Waiting To Get Better: A Dilemma Regarding Habits in Daily Occupations After Stroke

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The purpose of this study was to explore and gain an understanding of how habits are experienced when performing daily occupations after a stroke. In-depth interviews were conducted with 7 participants and a constant comparative method was used for data analysis. Four men and three women with stroke between the ages of 42 and 82 years participated in the study. The interviews were conducted 1.5 to 7 months after the participants had been discharged from hospital to their home. The findings show that the participants experienced frustration when performing daily occupations because changes in their performance meant that former habits could not automatically be reestablished; daily occupations had to be re-organized and planned with greater deliberation than had been required prior to the stroke. In reestablishing their daily occupations, the participants experienced an ongoing conflict about whether or not to develop new habits. Although adaptation and change would be beneficial in the short-term, both also represented giving up possible improvements, and participants seemed to consider that their eventual recovery and independence would be compromised if they allowed themselves to alter their habits. This dilemma led to a sensation of waiting; waiting to get better, waiting for another solution and waiting for the treatment to make an impact. As a result, few new habits were established in daily occupations. The findings suggest that occupational therapists need to be aware of the dilemma clients may perceive regarding decisions about whether or not to adapt and develop new habits during poststroke recovery.


Occupational therapy literature contains claims that habits and routines are important to the performance of everyday occupations throughout the life span (Christiansen & Baum, 1997; Hasselkus, 2000; Kielhofner, 1995; Reed & Sanderson, 1999). Understanding a person’s usual daily stream of occupation, patterns, sequences, periods of time and rhythms, is believed to be important if one is to be able to work effectively with that person in occupational therapy. Some tasks are repeated so often in daily life that they become habitual (i.e., they are performed at an automatic, preconscious level) (Christiansen & Baum). Although habits may be defined with some differentiation in the literature, the common conceptualisation of habits is based on learned and repeated experiences that becomes automatic actions (Clark, 2000; Kielhofner & Barett, 1998). Habits shape all activities, for example; the way a person squeezes the toothpaste or eats breakfast. Through repeated experience a person acquires a map for behaving in familiar environments. Because of habits one intuitively knows, for example, when it is time to leave for work and what turns to take when driving there. Habits ensure that we know, without thinking, the correct sequence of actions required to carry out an everyday event. They influence how one performs routine occupations, how one typically uses time, and one’s style of behavior.

Charmaz (2002) stated that the language of habit is silent; meaning that until their habits are challenged, people are largely unaware of them. Illness can oblige people to make changes to their daily habits and, although some of the changes might be small, others might be radical. One’s usual way of life can be altered and
one's ability to perform occupations can be severely impaired by illness. When a person's capacities are altered, previously established habits may become ineffective. The most profound problems may arise when an ill person starts to deal with the exigencies of ordinary life at home. Charmaz argued that learning what it really means to live with a chronic illness occurs through managing daily life. Occupational dysfunction can be viewed as a “breakdown in habits that leads to physiological deterioration with the concomitant loss of ability to perform competently in daily life” (Kielhofner, 1992, p. 30). Disability places unique demands on one's everyday habits.

In a study about adaptation, Macdonald (2002) interviewed women who had sustained a disability an average of 7 years prior to the study. The study showed that ability to perform occupational performance was related to a person's habits, to the form that they took, and the circumstances in which habits were applied. Steps of habit formation and influences on intentional habits were also identified in the Macdonald study. The women constructed new habits through much trial and error, and those habits required revision over time with any new changes in symptoms, occupations, roles, or environment. The participants described the process of designing and implementing new habits as important to adaptation and to maximizing independent function.

Thus habits are important for occupational performance. However, there is limited research regarding the development of routines, description of habits in everyday life, or effectiveness of intervention in reestablishing habits (Tickle-Degnen & Trombly, 2000). Trombly and Ma (2002) stated that: “Although occupational therapy historically has been the profession that seeks to help people sustain adaptive habits, let go of habits that are no longer adaptive and develop new habits given their changed abilities and capacities, no studies were retrieved that addressed habit formation and dissolution by occupational therapists” (p. 258). This knowledge gap compromises the ability of occupational therapists to effectively evaluate and treat disruptions in habits.

