The Meaning of Work After Acquired Brain Injury

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PURPOSE. Research in the field of brain injury rehabilitation has tended to regard return to work as a measure of outcome. Researchers have not paid particular attention to the experiences of people living with a brain injury. The aim of the phenomenological study reported here was to identify and describe what characterizes the meaning of work to those with acquired brain injury.

METHODS. Ten participants of working age were interviewed about the meaning of work 1–5 years after being inflicted with a brain injury. Data were analyzed and interpreted using the Empirical Phenomenological Psychological method.

RESULTS. The findings revealed a meaning structure consisting of four main characteristics. Work was no longer experienced as the primary event in life and the social dimension had become more important. The perceived competence and work identity were threatened after the injury. A common theme across all interviews was the struggle to return to a state of normality, and working was considered to be evidence of success.

CONCLUSION. The findings described the altered meaning of work 1–5 years after brain injury. This knowledge should lead to an increased understanding among occupational therapists engaged in work rehabilitation after brain injury and can serve as a basis for individualized intervention strategies.


Many people who incur a brain injury, and in particular those who have suffered a traumatic brain injury, are of working age (Hoofien, Gilboa, Vakil, & Danovickh, 2001; Koskinen, 1998; Steadman-Pare, Colantonio, Ratcliff, Chase, & Vernich, 2001). The rehabilitation process subsequent to brain injury, like traumatic brain injury or cerebrovascular accident, can last several years (Hoofien et al.; Webb, Wrigley, Yoels, & Fine, 1998). After an intensive period in inpatient rehabilitation care, a community-based rehabilitation phase follows, focusing upon reintegration into the community, including taking up different occupations. One common goal of this period is returning to work (Ponsford, Olver, Curran, & Ng, 1995), which is frequently associated with difficulties for many persons (Hoofien et al.; Johansson & Bernspång, 2001; Wall, Rosenthal, & Niemczura, 1998). For example, the return to work often means being assigned new, simpler work tasks and reduction of working time is common (Ponsford et al.; Johansson & Bernspång; Wall et al.; Stambrook, Moore, Peters, Deviaene, & Hawryluk, 1990).

In Sweden most work-related rehabilitation interventions include a trial period of work for which economic compensation is provided by a national social security system. As far as possible the trial is held in the former workplace, but when this proves impossible arrangements are made for it to be held elsewhere. This trial period is intended to provide an evaluation of the individual’s capacity to work, and it is concluded either with a return to the labor market or the allocation of a disability allowance. Wall et al. (1998) showed that this phase represents a difficult part of the rehabilitation because it involves a lot of hard work and therefore makes heavy demands on the client’s motivation. In a study of the factors motivating return to work in clients with chronic musculoskeletal pain, Gard and Sandberg (1998) found that, among what are referred to as “the structural factors,” the division of labor among the staff at work was an important motivator. In particular, the ability to work equally quickly and to the same standard as colleagues was...
considered to be important. Furthermore, doing work that could be considered to be meaningful by the worker and by others was considered to be motivating, as were relationships with colleagues.

Research in the field of brain injury rehabilitation for people of working age has mostly focused on reentry into the job market as an outcome, but the specific meaning of work to the individual has not been examined. This research area would be further clarified using a phenomenological approach, which focuses the individual’s life-world experiences (McLaughlin Gray, 1997). The philosophy underlying a phenomenological approach is based on the work of Husserl (1970). The life-world (i.e., the social and cultural world in which we live) is perceived as something that is always there, something that is taken for granted. The life-world experience is individual and a practical and nonreflective way of existing in the world. By critically examining life-world experiences, phenomenology seeks to describe the essence, structure, and character of that experience (Karlsson, 1993). The purpose is to trace out the essential characteristics that are embedded in the experience (i.e., the meaning structure of the phenomenon under study).

The experiences of those living with the consequences of a brain injury can give important information to the rehabilitation professionals to enable them to understand their clients better and to plan interventions appropriately (Kielhofner, 2002; Mattingly & Fleming, 1994; McLaughlin Gray, 1997; Nochi, 1998). One area in which there still is a lack of knowledge is the meaning of work for those inflicted by a brain injury. Therefore, the aim of this study was to describe and understand from a phenomenological and occupational therapy perspective what characterizes the meaning of work to those who have experienced acquired brain injury.

