ORIGINAL ARTICLE

The adaptation process after traumatic brain injury
An individual and ongoing occupational struggle to gain a new identity

BARBARA HOOGERDIJK¹, ULLA RUNGE² & JETTE HAUGBOELLE³

¹Rehabilitation Centre Heliomare, Department of Occupational Therapy, Wijk aan Zee, The Netherlands, ²Runge Consult, Copenhagen, Denmark, and ³University College Sjaelland, Faculty of Occupational Therapy, Naestved, Denmark

Abstract
The aim of this study is to understand better how individuals with traumatic brain injury make sense of their adaptation process and their performance of occupations within this process. For this study, four participants were interviewed twice. Thereafter analyses following a narrative approach led to the construction of four individual narratives. The results indicate that the adaptation process following traumatic brain injury is (1) a necessary struggle to gain a new identity; (2) facilitated by engagement in familiar occupations in familiar environments; (3) a protracted learning process that continues long after rehabilitation ends; (4) individual and situated. The results suggest that healthcare professionals including occupational therapists should: allow individuals with traumatic brain injury to test and practise their abilities within their own home environments; provide them with the necessary space to practise on their own; guide them in using their own and new strategies in a way that is both efficient and personally satisfying. Finally, this study discusses whether rehabilitation services should be offered over a protracted period of time. Professional support following the rehabilitation period—precisely the period in which they are trying to establish a meaningful existence with their disabilities—could be a more useful path to follow.

Key words: Occupational therapy, situated learning process, occupation, re-identification, narrative

Introduction
Brain injury has an enormous impact on everyday functioning and has been described as one of the greatest challenges to an individual’s quality of life (1). The network of daily occupations, routines and habits, which provided the individual’s life with structure and meaning, has been lost because of the sudden event of the brain injury. The onset of traumatic brain injury threatens the individual’s core identity precisely because it robs him/her of his/her perceived potential. In order for individuals to regain a feeling of agency again they need to accept their disabilities, reappraise their life roles (2,3) and develop adaptations to resume meaningful occupations (4). Kielhofner (5) presents adaptation as the construction of a positive occupational identity and achieving occupational competence over time in the context of one’s environment. According to Polkinghorne (6) identity makes sense of one’s self-process by providing an interpretive scheme through which the succession of experiences and actions that have made up our lives are understood and made meaningful. It frequently takes years to overcome a brain injury and people who have sustained a brain injury tend to agree that one never really recovers from a brain injury (4,7).

Literature shows that for stroke survivors the rehabilitation process plays an important role within the process of coming to terms with the disability (8). The expectation is that this also holds true for people with traumatic brain injury: discovery and gradual solutions to physical and cognitive problems are
characteristic of both patient groups. The study from Daniels et al. (9) shows that healthcare professionals and stroke survivors experience and perceive the rehabilitation process differently. This might suggest that healthcare professionals—occupational therapists amongst them—should acquire more specific knowledge about these differences, in order to integrate the individuals perspective and special needs into the rehabilitation process (10,11).

This study focuses on the experiences of individuals with moderate to severe traumatic brain injury. This group lives through a long adaptation process to adjust to permanent disabilities. At the time of the study there were few studies (4,12,13) that document traumatic brain injury in relation to the individual’s perspective on the adaptation process. The result is that healthcare professionals do not clearly understand the intricacies of the adaptation process. Such a study can lead to the optimization of the rehabilitation process and enable occupational therapists and other professionals to better assist persons with traumatic brain injury in adapting to their new situations. Better assistance in the adaptation process will improve individuals’ general quality of life.

Despite their differences, this study draws from relevant studies documenting stroke survivors. Stroke survivors, for example, initially experience feelings of suddenness and overwhelming catastrophe (14), creating a situation of unaccountability. Studies also suggest those individuals with stroke gradually discover problems, which leads to the development of ways of living with the consequences of the stroke (14–16). Home discharge is particularly important in the adaptation process. At home life turns out to be no longer as before and the individual needs to develop new routines and rhythms. Bontje (17), who researched the experiences of occupational adaptation amongst older individuals, found that active engagement is needed to overcome disabling influences on occupational functioning. Easton (18) suggests using familiar problem-solving strategies. Furthermore, Bontje notes that individuals need to actively explore the feasibility of a proposed solution as well as the belief that a solution can be found. Advice and encouragement also contribute to creating solutions.