People who have had a stroke constitute the largest single diagnostic group of adult clients treated by occupational therapists (Rijken & Dekker, 1998). In the extensive literature on stroke rehabilitation, habit and routine seldom feature as key words. Studies have focused on treatment of performance deficits of clients in order to increase their independence (Corr & Bayer, 1995; Trombly, 1995; Walker, Gladman, Lincoln, Siemonsma, & Whiteley, 1999; Werner & Kessler, 1996; Wù, Trombly, Lin, & Tickle-Degnen, 1998), the adaptation process after stroke (Forsberg-Wärleby & Möller, 199; Gibson & Schkade, 1997; Jongbloed, 1994; Tham, Borell, & Gustavsson, 2000) and life satisfaction and activity preferences after stroke (Månsson, Fredriksson, & Brinholm, 1995).

In summary, habits are an essential part of successful occupational performance and habit formation can be significantly affected by disability. Stroke is one of the most common causes of disability yet there is limited research that considers the impact of stroke on habits. Therefore the purpose of this study is to explore and gain understanding of how habits are experienced in daily occupations after a stroke and thus to assist occupational therapists in better addressing this essential aspect poststroke.

Method

The data gathering method chosen for this study consisted of in-depth interviews (Depoy & Gitlin, 1998; Kvale, 1996). The interviews collected information about the participants' experiences of daily occupations after stroke, focusing on habits. The constant comparative method was used for data analysis (Bogdan & Bilken, 1992; Strauss & Corbin, 1998).

Participants

Seven participants were included in the study. Demographic data relating to the participants are presented in Table 1.

Occupational therapists provided the researcher with names of clients who could be asked to participate in this study. The criteria for inclusion in this study were that clients at a rehabilitation clinic were having difficulty performing some daily occupations after being discharged from inpatient treatment subsequent to their stroke and were able to participate in an interview. Those with aphasia and severe cognitive problems were excluded. Four men and three women, 42 and 82 years of age participated in the study. The interviews were conducted 1.5 to 7 months after the participants had been discharged from hospital to their home. The participants had been inpatients in a geriatric or a neurological rehabilitation clinic in Sweden prior to the time of the study. All participants had returned to their home environments after being discharged. The participants were no longer in the acute stroke phase, but their recovery was still ongoing. They were all attending outpatient clinics where most of the occupational therapy was conducted. In these clinics, occupational therapy focused on performance components: neuromuscular treatment, sensory motor techniques, and cognitive-perceptual retraining within occupational performance areas such as daily living occupations, work, and leisure. Home visits were also carried out by occupational therapists to assess
the need for environmental adaptations and provision of technical aids.

The participants received written and verbal information regarding their participation and were informed about the aim of the study. Permission for this study was granted from the ethics review board at the local university.

Data Collection

Open-ended questions were used, the most common form of questioning used in naturalistic research design (Depoy & Gitlin, 1998). An interview guide was developed around the following themes: habits before the stroke, adaptation of existing habits after stroke and instigation of new habits since the stroke. The researcher conducted the interviews. The interviews were conducted in Swedish. The interviews took place at the participant’s homes with the exception of one participant who chose to come to the researcher’s place of work. Data collection involved a sequence of two interviews with each participant to enable areas to be covered in-depth. The first interview with each participant took place between 1½ and 7 months after their discharge from the rehabilitation clinic. The first interviews lasted between 50 and 120 minutes. The interviews were audio taped and transcribed verbatim, whereupon the interviewer conducted a preliminary analysis. A second appointment was arranged for a follow-up interview to review the interpretation of the first interview before final analysis of the data. The second interview took place about a week after the first interview and lasted from 30 to 45 minutes. The preliminary interpretations and translation of the data were checked with the second author to support more in-depth analysis and to strengthen trustworthiness (Lincoln & Guba, 1985; Krefting, 1991).