Methods

In this study, a modified form of the Empirical Phenomenological Psychological (EPP) method was used (Karlsson, 1993). The EPP method is a qualitative, interpretative, and descriptive method of analysis that aims to trace out the meaning structure of a phenomenon based on the participants’ lived experiences of the phenomenon under study (i.e., the meaning of work after acquired brain injury). In this study we replaced the psychological perspective with an occupational therapy perspective. This modified form of the EPP method has previously been used in several studies within occupational therapy (Erikson, Karlsson, Söderström, & Tham, 2004; Tham, Borell, & Gustavsson, 2000; Tham & Kielhofner, 2003). Approval for this study was given from the local ethical committee.

Participants

The participants in this study comprised 10 persons with acquired brain injury, mainly caused by vascular accident or trauma, who were of working age and admitted to an outreach rehabilitation program in Sweden. Participants were selected in collaboration with the occupational therapists at the clinic with the aim of collecting rich data representing varied aspects of the phenomenon under study. A choice was made to conduct one interview each with several (N = 10) informants representing variation regarding age, gender, and diagnosis and who had the ability to describe their experience. They all had had or were still undergoing a period of work trial subsequent to the brain injury. Some were back at work at the time of the interview whereas others were still on a government-funded work trial. In order to better understand the varied characteristics of the phenomenon under study (Karlsson, 1993), data from two persons who had received a disability pension were included in the study with the intention of examining the meaning of work from the perspective of those no longer considered capable of working.

The participants either had no remaining motor impairments or just minor ones. They suffered from minor to moderate cognitive impairment; some had major memory impairments. See Table 1 for demographic data describing the participants.

Data Collection

The interviews (one interview per participant) were conducted by the first author and took place in the participants’ homes, with the exception of two persons who preferred to come to the clinic. In order to acquire rich data representing the phenomenon under study, each respondent was asked to describe his or her past, present, and future experience of work and perspectives on the meaning of work in a narrative manner (Kvåle, 1997). The interviews were guided by a few open-ended questions. The questions focused on the informants’ experience of the content of the work, that is, the work tasks undertaken before and after the injury; the experience of not being able to work after injury; and the meaning of work in general. The participants were also asked about their thoughts on their future working life. Each interview took about 1 hour. The interviews were tape-recorded and transcribed verbatim.

Data Analysis

The transcribed interviews (consisting of 115 pages of text) were analyzed by the two researchers using the EPP method (Karlsson, 1993) aiming to identify and describe the essential characteristics of the phenomenon under study (i.e.,
meaning of work after acquired brain injury). In order to
trace out the meaning underlying the facts in the inter-
views, the researchers attempted to be as open as possible
and avoid presupposition during the analysis. The
researchers’ preexisting theoretical understanding outside
phenomenology, such as biomedical knowledge about brain
injury, was therefore bracketed.

The data were analyzed in five steps. Each of the 10
protocols was first analyzed separately (steps one to four)
and then compared with all protocols (step five). In step one
both authors read the interviews with the intention of get-
ting a good grasp of the material. In this step the researchers
tried to have an empathetic understanding, which aimed at
understanding the participant’s original experience related
to the studied phenomenon. In the second step the first
author divided each protocol (i.e., interview) into smaller
meaning units each time that a shift was found in the mean-
ing of the data.

In the third step each meaning unit was interpreted in
the light of the whole protocol in order to trace out the
underlying meaning embedded in the facts described by the
participant. The focus of analysis was on identifying the
meaning of work for each participant. The researchers dis-
cussed several possible interpretations before the most valid
interpretation was chosen.

The analysis continued in step four by synthesizing
the interpreted meaning units into a summary for each
protocol (Karlsson, 1993). Throughout steps four and five
the researchers returned repeatedly to the original proto-
cols to validate the interpretations. In the fifth step the
researchers compared all the summarized protocols in
order to identify a general meaning structure for all partic-
ipants, that is, characteristics that were visible across all
participants. The aim was to identify general characteristics
that together built up the meaning structure of the phe-
nomenon under study. The final meaning structure con-

sisted of four main characteristics representing general
characteristics across participants, each containing two or
more subcharacteristics. The subcharacteristics were
described to give examples of the different variations of the
phenomenon across participants. To investigate validity,
the “horizontal consistency of the interpretations”
(Karlsson) was examined by examining whether the inter-
pretation of each of the interview protocol was consistent
with the meaning uncovered “across” all protocols (i.e., the
parts were interpreted in the light of all data). To examine
trustworthiness, the interpretations were also subjected,
several times during the final phase of the analysis process,
to peer examination in a group of experienced researchers
and clinicians. Feedback from these seminars was used to
establish the final interpretations.