The stroke studies give little understanding regarding the development of the recovery process. For example the design of the study by Burton (14), which is phenomenological, results in themes around the recovery process rather than understanding of the process over time.

Tham’s study (19) indicates that stroke survivors adapt to their situation through occupation. What she discovered was that the persons gradually come to understand their limitations through experience and reflection. What she did not discover—because the study was done within a short period after the strokes—is how these individuals reordered their lives. Other studies also found that engagement in occupation is a powerful force in recovery (12,13,20,21).

According to Schultz & Schkade (22) the human being has a desire for mastery in occupational situations. A person needs occupational challenges from which he/she learns how occupations can be performed in a more efficient, effective, and satisfying way. Those challenges help the person in achieving mastery in occupational situations and in building a new occupational identity.

The above research literature concerning traumatic brain injury and stroke created a solid background for a study with the following research question: How do individuals with traumatic brain injury make sense of their adaptation process and the performance of occupations within this process? This study aimed to understand how individuals valued the performance of everyday life activities within their adaptation process and how those occupational experiences influenced the adaptation process.

Material and methods

Within this study the narrative approach is used. Narrative is concerned with human attempts to progress to a solution, clarification, or unravelling of an incomplete situation (3). For this study the narrative is a tool to gain a better understanding of the individual’s occupational experiences within the process of coming to terms with brain injury.

Selection of participants

The participants were selected from a group of individuals with post-traumatic brain injury. They attended an inpatient treatment programme at a rehabilitation centre in The Netherlands. Participating in the selection were a rehabilitation doctor and a psychologist. Persons selected had to meet a number of criteria, including: having suffered from traumatic brain injury between one and three years ago; having been discharged from the inpatient treatment programme for at least six months; having both physical and cognitive disabilities; and still possessing the verbal capacity to lucidly explain their current situation. Criteria of exclusion of persons were: the individual’s personal contact with the researcher; severe cognitive, emotional, and/or communicative problems that may hinder the adaptation process and affect the individual’s ability to properly reflect upon his/her situation. In the end of 2005 eight individuals who
met the given criteria were approached with written requests to participate in the study. Of the eight, four participated in this study. The four who did not or would not participate in the study did not do so for different reasons: the first was unreachable; the second lacked the necessary energy reserve; the third suffered from disabilities that were more the result of an earlier stroke than of traumatic brain injury; and the fourth, according to his mother, did not have the cognitive capabilities to reflect on the adaptation process. The four participants, all Dutch, are presented in Table I. The names of the participants are pseudonyms.

**Table I. Description of the participants.**

<table>
<thead>
<tr>
<th>Person</th>
<th>Simon</th>
<th>Patrick</th>
<th>Mieke</th>
<th>Dirk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Age</td>
<td>61</td>
<td>33</td>
<td>60</td>
<td>60</td>
</tr>
<tr>
<td>Time since traumatic brain injury event</td>
<td>27 months</td>
<td>20 months</td>
<td>23 months</td>
<td>21 months</td>
</tr>
<tr>
<td>Disabilities at admission</td>
<td>Mild right hemiplegia, mild memory deficits, reduced self-awareness, amnesic aphasia</td>
<td>Moderate left hemiplegia, double-vision, short-term memory problems, reduced planning of own performance, mild behaviour changes</td>
<td>Mild left hemiplegia, attention problems, short-term memory deficits, reduced initiative</td>
<td>Mild right hemiplegia, mild memory deficits, reduced self-awareness, changes of mood, mild behaviour problems</td>
</tr>
<tr>
<td>Social status</td>
<td>Married, 2 daughters living away from home</td>
<td>Married, 3 sons living at home</td>
<td>Married, 2 daughters living next door</td>
<td>Married, 2 children living away from home, 2 grandchildren</td>
</tr>
<tr>
<td>Work status</td>
<td>Retired from job as computer science teacher at university</td>
<td>Stopped working as owner of crane business, works as employee now</td>
<td>Stopped working as principal of school of fashion</td>
<td>Retired from job as maintenance mechanic</td>
</tr>
<tr>
<td>Daily occupations</td>
<td>Helps friend with administrative work, reading the newspaper</td>
<td>Works at crane business, spends time with family</td>
<td>Household occupations, gardening, canoeing, visiting friends, spending time with family</td>
<td>Baby-sitting, shopping, doing small jobs in the house and for mother in law, reading the newspaper</td>
</tr>
<tr>
<td>Type and duration of treatment</td>
<td>13 days' clinical treatment followed by 101 days' day treatment</td>
<td>84 days' clinical treatment followed by 69 days' day treatment. The day treatment was followed by 63 days' clinical treatment and contiguous 132 days' day treatment</td>
<td>43 days' clinical treatment, followed by 53 days' day treatment</td>
<td>115 days' clinical treatment followed by 74 days' day treatment</td>
</tr>
</tbody>
</table>