Data Analysis

In the final phase of analysis data were analysed using a constant comparative approach (Bogdan & Bilken, 1992; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Analysis began with an open coding process of all of the interviews. In the next step the analysis went back and forth across the interviews to compare the codes that had emerged in each interview. This iterative process of comparing the interviews to identify similarities and differences in the data continued until no new codes were found. At the end of this phase nine substantive codes were identified: “daily occupations take time,” “a struggle: think, plan, and reflect in performance,” “no automatic habits,” “change of structure,” “no time for enjoyable activities,” “new habits are not established,” “conflict regarding dependence,” “dilemma: new habits,” and “waiting for improvements and to get better.” In the next phase of analysis the substantive codes were theoretically conceptualized into three themes. In the final step of analysis these three themes were defined as subthemes that represent aspects of a “grand theme” present in all interviews. The codes, themes, and translation of data were checked in a peer-review process with the second author who was familiar with comparative analysis.

Findings

A grand theme of “waiting” emerged from the data analysis. The grand theme, present in all interviews, was labeled “waiting for the dilemma to be resolved.” This grand theme reflects an interim situation characterized by waiting. The participants were waiting because they faced a dilemma, about whether to adapt to and accept their new situation or whether to wait for more improvements. Three aspects of this grand theme, which related to habits, were identified from the nine substantive codes and were conceptualized as subthemes of the grand theme. The first subtheme, “the need to plan and organize,” represented how participants consciously planned and organized what was previously mostly unconscious habitual behavior. The second subtheme, “lack of reestablishment of former habits,” emerged from the perception that for participants, new habits now occupied most of the day and former habits had not been reestablished. The third subtheme, “new habits: a symbol of dependence,” expressed an ongoing conflict about development of or failure to develop new habits because of fear of change and of becoming dependent.

### Table 1. Participant Demographics

<table>
<thead>
<tr>
<th>Participants’ gender; age (in years)</th>
<th>Marital status</th>
<th>Work/retired or on sick leave</th>
<th>Localization of CVA</th>
<th>Months after hospital discharge before first interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Female; 65</td>
<td>Single</td>
<td>Retired</td>
<td>Brain stem</td>
<td>7 months</td>
</tr>
<tr>
<td>2. Male; 66</td>
<td>Married</td>
<td>Retired</td>
<td>Right hemisphere</td>
<td>2 months</td>
</tr>
<tr>
<td>3. Male; 82</td>
<td>Married</td>
<td>Retired</td>
<td>Right hemisphere</td>
<td>2 months</td>
</tr>
<tr>
<td>4. Male; 60</td>
<td>Married</td>
<td>Work; sick leave</td>
<td>Left hemisphere</td>
<td>1.5 months</td>
</tr>
<tr>
<td>5. Female; 61</td>
<td>Married</td>
<td>Work; sick leave</td>
<td>Left hemisphere</td>
<td>4 months</td>
</tr>
<tr>
<td>6. Male; 56</td>
<td>Married</td>
<td>Work; sick leave</td>
<td>Right hemisphere</td>
<td>4 months</td>
</tr>
<tr>
<td>7. Female; 42</td>
<td>Married</td>
<td>Work; sick leave</td>
<td>Left hemisphere</td>
<td>2.5 months</td>
</tr>
</tbody>
</table>

CVA = Cerebrovascular accident.
The Need To Plan and Organize

The study data suggest that problems with performance of habits after stroke, previously used to accomplish daily occupations had been disrupted. The participants had to plan ahead, think, and reflect when carrying out a daily occupation simply to manage their everyday lives. Despite living in a familiar home environment, many of the daily occupations that participants had previously done no longer seemed to be easy to perform and even if repeated often they didn’t become habitual. Participants felt that, no matter what they did, they had to think about and plan their daily occupations in advance. One participant said: When I am standing at the sink doing the washing-up and I need to throw something in the garbage, I cannot do it right away. First I have to sit down in the wheelchair, then undo the brakes and wheel myself back a bit so that I can open the cupboard to throw out the garbage. Then I unlock the brakes to move closer to the sink, lock the brakes again and then I can stand up and continue washing-up. Another participant said: When I walk I have to tell myself to do things slowly and to do one thing at a time otherwise I lose my balance and fall.