Findings

The findings describe the meaning structure of the phe-
nomenon; the meaning of work after brain injury. First,
three main characteristics are described, identifying the
altered meaning of work across participants. The final main
characteristic describes how the participants strived for nor-
mality. Subcharacteristics make explicit specific and essen-
tial features of the main characteristics and are exemplified
by concrete examples and quotations.

Work Had Taken on a New Place in Life

The participants described how work had taken on a new,
less central place in life in comparison to the role it had had
prior to the injury. Work was not the first subject the par-
ticipants thought of directly after receiving their injury. The
experience of having a brain injury had resulted in reflection
on a more existential level as thoughts about the meaning of
life and being able to enjoy life. Participants said that work
no longer gave the primary meaning to their lives anymore.
Even persons who had valued work as the most important
thing in life before their injury had had reason to reconsid-
er their opinion. One aspect of this was a concern about
whether it was the work that had caused the stroke.

Table 1. Characteristics of the Participants

<table>
<thead>
<tr>
<th>No</th>
<th>Age at time of interview</th>
<th>Gender</th>
<th>Time since injury</th>
<th>Diagnosis</th>
<th>Occupation at injury</th>
<th>Work status at interview</th>
<th>Marital status</th>
<th>Living with children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>50</td>
<td>Male</td>
<td>3 y</td>
<td>Stroke bilat</td>
<td>Engineering</td>
<td>Work: Part-time</td>
<td>Married</td>
<td>No</td>
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<tr>
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<td>2 5 m</td>
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<td>Unskilled work</td>
<td>Work trial</td>
<td>Single</td>
<td>No</td>
</tr>
<tr>
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<td>4 7 m</td>
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<td>Clerical work</td>
<td>Work trial</td>
<td>Married</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>58</td>
<td>Female</td>
<td>1 6 m</td>
<td>Stroke right</td>
<td>Clerical work</td>
<td>Work trial</td>
<td>Cohabiting</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
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<td>Female</td>
<td>4 8 m</td>
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<td>Unskilled work</td>
<td>Disability pension</td>
<td>Single</td>
<td>Yes</td>
</tr>
<tr>
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<td>Female</td>
<td>5 6 m</td>
<td>SAH</td>
<td>Clerical work</td>
<td>Disability pension</td>
<td>Cohabiting</td>
<td>No</td>
</tr>
<tr>
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<td>Male</td>
<td>1 9 m</td>
<td>Stroke left</td>
<td>Administrative work</td>
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<td>Married</td>
<td>Yes</td>
</tr>
<tr>
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<tr>
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<td>Married</td>
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</tr>
<tr>
<td>10</td>
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<td>2 8 m</td>
<td>Stroke left</td>
<td>Clerical work</td>
<td>Work: Part-time</td>
<td>Cohabiting</td>
<td>No</td>
</tr>
</tbody>
</table>

Note. SAH = subarachnoid hemorrhage.
Work had taken on a new place in life
–The importance of work had decreased
–Work had caused the stroke
–Work tasks had become less meaningful
–Work provides significant structure to everyday life

The social dimension of work had taken on an expanded meaning
–Colleagues had come to play a more important role in life
–Working life had an influence on social life outside work

The person’s perceived competence and work identity had been altered
–The old work identity had been threatened
–Uncertainty in the assessment of one’s own competence
–On the way to finding a new identity

Striving for normality
–Symbol of success
–Work as means of rehabilitation

Figure 1. Summary of the main and subcharacteristics.

Work was also assigned a new place in life because the participants no longer faced the same situation when it came to choosing among work tasks. The work tasks did not give the same pleasure as they had before the injury and some questioned whether the reward was worth the effort. Nevertheless, there were some benefits to be obtained from working: It had become obvious that one quality of work was that it gave a structure to everyday life in general. Participating in work also brought a structure into leisure time, a structure that seemed to be significant for the participants’ experience of satisfaction with their everyday life.

