpredictable body encompassed three related aspects: The nonspontaneous body, the vulnerable and defenseless body, and the unreliable and betraying body.

# The Nonspontaneous Body

The nonspontaneous body is an expression of a body that was no longer able to do different things without consciously thinking about how to do it. After the stroke, the women needed to think about and to instruct their bodies: "You need to think about things which were a matter of course before the stroke." Sarah (70), for instance, described in detail how she guided her body when she was getting into a car, how she drove the wheelchair close to the car, and how she moved her feet, turned around, and sat down in the car. She gave the same detailed description of how she took the dishes from the dishwasher and put them in the cupboard. She was consciously aware of how to do these things:

Researcher: In order to get your arm and foot to function, do you feel you need to think about how to do it?

Sarah: Oh yes I have to. I have to think about everything I have to do. Everything I have to think about.

Researcher: You have to tell your foot that now you have to do this and that?

Sarah: I have to say to my foot: now you must help me.

Another woman, Signe (53), complained that she needed to concentrate very hard on almost everything that had to be done: cutting a slice of bread, baking cakes, driving the car, and getting dressed.

#### The Vulnerable and Defenseless Body

The participants described both physical and mental vulnerabilities after stroke: "The body is in a way defenseless." The body seemed disposed to complications or additional problems after the stroke, which delayed the rehabilitation process, interrupted the planned and expected health rehabilitation goals, and led to despair and exhaustion. Amalie (78), whose right side of the body was weakened but who could do most things except clean her house, said that she could not complain about the situation caused by stroke, but she suffered from pain in her left arm and shoulder. She described this pain as "terrible" and could not sleep during the night because of it. The pain was related to her "doing something wrong" with her weakened right side when she was trying to get up from the bathtub. Sarah (70) fell and broke the neck of her femur the day before she was due to go home from the rehabilitation unit. This incident delayed her rehabilitation and homecoming for several

weeks. Inflammations in both the impaired parts of body and the nonimpaired parts were common problems. For incontinent stroke survivors, urinary infection often became a chronic problem.

Lene (57) said that the worst thing after the stroke was that she was, in a way, "back to zero." She often became distressed over rather insignificant things, and others hurt her feelings more easily than before. She also felt betrayed more easily by others. She felt that she had lost her defenses.

Other informants said that they became exhausted by reading about or listening to something sad even if it did not involve them or anyone they were concerned about. Starting to cry and becoming very angry or disappointed over unimportant things were also reported by some women. Increased vulnerability to "noises," such as several people talking together, was also described by some.

# The Unreliable and Betraying Body

Many of the informants had experienced that the body was unreliable and felt that they were betrayed by their bodies in several ways. Sarah (70), who was hemiparalyzed, experienced that her paralyzed arm abruptly and without control was lifted up on the table, with the result that everything on the table was pushed onto the floor. She felt ashamed of herself for causing extra work for the nurse. Another time, when she was being trained, for example, practicing walking in her living room, Sarah fell down suddenly and was not able to get up.

Stine (70) was afraid that the community nurse thought she was a little bit indolent, and therefore she tried to walk 50 meters to the mailbox every day. She managed this walk for a few days, but suddenly one day when she stood at her mailbox, she could not move her feet and had to shout for help. After that, she was afraid of walking outside: "I could not trust my feet any longer." Lisa (61) had prepared to read a story at a Christmas party when she experienced her body's just stopping. She could not say a word. The same thing happened when she tried to introduce some people at a meeting and experienced it as very frustrating. Experiencing the urine flowing out and the clothes getting wet was a debasing experience for informants with incontinence problems. Marthe (74) was very much worried and felt ashamed when she could not remember words in conversation with strangers. Kine (78), who had almost totally recovered after her stroke, had stopped bicycling because she did not trust her body. Some informants had stopped driving or restricted their driving considerably, even if they had passed the driver's test after the stroke.

# The Demanding Body

The unpredictable body is demanding in different ways in everyday life: It is time consuming, limiting, dependent, and conspicuous.