Former habits were not automatically included in daily occupations after stroke; as a result it was very difficult to do things spontaneously. One participant said that prior to her stroke she had taken management of the occupations involved in daily life for granted because she had not had to think about how to carry them out. Shopping, for example, needed more planning than it had previous to the stroke and was more time-consuming. It was not possible to simply get into the car and drive to the store, or to stop by a store on the way somewhere else. Transportation had to be planned and arranged. Shopping also meant securing assistance in the store with things such as reaching provisions from the shelves and putting them in the grocery cart, pushing the cart and carrying the bags with the provisions. Cooking also now needed more planning. Would it be possible to open packages and jars? Were some of the ingredients too heavy or too slippery to handle? If a specific recipe were complex, it would take even longer to cook and prepare than it had prior to the stroke.

All this planning and increased time were perceived as a source of frustration for participants. One participant said: The other day I did the vacuuming. I had forgotten how heavy the Hoover was. I feel really useless not being able to do everyday activities. Another participant said: The plants by the windows now cause me a problem because I cannot reach to water them. The home helps do not realize that they have to water the plants so I always have to tell them. And one participant said: Now I cannot do very much at all. There are so many things you do with both hands. I cannot even open some of the spice jars because I cannot use my right hand. Instead I have to ask for help or decide not to use spices at all.

Being mobile was no longer something that could be taken for granted and as a result the world that was accessible to the participants had shrunk. For example, several of the participants expressed frustration at not being able to drive a car. One participant had always driven her children to their activities, now she had to plan ahead and arrange for her husband, her parents, or the parents of other children to do the driving. Another participant felt frustrated having to sit beside his wife as she drove because he had always been the one who drove the car prior to his stroke. Further, he could no longer spontaneously get into the car and drive off but instead had to plan ahead and arrange trips with his wife. For one of the participants, not being able to drive interfered with his opportunities to participate in leisure occupations and his ability to participate had been very important to him. He used to go to the forest to hunt, a leisure occupation that had been a relaxing routine for him. Nowadays he always had to plan trips in advance and arrange transportation with friends or with a transportation service. He felt that all the planning hindered him from participating as he would like to do and made what would have been a relaxing experience in the forest something of an effort.

The first subtheme showed how former habits were not automatically included in daily occupations. It represented how participants needed to consciously plan and organize what was previously unconscious habitual behavior.

Lack of Reestablishment of Former Habits

The participants in general had not reestablished their former habits and, on the whole, few new habits had been established to deal with daily occupations. One of the participants quite simply said: I have not developed new routines yet. Another one said: Sometimes I do it this way and sometimes I do it another way. I try to work out which is the best way to do an activity. Everyday routines occupations now filled most of the day; a participant who expressed frustration at this situation said: I have to keep doing things all the time and still so little gets done. One participant stressed the increased amount of time it took just to carry out the morning occupations.

Indeed, the amount of time taken to perform routine daily occupations was a common concern among the participants. The participants found it problematic that they could no longer manage to perform as many routine occupations in any one day as they had before their stroke. One of the participants said: I am kept busy all the time trying to carry out basic everyday activities, while another said: The days are very different now than they were before I had a stroke. I used to be so active, now I do nothing, which is something I find tough.
The previously stated structure of the days had also changed. Most described how they took one day at a time. Daily occupations had to be planned, but it was difficult to plan too far ahead. One said: *I take the days as they come; that is best right now.* Another said: *I used to plan and have a structure in my daily life. I was so busy and I always had to use a calendar. Now it is different and I find it difficult to plan too far ahead.*