Ethical considerations

Judging the method of research and its potential adverse effects, the Medical Ethical Commission at the rehabilitation centre approved the study and the recruitment methods. All participants were provided with both written and verbal information on the study. This included a telephone conversation outlining the purpose, the content, and the potential personal consequences. Furthermore, each was informed that participation was voluntary and that all information provided would be confidential. The four participants provided both their verbal and written consent.

Data collection

Each participant was interviewed twice in his or her home, with a three- to four-week period between each interview. The interviews lasted from 50 minutes to 90 minutes and subsequently were taped and literally transcribed. The methodology of the first interview consisted of open-ended questions, including: their experience of occupations, the changes over time, and how they arrived at their current situation. More specifically, questions during the first interview included: “Did something change in your experience with this activity?” and “How did it come about that you tried that way?” The second interview functioned as a follow-up to seek out more detail regarding the participants’ experiences and adjustments. Specific questions included: “What specific occurrence brought you to the realization that you had to alter the way you work?”; “Did you realize yourself that your performance was worse than before, or did the rehabilitation centre bring this to your attention?”
Data analysis

The four resulting narratives were constructed in accordance with Polkinghorne’s narrative analysis (3), using the five phases for this narrative analysis described by Molineux and Rickard (23) as guidelines. The plot must explain how the end of the story has come about (24). The plot was constructed by labelling the interview’s content. By using the hermeneutic circle between the labels analysed and the narrative it was possible to form ideas about the plot consistent with the data. A concept narrative was created, using the participants’ own words. According to Kinchelow and McLaren (25) it is the participant’s personal, social, cultural, and historical context that gives specific meaning to events. A core plot was created by moving seamlessly between narrative and data and seeking out contextual features in the participant’s current situation. The core plot could be found by analysing the connection between the participant’s actions and the end of the narratives. During this process the five analysis phases were passed through several times, and once a common plot was found within the four narratives, the stories were re-written.

Results

Simon, Patrick, Mieke, and Dirk have been experiencing and reflecting upon occupations to create new identities for themselves. The four narratives demonstrate that several experiences of occupations are needed to develop a new concept of one’s self as part of the new identity. The narratives show that the process of developing a new identity requires person-specific occupations and different patterns of adaptation. The new self-concept is important in enabling them to discover new ways of living with the consequences of brain injury and reappraising their personal priorities. For some the old self has not totally disappeared, because the new self is not yet an accepted self, but also because the old ways of living are a part of one’s present self.

Simon

“I’m not normal: it will never be like I was before. I think differently and I feel different.”

For a long time Simon had, in his own words, tunnel vision: he did things in his own way, resisting all outside impulses and influences. Simon likes to use the dolphin as a metaphor to explain his predicament: “The dolphin swims and thinks: there is more sea on the other side of that beach and I’m certain to find fish there. But no, the dolphin thinks, I won’t swim around the beach; I’ll go straight through it because the food is right in front of me.” In the end the dolphin strands himself on the beach and dies. Be that as it may, the dolphin was right.