# The Time-Consuming Body

Many informants complained that the body "needed" more time than before to do different things. It was no longer possible to speed up the body. If one tried to do so, the body simply stopped. When Signe (57) tried to work in a restaurant, but during

a busy time, she was not able to speed up the body to do the work very quickly. Her body stopped functioning, and she could not do anything at all. She had to sit down. Signe explained,

I need a lot of time for everything I have to do. What I needed one day to do before the stroke, I now need several days to do. I manage to do only a little every day, and everything needs to be planned. Nothing can be done spontaneously, which was no problem before. Then I managed almost everything.

The body itself also demands time. Some informants had to exercise several times a week to improve or keep up their body's functional level. Lisa (61) went to a physiotherapist twice a week and to group training with other stroke survivors once a week. After each training session, she needed to rest or sleep for 1 to 2 hours. Stine (72), who suffered hemiparalysis and was incontinent, needed 1½ hours every morning to get dressed. First, she had to get up and pass water. Then she had to go back into the bed to catheterize herself to control her residual urine. After that, she got up again and went into the bathroom to wash and dress. She also had physical therapy several times a week. During one period, the physiotherapist came to her home. Later, she had to get to a nursing home for training. She spent hours training her body. Stine was also encouraged to train herself every day, preferably several times a day (to stay on her feet, to walk, and so on). She planned to do it every morning, but often she did not manage to do it. Stine felt that she had busy days and complained that she had no surplus of time to do the things that she enjoyed that needed doing in her house.

## The Limiting Body

Many informants experienced their bodies as limiting. The body "cannot" walk, cook, wash, carry out personal care, or attend to work (either employment or housework), nor can it control one's natural functions, such as passing water and take care of one's social roles. The body created limitations in the stroke survivors' lives. During the first interview, which took place in the hospital, Sarah reeled off a lot of things she (her body) could not do and that prevented her from staying at home in anticipation of a place in a rehabilitation unit. Her body also prevented her from eating the food she was offered and from traveling with her friends. In the third interview, she said that the worst thing about being hit by stroke was that

I can no longer participate in everything I want to. I cannot do that. Before the stroke I could. Before the stroke, I could just take the bus to the city. I cannot do that now. I miss it.

Stine (72) had traveled extensively in her life. She very much enjoyed visiting big cities around the world, going to museums, walking along the streets, and sitting in a pavement café watching people. When she retired, she had planned to use all her money on traveling, but after the stroke, she acknowledged that her dream could not be realized. She had been in contact with several travel agencies and found that there would be too many difficulties with a hemiplegic and incontinent body.

Most participants complained that they felt very tired and had very little energy, and pointed to the limitations that this represented in relation to their everyday life activities. Marthe (74), a widow, spent most of the day on the sofa in front of the television or looking out the window. She talked about all the things she had to do—washing, exercising, gardening—but she had no energy: "What I complain of is that I am not capable of doing anything." She improved a little over 1½ years. Other participants experienced that they needed to rest often and to sleep a few hours twice a day.

Most of the informants had been hard working and had experienced tiredness because of hard work. The kind of tiredness they suffered after the stroke was different: It was tiredness without a specific understandable reason that rest did not alleviate. Signe (53), who was a farmer's wife and had a big house to take care of, did not feel comfortable lying on the sofa, but she had no choice. Lisa (61) described her tiredness as follows:

This tiredness made the difference from before stroke. Such tiredness is a new thing for me. You feel quite empty. You get problems with speech and the urine is flowing out.

Many of the women said that they fell asleep immediately when they sat down, which prevented them from enjoying watching television or participating in parties or other social activities. Some informants also experienced that their condition varied from one day to another. On "good" days, they could do a great deal; on others, they mostly had to lie down on the sofa. Some of the participants were grandmothers who wished to spend time with their grandchildren and help their children and in-laws, but after one day with the grandchildren, they felt completely worn out and needed to rest for several days. That challenged their way and understanding of being grandmother and a "caring" person in their family. A few of the women expressed that they were in a good condition when they left the hospital or the rehabilitation center but that they experienced tiredness when they had been home for a while.