The following subcharacteristics describe different aspects of how work had been assigned a different place after the brain injury.

The Importance of Work Had Decreased. After the injury, the participants had reconsidered what was meaningful in life and had discovered that there were other things, besides work, that were of importance for a good life. One woman who had been very dedicated to her work described how she had discovered a new dimension to life after the injury:

“There was a life outside my work that I had not known existed before.” Respondents had gained a new insight into how their ability to enjoy life had become more important than just being able to work. One man, for example, described activities he had been unable to do after the brain injury but that he wanted to do: “Sometimes I feel that I would like to be able to read, and I want to be able to play (the piano), I want to be able to revel in life.” Most of the participants wanted to give their families higher priority than before. Some of the respondents described how, through what happened to them, they had gotten the chance to discover this social side of life: “Now I am lucky—if you can put it like that—to have had the opportunity to choose to spend time with my children.”

The participants described how meaning in life was not solely dependent on reentry into the job market, even if work still had a particular value. What used to be a way of living for some of the participants had altered to become more akin to a way of being occupied with something meaningful. Everyday activities that, for example, had previously been taken for granted—like the ability to get up in the morning—felt more valuable now when they had been regained.

Work Had Caused the Stroke. Another reason why work had been assigned a new place in life was that some of the participants with stroke had started to reflect upon the extent to which their work had caused the stroke. They expressed thoughts concerning their former habits, such as how stressful their work had been, asking questions about whether it had impacted on their health. According to them, work had been a strain and it was possible that it had impacted on their health so badly that it had provoked the stroke. They also had thoughts about how they now lived with the risk that this could happen again. One man expressed his feelings like this: “If I continue in a high tempo maybe this can happen again at some point, but I try not to think about it.” The respondents put the responsibility for their intensive working pace on themselves. They did not blame their work or their employer.

Work Tasks Had Become Less Meaningful. Some of the participants described how they had longed to go back to work after their injury, but being back at work they found a change: “I was longing to get back to work; but when I got back there, it was not as much fun as it had been. It isn’t that I am bored, but, well . . . it was simply more fun before. It could be that I think in a different way now. It (work) is not as important as it was; now I factor in other things.” Work was no longer the satisfying pleasurable experience it had been.

Another component of the experience that work was less meaningful than it had been was the limited possibility to choose among different tasks. From the interviews it seemed as if the participants’ remaining impairments after the brain injury had affected their opportunity to choose between as wide a repertoire of tasks as before. The participants described how they could no longer perform some of the tasks they had valued most, and this they experienced as a loss. Thus, these no longer figured in the choice of options; and the new, modified work tasks that the participants were given instead were experienced as simple and did not give the same amount of contentment as the previous ones had.

Some of the cutting back was seen as an opportunity to avoid stressful work, but the participants generally
experienced it as a loss because they were not able to choose more interesting and challenging work anymore. This limitation also had a devastating effect on the future career prospects which was difficult to accept. For one of the participants working in a travel agency, driving always had been the most valuable work task. He described his feelings about not being able to drive like this: “I have still not accepted it. I have learnt how to handle it, but, frankly speaking, now and then I find it a damned shame.”

The participants also said that they needed to evaluate the amount of effort that would be needed to perform an occupation and determine whether or not it would be worth doing. The price, as for example experiencing a devastating fatigue afterwards, was sometimes found to be too high. One woman struggling with fatigue expressed the situation in this way: “There were also a lot of tasks that I had to turn down. . . . I tried to do them, but it was no good because I was so weak afterwards. I found it was not worth it.” She chose to save her energy for other situations. The experience of work tasks claiming so much energy took away the joy of doing them.

Work Provides Significant Structure to Everyday Life. A new meaning that work took on was that it seemed to help the participants to maintain a structure in their everyday life, a structure they had lost after the brain injury and that they needed to have to be able to function on a daily basis. Their experience of work was that it also gave structure to their leisure time. When work had been on an appropriate level, with neither too much nor too little being done, it had been easier to achieve other everyday occupations. Work was experienced as a stimulator of activity, an important means of getting things done. It seemed to give a better balance throughout the day. One woman described her experience from a period when she was signed off on a new period of sick leave after a work trial: “I noticed myself backsliding (when she did not go to work), I did nothing . . . I felt such hopelessness for a while.” She expressed a fear that the same thing could happen again if she did not continue working.