Slowly, Simon’s tunnel vision is subsiding. He experiences that things are “different” while doing activities and while in contact with others. Nonetheless, he is unable to pinpoint precisely what he is missing. He misses the sensation he once felt when embracing his daughters, for example, but he does not categorize this as a major loss or problem. Reflecting on this, Simon says that at that time he had not found out yet that he was a man of feeling as opposed to being rational. His relationships with his wife, daughters, and friends have catalyzed moments of self-criticism and spurred comparisons between the man he once was and currently is. A Leonardo da Vinci exhibition helped him understand more about his emotional state. When pondering da Vinci’s two hemispheres of the brain, Simon realized that the emotional part of his brain was damaged. This, in turn, helped him understand why he showed no emotion when a close friend underwent a serious operation. It was not that this information was new to Simon; it was only now that he was able to understand it. All in all, it made him aware of the fact that, emotionally, he is not the man he was. This growing awareness created a unique conflict in Simon’s situation. On the one hand, this egoism contributed to his self-improvement. On the other hand, his inability to sympathize with others was in direct contradiction to the type of person he was before the brain injury.

“It was good that she did it like that.”

For Simon, returning to work full time was an important aspect in becoming “normal” again. In a confrontational conversation Simon’s boss made it clear to him that his position would be re-evaluated because he would never be able to function at the same level as before. She did not say it in so many words, but to Simon the message was clear. At the time, he thought: “She doesn’t understand this and I’ll have to prove her wrong.” But in the following months Simon could neither function full time nor at the same capacity as before. His boss allowed him to work from home when he felt it was necessary and he did. Eventually, her approach encouraged him to retire. Some time passed before he realized she was right about his abilities. “She judged the situation better than I realized at the time,” he said. “Actually, I couldn’t perform my job properly any more. I pretended I could, but I couldn’t.”

“I’m still at the stage where I don’t know where it ends.”
Nowadays Simon is doing some work for a friend. He likes the work since he learns new things: “I have never worked in a commercial organisation so I am learning a lot about that.”

Despite his emotional progression, Simon no longer expects much more change. Whereas he once wanted everything back to how it was before, now “not everything needs to change back”. He admits that he has accomplished a lot. Emotionally, Simon is currently entering new relationships with the people around him. He is trying to be more considerate of them so as to be able to concentrate on the most important thing: living together. “We are not there yet”, he says. “It is only the beginning.”

Reflections of the researcher

Simon needed several social experiences to better understand his situation and to more lucidly compare the man he is with the man he was. One cannot ignore the impact of the views of others on the view we have of ourselves. In the end it was his boss who made him realize he could no longer work. His boss gave him the time and space necessary for him to come to terms with his new self, and in turn he made the decision on his own to retire. Naturally, without the pressure and concerns of work, Simon can now more realistically evaluate his disability, so much so that the retirement itself was a turning point in the adaptation process. Simon continues to try and be the man who is accepted by those around him. The small changes he notices in his emotional functioning towards others motivate him to keep going.

Patrick

“When I succeeded in doing something, it made me stronger, and the next day I tried it on my own.”

At the beginning of his rehabilitation Patrick was very afraid to make mistakes. He needed others to motivate him. Staff compliments gradually gave him the confidence to continue with his occupations, and eventually Patrick was able to motivate himself. He often practised alone without the peering eyes of others, over and over again. Patrick also tried different ways to manage tasks like buttering the bread in the other direction.

From “I wanted to mind my own business” to “I can’t be the owner any more since I can’t combine the different tasks”.

Independence is a key element in Patrick’s story. Patrick owned a small business, and for years, he has been a workaholic. He was a capable businessman and readily made decisions. The first time Patrick returned to work it was a disaster. It lasted a week before his wife would not let him return. “I was so frustrated”, he says. “I didn’t want to listen to her, and I was quite sure it wasn’t my fault but hers. I was very unrealistic.” Eventually, discussions and confrontations with professionals at the rehabilitation centre made him realise that his limitations were causing the problems at work. This conflict brought him to the realization that he could not just pick up where he left off. This setback served as a turning point for him and those around him—for others because they now had to learn to deal with him in a different way.