As mentioned previously, the participants needed more time to do almost everything that had to be done. It gave the experience of a slow body, compared to their body before the stroke. Kine (73), who was a farmer's wife with 6 children and who always had a lot to do with a big house and so forth, repeated over and over again through the two last interviews, "I am so slow." She talked about both physical and mental slowness. Kine had no visible paralysis. She did her work very slowly, and she needed to read the newspaper very slowly to understand what she was reading. When she was out for a walk with someone, she had problems keeping up with their pace.

#### The Dependent Body

From what is described above, it is obvious that the body is experienced as dependent on different kinds of help and support from relatives and health care professionals and also on different kinds of aids. Dependence represented a new, demanding situation for many informants and was experienced as a great challenge compared to their prestroke condition. Dependency led to reduced freedom and flexibility, and required adjustment and reconciliation. Sara (70), for example, was not able to get out of bed and complete her personal care without help. She had to wait for help, and she was forced to go to bed when the community nurse arrived. Tine (72) was

incapable of completing her personal care, preparing her meals, and doing her housework, nor could she go outside the house alone because she would get lost. She was very dependent on helpers and her walking stick.

# The Conspicuous Body

Some informants had to use a wheelchair, a walker, or some other remedy to get around or perform specific tasks. This made their bodies conspicuous. The body also became conspicuous after the stroke because of its appearance, which led some informants to experience meeting other people as problematic and a strain. Sarah (70) had a contracture in her paralyzed arm, which made her hand look like a "claw." She also suffered facial paralysis, which made her face look "abnormal" and caused saliva to leak through her lips on the paralyzed side. Although she did not feel it a strain to meet other people, she felt that other people found it difficult to meet her. Lisa (61) felt very disappointed and became angry when a nurse or the occupational therapist observed her during her morning toilet to teach her how to use and train her paralyzed arm during daily care. She experienced too much focus on her body, which "could not do" several things. Some informants had gained weight because of a more quiet lifestyle following the stroke. That gave them bad feelings. Furthermore, as described above, some informants felt ashamed and "irregular" when they could not remember an event or a word during conversations. They felt that they were being looked at and were afraid that other persons thought them stupid:

Researcher: How do you feel when meeting "the world"—your relatives and others—when your appearance has changed?

*Informant:* I find it difficult. Not meeting my closest relatives, but others, because I so often start to cry. Yes, if you meet them outside you are crying. It is difficult.

On the other hand, several participants directed much attention, time, and money to making themselves look well and attractive. Lisa (61), for example, was very conscious about dressing differently every day in the hospital. She said it was a kind of therapy and a conscious striving against indifference toward herself. Other participants stressed the importance of having their hair and nails done and keeping well dressed and their bodies well kept. This underscores the women's concerns about the appearance of their body.

### The Extended Body

Many stroke survivors in this study needed tools or remedies, such as a walking stick, crutches, a walker, a wheelchair, large-handled knives, forks, and spoons, special pen and pencils, and braces. Sarah (70), who needed a wheelchair both inside and outside, termed her wheelchair her "feet." A doctor advised Amalie (78) against using a walker, because he thought that she would be able to walk without it and that it was not a good idea to be "dependent" on such a remedy.

Some informants needed "helpers" in their everyday life. Three kinds of helper were identified: (a) professional helpers (such as community nurses, physiotherapists, speech therapists, occupational therapists, and home helps), (b) family

members, and (c) neighbors and friends. Sarah (70) received help from all three kinds of helpers. A community nurse came every morning to help her get out of bed and assist with her personal care.

In the evening, the community nurse helped her to bed. Family members performed any jobs that might turn up. If something needed to be done, she could call her sons or daughters. Neighbors and friends brought her the newspapers every morning, took care of her flowers, phoned her every day to ask how she was, and took her out shopping or for a walk. For Sara and for some other informants, one could say that the helpers represented an extension of her body. When she and the helpers developed confidence in the situation, everyone knew what to do and how to do it. The situation functioned well. Sarah had integrated the tools and the helpers with the body, so to speak. For others, and also for Sara when she received help from unfamiliar people during holiday time, getting help was a straining experience.