Some of the participants also explained how work protected them from developing feelings of self-pity and falling into bad habits. After a day of work, they felt a greater sense of satisfaction and were in a good mood.

The Social Dimension of Work Had Taken On an Expanded Meaning

The interviews revealed that the social dimension of work had become more apparent. During the rehabilitation process the participants had the experience that colleagues played an important role in their motivation to conduct a work trial. Colleagues were described as being more important for the sense of belonging to the workplace than supervisors were. Another example of the expanded meaning of the social dimension of work was that the participants had also become aware of the way in which work had an impact on their social life, even in their spare time.

Colleagues Had Come To Play a More Important Role in Life. The participants described how good relationships with colleagues had always been a matter of course, but how this had changed after their injury became more obvious to them—how valuable it was to have nice and friendly colleagues. A good relationship was no longer taken for granted. Some of the respondents stressed the importance of believing persons in the workplace really cared and that their colleagues tried to understand the situation from the perspective of the individual with the brain injury.

The participants’ experiences were that their colleagues had been decisive for their degree of motivation to return to work; the lack of colleagues was crucial for one of the respondents who made a decision to apply for disability pension. As she had neither satisfying work to do nor any colleagues, she decided to quit her job.

Participants also discussed how good workmates could compensate for work tasks that were not so engaging, even if several respondents claimed that a good job should contain both good colleagues and engaging tasks.

Working Life Had an Influence on Social Life Outside Work. Participants described how work occupied a significant part of everyday life and that it had an impact on social life outside work. After quitting work or shifting to part-time work, it had become obvious to the participants that the content of their life had changed. One woman who had been awarded a disability pension described feeling a void. Experiences at work had given substance to the conversation with the family during dinner and now she did not know what to talk about at mealtimes. There was not very much that happened to her during the daytime now.

“You feel so lonely when you just stay at home and I think it is very important for the self-esteem that you have something to do and, above all, someone to talk to. When you just stay at home you have no input . . . in the evening when you meet. Before you had so many things to tell. Now there is nothing. Life becomes empty.”

It seemed as if work had taken on an extended meaning in fulfilling the participants’ social needs after their injury. The participants feared that if a return to work was not possible, they would lose contact with other adults. They also expressed that social activities were not as easy to accomplish after the brain injury and their experience was that their work facilitated these contacts. It gave a structure
to their interaction with other people. One woman who had decided not to work described her feelings in this way: “I have applied for a disability pension now, but I have been depressed about this because I have been thinking that I will no longer meet anyone other than my children. Still, I am an outward-looking person.”

**The Person’s Perceived Competence and Work Identity Had Been Altered**

The participants felt that they were no longer attractive in the labor market, which influenced their sense of identity. Their worker role had changed; their opportunities for personal development and the possibility of getting appreciation through work had altered. Participants also described a feeling that their personal value as individuals was not the same as it had been before.

The participants had been familiar with their own competence prior to the injury, but now they sometimes had a fear that something was different. They expressed hesitation if there was a discrepancy between their own apprehension and that of other people about their work capacity. This gave rise to feelings of insecurity and worry about their future work situation.

After a long period of rehabilitation, an adaptation process had started in which the participants tried to adjust to new circumstances. A new sense of identity was developing.

**The Old Work Identity Had Been Threatened.** The participants had experienced that their old work identity, their sense of having a position in life, and their knowledge of their value had been threatened. That is, the situation had altered and their assessment of their new position was that the possibility for them to have a career did not exist anymore. They had found out that there was no longer a place for them in the top ranks:

> If I apply for a new job I would fail to pass an interview if I were to apply for a new job when asked about my health. [sic] Then I must tell them (about the stroke) and then they will not engage me. Even if they look at my qualifications ... they would never engage such a person.

Work tasks requiring better qualified people were not considered for a person with some limitations to his or her capacity.

The participants described how it was a long-lasting and sometimes painful process becoming aware of their altered position in working life. One man said: “It was a traumatic experience until you came to understand that you had just gone down 10 stories—to the basement. And the significance of this ... well, it took quite a long time for me to understand, anyway.”