There was one notable exception, however, to the failure to establish new habits in daily life: the need to plan a period of rest in the daytime. All participants in this study mentioned their fatigue. Most of the participants had to take a rest during the day so that they had the energy to cope with their daily occupations. One participant said: *I get so tired and I have to rest in the daytime.* Another participant said: *I have to rest, otherwise I get a headache.* Another said: *I am often tired and do not have the energy to do things like I used to do.*

Although routine occupations filled most of the day, participants also talked about other occupations that had taken on a new meaning for them. These occupations too required more effort than they had previously, which led to fatigue. For example, meeting and socializing with people required effort. One participant said: *We went for dinner at a friend’s house the other evening. It was nice but I was totally exhausted the next day.* Another participant said: *I am so tired and exhausted every time we have guests.*

The second subtheme emerged from the perception that new habits now occupied most of the days and that former habit had not been reestablished. The participants could not perform as many routine occupations as before the stroke and the structure of the days had changed.

**New Habits: A Symbol of Dependence**

The very acceptance of the need for adaptation of daily habits presented a dilemma to the participants. The dilemma was whether to change new habits and admit that the recovery was over or to refuse to change and continue to struggle. Reluctance to becoming dependent on other people was discussed. For example, one participant could not carry his new computer up to the second floor and thought he would have difficulty installing it, but he did not want to ask for help. He was striving to retain his independence and did not want to get into the habit of being dependent on other people. His plan was to wait for some improvement, at which time he hoped that he would be able to do it by himself.

Some technical aids were used and some environmental adaptations had to be made, but these were not fully accepted by the participants. There was a fear of changing daily routines some participants were apprehensive about compensating for physical dysfunction with technical aids and environmental adaptations. The introduction of such habitual compensation was thought to prevent further improvement of physical function. One participant said: *I do not want to raise the height of the toilet seat at home because then I would get used to that height and would have difficulty using an ordinary toilet seat when visiting other people.* Another participant said: *I do not want to adapt my kitchen yet. I still hope that I will be able to walk so that I will be able to use my kitchen without changing it.*

Despite the fear of becoming dependent, however, some participants had been able to change habitual ways with the use of technical aids. Aids for increasing mobility, such as walking canes, walkers, and wheelchairs seemed to have a degree of acceptability and in regard to clothing, participants had also begun to introduce certain adaptations. They described developing new habits in relation to the purchasing of new clothes and in considering what kind of clothes to wear, seeking those that were easy to put on and take off and easy to wash.

The last subtheme expressed an ongoing conflict about the development of or the failure to develop new habits because of fear of change and of becoming dependent on other people, technical aids, and environmental adaptations.

**Waiting for the Dilemma To Be Resolved**

During data analysis an overall grand theme of “waiting” emerged. This was characterized by a dilemma experienced by the participants concerning the acceptance and introduction of change in their lives. One component of this dilemma was attributed to the breakdown of former habits and former daily occupations. Upon discharge, the participants had returned to their familiar home environments, but it had not been possible for the participants to reestablish their daily occupations and former habits spontaneously. This in itself was frustrating and gave the day an unsatisfactory balance with personal care and household activities occupying the majority of each day instead of work, leisure, or some other more productive or enjoyable occupations. In this situation, adaptation and a change in the structure of the day seemed to be necessary for the participants to be satisfied with their everyday life and with the idea of establishing new habits.

However, and this is the second component of the dilemma, accepting adaptation was felt to represent giving up and relinquishing the struggle to get better. Thus the participants experienced a conflict about whether to develop new habits or not because they associated change with becoming dependent on technical aids, environmental adaptations, and other people. In other words, although adaptation and change seemed to be necessary, they also represented abandoning possible improvements and the hope for independence. One participant said: *If I became unable to do something then I would think of using technical...*
aids. But I think if you start using technical aids then you will become dependent and not improve.

This dilemma led to a state of limbo and a waiting situation: waiting to get better, waiting for another solution, and waiting for the treatment to have effect. In this situation, few previous habits were adapted and few new habits were established to effect performance of daily occupations.