Patrick spent much time trying and analysing his occupations, in order to regain his old stature. Work gave him a critical ground to judge his own abilities. When he failed to complete a few welding jobs, a colleague advised him to take more time to prepare for the job rather than just jumping in. Later, Patrick sought out explanations for his inability to perform tasks he previously could, such as building a crane in a day. “I think I used the right method. My colleagues confirmed this. The problem was that I worked too slowly.” His work confrontations have enabled Patrick to understand his specific disabilities. He generalizes this knowledge and applies it to his functioning as an owner. “I can’t do organizational tasks like making calculations alongside the normal work since doing two tasks at once simply doesn’t work any more.” Today, Patrick is an employee and no longer one of the owners. His colleagues have taken over many of his tasks to reduce his workload. Although Patrick fully understands the new situation, he still finds it irritating.

“I have read a story of a woman with brain injury who said that you have to stop trying to be who you were. It’s exactly like that.”

Patrick is ashamed that he cannot do everything any more. He still ponders the option of starting his own business. “Then I can make my own decisions again and establish a relationship with employees who only know me how I am now.” Yet his doubt is whether he will ever regain what he once had. “Things just aren’t the same and I am trying to accept that, more and more.”

Reflections of the researcher

In light of Patrick’s background, his frustration concerning his dependency on his colleagues is understandable: he used to be in complete control of himself and his work. Patrick’s admitting that he
“was very unreasonable” shows that he can properly reflect on his altered emotions and cognitive abilities. When returning to work, he was not entirely aware of his disabilities. Rehabilitation jerked him out of inactivity and motivated him to be more active in trying occupations. This in turn led to a greater understanding of his situation and his person. While not satisfied with his current identity (an employee rather than employer), his ambition to start his own business again mirrors the ambition of the man he was before. It also shows a wish for further occupational development. He is drawing on his understanding of the personality traits and characteristics that made him successful in the past.

Mieke

“They needed to tell me how I should practise things.”

In the beginning Mieke did not grasp the seriousness of the situation. She did what other people told her to do, but she was not aware what she was doing. According to Mieke, awareness came by way of knowing the story about the accident—she could not recall it—and its consequences. She needed information from her husband about the accident in order to understand better why she could not perform certain tasks any longer. “I couldn’t rub cream on my face any more and I questioned why that was.” This growing awareness helped her realize that she needed to practise to improve her situation. In the beginning she needed professionals in the rehabilitation centre, but she quickly began exercises and occupations on her own to train her body and mind. She adapted the exercises from the centre in such a way that she could do them at home: “During physiotherapy I practised bending my legs between parallel bars; at home I did it between two chairs.” Her motivation for bending her knees, for example, was that she wanted to sit in her canoe again and work in her garden.

“Fairly back on track.”

Not being able to canoe and work in her garden created personal conflicts precisely because they were important activities in her life. While Mieke does not speak a lot about these occupations, her reflections—“I’m looking forward to the spring when I can begin working in my garden again”, or “Last time I needed their help in getting into the canoe”—tell us that she is still gardening and canoeing. Today her normal preoccupations are self-care and household activities. She reflects on her improvements—from having to seek help to clean the windows to being able to stand on a ladder and do it herself. Her days are mainly filled with these types of occupations, and she retains little energy for other activities. Mieke has accepted her fatigue as a permanent handicap: “I have to accept that I get tired quickly and do things piece by piece”, she said, not showing much emotion on the subject.

“I think it’s very important to hear the story about what has happened to you, as it is the only way to piece the puzzle together.”

Mieke’s physical improvements increased her awareness of what she can and cannot do. This awareness made it possible for her to fill in the blanks of her story. Mieke says: “It has been only recently that I’m coming to understand what happened.”

“My body and mind aren’t 100% yet. I’m still working on it. Who knows?”