Being reduced to performing unqualified work was not in accordance with the image that they had had of themselves before their injury: that of being gainfully employed. One of the participants explained how she used to sit in her old office watching her colleagues performing her former job and she told of how she had suffered while she was on her trial period at work. She described how she compared herself with her colleagues and felt that she was useless, which had influenced her image of herself:

> My self-confidence took a further bashing. It had already taken a knock and this did not make things any better. I sat there watching as people did my old job while I sat and put papers into files. That was all I was able to do—I could not cope with anything else. It was awful.

The experience of having limitations to her performance, in terms of being able to learn new operations and being able to embark on tasks at work without assistance, was experienced by this woman as a threat to her work identity.

**Uncertainty in the Assessment of One’s Own Competence.** The participants expressed insecurity about the future and about their working life. Did their own assessment correlate with others’ judgement of their personal competence? What did one really know about one’s own capacity, and to what extent could this be a misjudgement? This feeling of insecurity was described by one of the participants when he discussed his capacity for work in the future: “... and supposing I find that I have misjudged the situation . . .”

Evidently he had some doubts concerning his own apprehension of his competence.

Throughout the trial period of work the participants had the opportunity to try different tasks. Nevertheless, the participants expressed uncertainty about what they were capable of doing, demonstrating that they had had difficulty appraising themselves. Sometimes this meant that the participants avoided certain tasks without giving a reason why, as was the case with one woman who did not answer the phone at her office. It was a part of her job, but she refused to do it because she did not feel that it was something she was comfortable doing.

The participants also described how they had a feeling of insecurity from being exposed to other people’s judgment. Their uncertainty in their new situation included being at the mercy of the authorities who estimate the work capacity of individuals and their right to financial compensation. Participants expressed a fear that the authorities, like officials from the regional insurance office, would not consider them to have the competence needed to perform a job. This fear caused them to cover up signs of weakness, such as having flu. Instead of reporting that they were at home with flu, they took compensatory time off for overtime.
done. One of the respondents expressed his anxiety with: “The older I get, and then... having this injury, well, it is like finding oneself a little bit off-side. I wonder what it would be like if others decided not to use my capacity.”

On the Way To Finding a New Identity. The respondents considered that adapting to their limitations was a process that took a long period of time. During the period of rehabilitation they started to reevaluate their image of themselves, to value themselves more as a person and not only by what job they had performed. This process was still going on after several years: “This is what my life looks like. One could say that it has taken 4 years... Yes it has taken 4 years to give oneself a value of some sort.” The participants described how they had been striving to find their new identity and to get other people to recognize it. They had doubts about whether they were good enough, even if they were still in the process of recovering some of the limitations to their capacity. Their pride as a professional worker was affected.

From the interviews it became apparent that the immediate focus of their work was changed. In particular, some of the participants said that their most significant motive for work had changed from a professional pride, that is, being a competent worker who could take on a challenge, to being a straightforward wish to do something that was valuable to others and that one could consider as “normal.”

Striving for Normality

From the interviews it became apparent that the immediate goal of the rehabilitation was to get back to a “normal” way of life. Being “normal” again or getting back to “normal” was repeatedly mentioned by the respondents as being the most fundamental issue. Work was considered as evidence of being back to “normal” again.

One aspect of “normality” was to regain the familiar feeling of mastering one’s own body and of being able to use the old repertoire of skills. During the endeavour to reach that goal, work had been experienced as a motivating factor. Being a “normal” person again was also described as being like everyone else. The participants discussed how it is that, at some point in life, every person encounters situations in which he or she experiences limitations.

Symbol of Success. The participants’ strength was put into the effort to become “normal” again after the brain injury, and getting back to work became a symbol of success in this. Going back to work was considered to be equivalent to a state of “normality.” One of the participants said: “I wanted to get back (to work) very quickly. I was on full-time sick leave for 7 months and I was pushing too hard, I believe. I wanted to become normal. Mostly because I wanted things to return to being the same as they had been before.” Having a job was considered to be proof that one had recovered after a period of illness, that the participants were no longer trapped by their illness. One woman expressed the feeling of being back at work like this:

Yes, it is evidence [sic] that I have recovered in some way... that I had a stroke and I have recovered from it. And it (work) has been an incentive in this... because it (getting back to work) is what I wanted, it was my goal.

On the other hand, not being able to go back to work was described by the participants as a defeat. Not because work in itself was so important, but because it represented getting better. Not being able to work was experienced as a sorrow, and applying for a disability allowance was a very hard decision to make.