#### **Toward Reembodiment**

From an outside perspective, a few participants recovered totally after the stroke. Thea (78) was one example. She had no paralysis or reduced strength in her limbs 1½ years after the stroke. She lived alone and needed no help. She did almost everything she did before stroke. She was a very healthy 78-year-old woman. Even so, she said that there was "something" about her body. Something was changed with her body compared to her prestroke condition and self-understanding. She was not what she had been before the stroke. She experienced an "unbalanced body." Similarly, Signe (53) underlined what might be understood as an experience of a vague but general change in her body:

It is a bad thing when people say that you look so healthy. Then I get a bit angry. Then you feel hypochondriac and indolent. You are not able to do what you have done before. It is impossible. Also my immune defense system is impaired. I have had infections several times. I don't know how to explain it, but there is something inside that has changed.

In the first interview, Lisa (61) described how she sometimes forgot that her arm was paralyzed and proceeded to do things in the way she used to. When she was going to move her flowers from her bedside cabinet, for example, she unconsciously used her paralyzed arm as before the stroke, with the result that the flower vase was thrown to the floor. In the second and the third interviews, she gave descriptions of how she instructed her body when doing particular things, with the result that she managed it. The same was the case for many informants, who shortly after the stroke sometimes experienced that they forgot that their body had changed and lost its function, and, for example, "started to walk and fell down." Little by little, they seemed to work out a technique or a method for doing several things, such as that mentioned by Sarah of how she got in and out of the car and took dishes out of the dishwasher. Signe (53) expressed it in this way:

I have to command my arm. I use my arm a lot and I have to tell it; now I shall grasp something and now I shall lift it and so on, but this has become a routine too. I don't think so much about it anymore.

Most participants experienced that they had improved their body functions considerably during the first 1½ to 2 years after the stroke, and for most of the informants, it was obvious that this was the case. For a few others, the development was not so obvious from an observer's perspective, at least not in the period from the second to the third interview. Perhaps their experience of improvement might be interpreted in part as their becoming more familiar with their unfamiliar body and having learned to use their bodies in a way that gave feelings of improvement and coping.

#### **DISCUSSION**

Our aim in this study was to gain knowledge of how female stroke survivors experience their bodies after a stroke. The body was characterized by profound, disturbing, and, in part, unintelligible changes—changes that were experienced from days and weeks before the onset of the stroke and throughout the whole investigated period. The bodily changes led to a thematization of the body, that is, a conscious experience of the body and its deviation from a normal and familiar state of the body. In line with Leder (1990), this is a change from a dis-appearing body to a dysappearing body, which is typical for the ill body.

The stroke survivors also seemed to experience other changes, changes that might be interpreted as reembodiment. That means that even if the body was still unhealthy and present for self-awareness (e.g., still paralyzed), the participants became more familiar with the unfamiliar body. In other words, the participants seemed gradually to incorporate and "re-own" their changing body. That might involve getting used to instructing parts of the body in how to do different tasks or feeling comfortable with a paralyzed arm that is "only hanging there dangling."

The stroke survivors' bodies continued to be in a condition of dys-appearance. This is in line with Doolittle (1992, 1994), who found that after a stroke, the informants described a "mind in control of the body experience" and that the body had lost its taken-for-granted, smoothly functioning ability. In line with our findings, her participants seemed to become gradually more familiar with a body that could no longer be taken for granted. Easton (1999), who described the poststroke rehabilitation process as a journey from agonizing to owning, supports these findings. She described the phases between those extremes are fantasizing, realizing, blending old loves to new life, and framing. Easton did not mention the body explicitly but, rather, described the rehabilitation process and the development of a new life. However, given the strong connection between the body and life world and that the body is fundamental in experiencing or creating the life world (Merleau-Ponty, 1945/1994), her findings seem closely related to ours.