Discussion

The findings identified a dilemma experienced by the participants of whether to adapt their former habits, to develop new ones, or to wait for further improvement. This dilemma may have significant implications for the course and outcome of ongoing occupational therapy. For participants in this study, in the subacute phase of their rehabilitation, daily occupations that had formerly been taken for granted had become problematic as previous habits could not be reestablished after stroke and limited effort had been made to develop new habits. Instead the participants focused on eventual improvement and put a strong emphasis on rehabilitation.

For a person to develop new habits, Kielhofner (1995) states there must be redundancy and stability in his or her environment. However, stability was not present in the structure of the participants’ daily lives and their routine daily occupations had not become habitual. The participants in this study experienced frustration in their daily occupations, yet they struggled against change, thereby establishing few new habits. Although both reestablishment of former habits and development of new ones can be looked upon as long processes, there is little evidence of early progress at this point in their rehabilitation.

Occupational therapy literature claims that habits are important components of daily occupation. Hospital care facilities are often unsupportive of habit acquisition and maintenance because they are organised around the routines established by staff. With reduced time assigned to rehabilitation in managed care, it is difficult to help clients to develop routines that may become habits over time (Holm, Rogers, & Stone, 1998). The experience of habits being inadequate for the performance of daily occupations and the disruption this causes may only become apparent after clients are discharged from the inpatient rehabilitation setting. Consequently people with stroke may face new challenges at a time when they have limited formal support from health professionals.

When working in a client-centered manner (Law & Mill, 1998), it is important for occupational therapists to be aware of the disruption of habits that affects a client’s daily occupations after a stroke. Occupational therapists should also be aware of the dilemma that clients face regarding adapting and thus accepting a limited recovery or avoiding adaptation in the hope of continued improvement. Although the findings of this study cannot generalized beyond this group of 7 participants, they may give occupational therapists a greater awareness of the client’s sense of dilemma and enable them to assess how best to assist clients to develop strategies to reestablish former habits and establish new ones. The qualitative study by Chang and Hasselkus (1998) showed that clients and therapists involved in stroke rehabilitation might have different expectations from therapy, the goals of therapy, and its outcomes during the rehabilitation process. It is important for occupational therapists to be aware of the disruption of habits used to carry out everyday occupations experienced by clients after a stroke and, in particular, that they may become most aware of this disruption after discharge from the inpatient rehabilitation setting. This is likely to be a turbulent period for people with stroke, a time full of frustration, characterized by struggle and a sense of dilemma when attempting to carry out daily occupations.

The findings of this study may have implications for how occupational therapists can guide and support people with stroke at the point of discharge from the inpatient rehabilitation clinic. Occupational therapists should consider spending time preparing clients for the way that their decreased cognitive and physical abilities may affect and challenge their habits in the home setting. As Charmaz (2002) stated, learning what it means to live with chronic illness occurs through management of daily life. By understanding the client’s life-world experiences, occupational therapists can become aware of the client’s previous daily life, occupations, habits, and the relation of these to their life situation post-stroke. This study may give some contribution to why clients with stroke not always follow recommendations made by occupational therapists during this phase of recovery.

The “waiting situation” identified in this study, where clients were unable to resolve the dilemma, may prevent them from making necessary adaptations in their daily occupations and developing new habits. Occupational therapists should be aware of this potential dilemma as they provide treatment, and be aware that guidance might be important for overcoming barriers in the adaptation process that hinder clients from establishing satisfactory everyday lives poststroke.

Although this study had provided some valuable insights into the experiences of clients’ poststroke it focused on an early stage of what can be seen as a long recovery process. Given that recovery from stroke can take years, further studies would need a longitudinal design covering a period of at least 2 years. Such studies could address whether the
participants eventually manage to adapt their habits in relation to carrying out daily occupations successfully or are able to establish new habits, or remain frustrated by their inability to perform daily occupations in a satisfactory manner.

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References