Work As Means of Rehabilitation. Work was regarded as means of rehabilitation, but also as an incentive to continue the struggle to get back to the person’s former life, a “normal” life. The respondents stated that after the brain injury, it had been hard work to get back to everyday life and, during that process, work had become a motivating force for rehabilitation. One of the respondents described how work had been important when he had determined the goals he had for his rehabilitation. It was something to struggle for: “... one has a sort of driving force. At first I saw myself as a handicapped person sitting in a wheelchair... but I’ll be damned if I’ll not live a normal life again.”

It seemed as though, especially at the beginning of a work trial, the meaning of work was to give an opportunity for exercise aiming to regain the ability to do the things the person had liked to do previously. One of the participants put it like this: “The task has been... to claw one’s way back again.” The attention was not focused on the tasks conducted at work in that phase; work training was primarily experienced as an opportunity to practice different skills with a view to returning to normal functioning in spite of any remaining impairments.

After the brain injury the participants had to learn to live with some new limitations, and one challenge had been to reconsider whether this was acceptable in the light of their desire to be normal. One of the participants described his thoughts about normality in this way: “I will have to put up with certain things and I can deal with them. But it will not keep me from... well, I do not feel like it is a hindrance to being able to become like everyone else. Because other people, well, what of them? Everyone has their limitations in some way.” The thought that many people experience...
some kind of limitation in their life at some time contributed to the participants’ feeling of normality.

Discussion

This study has identified what characterizes the lived experience of work for those who have acquired a brain injury, with a particular emphasis on the meaning that work had taken on for those concerned. The phenomenological analysis explicitly revealed that the meaning of work had altered in different ways after injury in comparison with before injury and that the participants expressed a striving to achieve normality through a successful return to work, which has implications for occupational therapy practice. Knowledge of the meaning that work holds after brain injury can contribute to attaining a better understanding of how the needs of people can be met through their work rehabilitation, including work trials.

One main finding was that, in different ways, work had been assigned a new place in life by the participants. Such a reevaluation of what is important in life was also described by McColl and coworkers (2000) in a study of persons with either brain injury or spinal cord injury. In their study, however, which was conducted within 2 years of the discharge from rehabilitation, it was not yet apparent to the participants how they valued different facets of their lives, but it was evident that they expected this to become clear with time. Another discovery made by the participants was that work, when it was done sufficiently, but not too demanding, gave structure to their everyday life. This is in agreement with the findings in a study of unemployed persons (Jahoda, 1979) who suffered from a lack of structure in everyday life. Likewise, in a study of persons with mental illness, Gahnström-Strandqvist, Liukko, and Tham (2003) found that joining a working cooperative provided a temporal order to the day; the participants experienced an increased sense of occupational balance and were able to reestablish a rhythm in their everyday lives.

In their investigation of the retirement process, Jonsson, Josephsson, & Kielhofner (2000) found that the participants reported experiencing difficulties in creating their own routines, when they no longer had external demands imposed upon them by their work. The findings in our study are in agreement with previous research showing that work gives structure to everyday life. It is probable that the participants in our investigation had a more pronounced need of a clear external structure owing to their cognitive impairments, as these would influence their ability to plan and organize the performance of everyday occupations (Ponsford et al., 1995). Rehabilitation interventions aiming to support those with a brain injury to get back to work should be adjusted to fit the individual’s ability by, for example, altering the demands made to ensure that they were appropriate. Occupational therapists play an important role in ensuring that there is a fit between the demands of the workplace and the brain injured patient’s ability during a work trial, which means that it might be beneficial to increase the demands during the trial.

Our findings emphasise that the value of going back to work is more than just having a job to go to. Work also has a positive influence on everyday life outside working hours. This additional value needs to receive attention in the planning of individual rehabilitation programs. The participants in this study stated that social relationships at work had become more important since their injury. Similar findings have been reported by Jonsson and colleagues (2000) in their study of the retirement process, where they discovered that relationships at work were quite special and could not be easily replaced. Social relationships at work did not only involve working together, but also sharing each others' everyday problems during coffee breaks. Several investigations have revealed that brain injury has additional consequences in the form of stress within the family or social isolation (Clarke, Black, Badley, Lawrence, & Williams, 1999; Crisp, 1994; Finset, Dyrnes, Krogstad, & Berstad, 1995), but the social relationships at work after brain injury have scarcely been examined in research.