The bodily changes experienced before the onset of a stroke were vague. According to Leder (1990), these changes were experienced by what he named as "the inner, in-depth or the recessive body," which is hidden from the surface, or sensorimotor, body. These changes are experienced by "interoception," which refers to sensations of the inner organs of the body. The "interoceptive" vocabulary is not well developed compared to the "extroceptive," which refers to our five senses open to the external world (p. 39). Each organ often has its stereotyped ways of responding to almost any noxious stimuli. In this study, some informants

suffered headache days before the onset of the stroke. This is the brain's stereotypical way of responding to stress, brain tumor, endocrine changes, and so on. Headache is also a habitual worry for women (Botten, 1993; Nilsen, Lande, & Malterud, 1998) Another vague experience was tiredness and the feeling of being worn out. This was an experience from the whole body. Women are familiar with changes in their inner body during puberty, the menstruation cycle, pregnancy, birth, and the climacteric (de Beauvoir, 1974). This might prepare them to be attentive to bodily changes and to distinguish between "ordinary" headaches and a headache that signals that something is wrong. One informant had contacted her doctor several times because of her vague body changes, but, she felt, he had not taken her complaints seriously. The women's trained ability to experience bodily changes might result in the experience that "something was really wrong" with the body.

When changes hit the sensorimotor organs or the surface body (Leder, 1990), they become more specific and are experienced in more shades and colored themes. The themes that emerged from the data in our study, which dealt with the results of a manifest stroke, seem to correspond mainly with themes identified in the studies of Morse et al. (1995) and Bleeker and Mulderij (1991). One distinct theme that emerged in our study that was not expressed in these two studies was The Time-Consuming Body. Our informants experienced a change from a body that "saves" time, which is characteristic of a strong, active, and healthy body, to one that consumes time. According to de Beauvoir (1974), women are familiar with spending time to care for their bodies "to serve the race" (p. 55). In addition, she claimed that the body is women's most important capital on which they spend time, energy, and money preening and slimming, to enhance their facial and bodily beauty to become attractive. In that way, spending time on their bodies should not be a foreign experience for women. In this study, most informants were concerned about their appearance. They spent time, money, and energy on clothes, shoes, hairdressing: on "looking good." Looking attractive seemed still to be a part of their femininity. Even if de Beauvoir claimed that what she called narcissism is a particular form of alienation for women in a patriarchy, to have the ability to take care of the body might be a resource for one's self-esteem and feelings of well-being. Having a strong body with the ability to do a lot of hard work—"always doing something with the body, work or handiwork, and not remaining passive"—also seemed to be an important asset and part of femininity for most informants in our study. The female working body is concerned about the needs, expectations, and demands of others. The change from a body that could be used to perform many things to a body that had to be "worked on," from a body that gives attention to other persons or things to a body that demands attention and work, seemed to bother the informants strongly.

de Beauvoir (1974) clamed that women are exposed to others' gaze and assessment concerning femininity. Stroke survivors in this study deviated from their own and also others' understanding of femininity. They experienced their bodies as conspicuous in different ways. Leder (1990) introduced the concept of social dysappearance to signify the power caused by the society and of "the gaze of others," whereby women are not free to experience from a tacit body but, rather, are expected to pay attention to their surface appearance. That is what de Beauvoir described as narcissism. Social dys-appearance can lead to biological dys-appearance, and vice versa, because the body is at once a biological organism, a social construct, and the basis of personal identity. In line with the ideas of de Beauvoir,

women with disabilities, such as female stroke survivors, are exposed to both biological and social dys-appearance.

Måseide (1997) argued that the body is a source for presentation of both morality and character. Bodily changes express a moral condition, because it is socially stigmatizing and degrading to be unable to control the urine flow, a foot, or an arm; to be unable to speak or take care of oneself properly; or to work very slowly. This interrupts both the "order of the body" and "the order of interaction" (i.e., what is considered normal and acceptable in the society). Female stroke survivors might then be exposed to the gaze of others in terms of violation both of norms of femininity and of normality (Duesund, 1995). One might argue that because women are familiar with being exposed to the gaze of others, being a stroke survivor makes little difference. On the other hand, being a female stroke survivor might be a double burden, because these women are exposed to critical dissecting gazes, which might have negative consequences for their self-esteem. Some of the women in our study experienced the conspicuousness of their body burdensome. This is in line with the experiences of women suffering paralyses in Seymour's (1998) study.

According to Lawler (1991), the nursing profession is deeply concerned about caring for ill bodies and is responsible for helping sick people to be comfortable with what happens with their bodies in illness, recovery, and death. Female stroke survivors experience great changes in their bodies over a long period, perhaps for the rest of their lives. It is a great challenge for nurses and other health professionals to attend to bodily changes, not only from a medical or objective point of view but also to capture the changes from a phenomenological point of view. Understanding the complex bodily changes that follow a stroke is mandatory to help stroke survivors reintegrate and "re-own" their bodies and to adjust to the implications of the changes. This can prevent then from being unduly restricted by their impaired bodies. Understanding bodily changes from a phenomenological perspective has wide implications for the way in which nurses provide direct personal care and support, how their assistance is structured over time to reduce discomfort and enhance comfort, and how patients are counseled and supported in their own recovery, adjustment, and reconciliation process. Much work is required to develop caring practices based on these insights.

A stroke is a serious illness with major consequences for the sufferers' bodies, health, and lives. Preventing and limiting damage is sometimes possible if the patient receives early treatment (Bovim, Johnsen, & Zwart, 1995; Magnæs, 1995; Thomassen, 1995). Some of our informants experienced vague symptoms days and weeks before the onset of a stroke that neither they nor their doctors took seriously. Concerning "undefined" disorders in female patients, Malterud (1997) complained that because medical knowledge is based on facts or objective signs, and primarily on research on men, the medical profession does not pay attention to subjective or vague symptoms, and particularly not those voiced by women. From a medical point of view, phenomenal experiences such as the themes emerging from our study are subjective. Malterud (1993) has claimed,

Male patients may certainly suffer from silenced voices too, confronted with expert power. However, female patients are exposed to not only expert power, but also gender power as well. Gender power may be displayed obviously in the doctor-patient relationship if the physician is male (which is often the case). But gender power is also deeply internalised in the female patient herself, being a woman in a

1308

society where power is assigned to the other sex. Therefore the voices of female patients may not necessarily sound themselves even if the physician is a woman or the patient trusts her own symptom presentation. (p. 367)

Nurses and other health care workers must empower the voice of women by listening to their stories and encouraging them to trust their own bodily experiences.

#### LIMITATIONS

The purpose of this study was to gain a deeper understanding of how female stroke survivors experienced their bodies after a stroke. Only female stroke survivors were recruited. This might be regarded as a limitation, as it might have been possible to articulate more clearly the particular experiences of women if they had been compared to those of men. The informants in this study were interviewed three times at approximately 6-month intervals. If the informants had been interviewed more frequently, the process of change might have been identified in a more nuanced way than was possible in this study.

#### **CONCLUSION**

Our aim in this study was to gain a deeper understanding of how female stroke survivors experienced their bodies after a stroke and to develop gender-based knowledge, which is lacking in the nursing and medical professions. The stroke survivors' experiences of their bodies were characterized by profound, disturbing, and, in part, unintelligible changes during the onset and the process of recovery from the stroke. Their experiences can be summarized under three major themes: The Unpredictable Body, The Demanding Body, and The Extended Body.

During the recovery process the first 1½ to 2 years after the stroke, the women experienced periods of rapid improvement and of slow and almost undetectable changes. Most informants experienced additional negative unexpected changes, such as pains, infections, fractures, or a new stroke. These changes were related in part to overload of both the healthy and the impaired parts of the body and were associated with decreases in functional level. A silent but significant change occurred as the informants gradually seemed to become more familiar with their strange and unfamiliar body.

#### **NOTE**

1. The women are assigned fictitious names to ensure anonymity.

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