One implication based on the findings of our research is that occupational therapists play an important role in giving information and support to colleagues of the brain injured client, as they constitute an important source of motivation for him or her in the laborious period of returning to work.

In occupational therapy theory, it is argued that occupation is the way in which people show others who they are (Kielhofner, 2002; Schkade & McClung, 2001; Wilcock, 1993). The findings presented here demonstrate that the participants’ identities as workers had been affected and that they had either wholly or partially lost their former role as competitive workers. They also expressed the difficulties they had evaluating their own performance at work, which probably resulted in a more vague self-image. According to Nochi (1998), brain injuries often pose a heavy challenge to a person’s sense of identity because of the difficulty that those afflicted have in constructing self-images based on their experiences. In line with this, the participants in our study described how they needed to obtain feedback from others to understand what they are capable of doing. Schkade and McClung suggest that we adapt our (occupational) performance when we meet challenges in our everyday lives. In direct confirmation of this, the persons with brain injuries seemed to find it important to be aware of the
challenges that they would encounter in their everyday lives; but as they were unable to rely on their own assessment of how well they were able to do things, they were reliant on feedback from others to adapt their performance appropriately. Thus, it was only through external feedback and subsequent adaptation of their performance that they seemed to be able to recapture a work identity with confidence. According to Kielhofner, people's identity and competence influence how they adapt to perform everyday occupations.

He assumed that competence is more strongly affected by disability than identity. The participants in this study, however, reported that both their identity and competence were influenced by the brain injury. The struggle to achieve “normality” was a recurrent theme in the interviews, and being able to work was considered to be a significant aspect of what the participants considered normality to entail. This is in agreement with the study by Gahnström-Strandqvist, Liukko, & Tham (2003) of mentally ill persons, in which they reported that having a job was something that the participants considered to be “normal.” In a study of persons with traumatic brain injury, Nochi (1998) found that the experience of being labelled as normal also had a negative aspect for some of the respondents; some of those who had been labelled as normal felt that society imposed higher demands upon them as a direct result of receiving this label and believed that there was also less support available to assist them with their recovery. The reflection that being considered to be normal had a negative component to it was not, however, something that was found for the participants in our study.

The results of this study have implications for rehabilitation where a return to work is an integral part of the occupational therapy interventions after brain injury. It is important that the occupational therapists listen to the clients’ experiences if they are to be able to design individualized intervention programs for the rehabilitation. Occupational therapists are often involved—along with the rest of the rehabilitation team—in helping clients to find a structure for performing everyday occupations, and the findings of this study could be useful in planning interventions of this type.

One limitation of this study might be the mixture of diagnoses among participants, that is, traumatic brain injury and cerebrovascular insult, which may decrease the ability to compare our findings with those of other studies investigating a more homogenous group of patients. However, it was decided that it would be preferable to incorporate persons with both diagnoses in our research because such a sample is a typical group of patients of working age participating in rehabilitation. Another limitation might be that a choice was made to interview a number of informants with a varied background, which resulted in the participants only being interviewed once in order to minimize the amount of data for the phenomenological analysis. According to Kvale (1997), repeated interviews with each participant will result in more extensive, nuanced, and reliable data (Kvale).

From the findings, we believe it is important to stress the long-term perspective that work-directed rehabilitation after brain injury needs to adopt. It would be preferable for future studies to use a prospective, longitudinal design with repetitive interviews being conducted over a long period of time in order to study the lived experience of the process of adaptation back to work after brain injury.

This study showed that the social dimension of work expanded subsequently to receiving a brain injury. Further research aiming to deepen the understanding of this phenomenon and to pay more attention to this part of reintegration into the community would be of interest. In such a study, the client and his or her relatives would be involved to give different perspectives of this experience.

Finally, it should be mentioned that the EPP method (Karlsson, 1992) used to seek characteristics that are general across participants, revealed a meaning structure that might also be applicable to persons undergoing work rehabilitation for reasons other than brain injury.

We recommend that future studies examine whether the general characteristics identified in this study could be used to construct a hypothesis about a more general meaning structure for the phenomenon of meaning of work after disability. ▲

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