Mieke has discovered precisely what her disabilities are by training her body and mind through different occupations. She is still working to improve certain abilities like recollection by following a marine telephone course. She notices she has difficulties understanding what she reads and that she forgets things easily. “I have to repeat things and say things out loud and ask my husband for an explanation.” She adds: “I’m not the old one yet.”

Reflections of the researcher

The information from Mieke’s husband played a crucial role in helping Mieke understand more about her disabilities, presenting her with an important turning point in her rehabilitation. Her want and need to improve her situation corresponds with her former personality as an independent woman. Actively pursuing and reflecting upon occupations helped her piece her personal puzzle together. This personal puzzle shows how she is evolving, where it is leading to and who she is now. It gives her clarity about herself; a feeling of control over her thoughts and actions. Her reflection “I’m not the old one yet” indicates she is still anticipating progression. She has only recently started to piece the puzzle together. It is natural that she is still unable to make up her mind about who she is.

Dirk

From “I will be OK in 3 weeks” to “There is probably something wrong with me”.

Immediately following his brain injury Dirk assumed he would be OK in three weeks. His expectation was rooted in the knowledge he had at that moment: up to
that point he had enjoyed a quick recovery. But various events at the rehabilitation centre made Dirk aware that all was not OK. “They didn’t let me go home for the weekend a few weeks in a row, which made me think that there was probably something wrong with me.”

From “Why didn’t I succeed in connecting the equipment?” to “I’ll show the manager how to do it”.

Dirk is a handyman. He has the personality of someone who can repair anything. He was therefore confronted one weekend when he discovered that he could not even perform the smallest tasks. It made him feel like a little child. This was the beginning of Dirk’s confrontation with himself. He gradually moved from seeking explanations for why he could not manage simple tasks to pondering ways in which he could. “It takes longer and requires more attention.” He sought out solutions on his own instead of asking others for guidance, which he considers a cop-out. Dirk feels asking others for help is not conducive to his rehabilitation. Dirk started to reason his situation from his own experiences with small jobs “It’s not entirely OK, because I can’t think very lucidly.” Dirk can, however, complete small jobs, though with much effort. He’s convinced that he came this far because of his will to be the man he was before.

“I still have balance issues even though they should be over by now.”

Hope seemed to have played an important role within Dirk’s recovery process. In the beginning he heard that specialists still do not know everything about the brain, which gave him the hope that he would be OK again. Recently, Dirk’s neurologist told him that part of his brain remains damaged and that he will never be totally OK. Dirk is now more convinced about this message because of his own experience that certain things are not yet OK, despite practising them. Dirk holds on to the two years in which improvements can be made. His only straw of hope is the two months he has left.

“I can no longer do the difficult work.”

Dirk’s effort to practise and analyse his own occupations has enabled him to fill in the blanks about the man he has become. “I can do small jobs again, but I can no longer do the difficult work.” The fact that he has difficulty reading a newspaper indicates to him that he does not understand things well any more. He no longer feels capable of solving difficult problems. Dirk always aimed to take on more difficult work slowly, but both the company and its physician did not want to risk it when Dirk suffered a blackout they had to relieve him of his duties entirely. Dirk quite easily came to terms with this decision as he was planning to retire anyway. Of his current situation Dirk says: “It’s not how it should be, but I still have time left.”

Reflections of the researcher

Dirk’s expectations of recovery immediately following his injury were unrealistic. This slowly changed: it seems he was basing his expectations on information provided by others rather than on his own experiences. A turning point occurred during a weekend leave when he could not perform basic tasks. Analysis and experience led him to realize he could not perform important occupations any longer. This resulted in a more realistic view of his rehabilitation and the man he had become. Regarding his work, Dirk seems to have made his peace with his situation, which is understandable as he was planning to retire anyway. More important to Dirk is that he regained a part of his old self, namely the ability to perform small tasks. This has improved his self-esteem.

Hope and willpower have given Dirk the strength to try occupations in different ways when he does not succeed at first. This gives him hope, even though he doubts a full recovery will ever take place.

Summary of the narratives

This study aimed to explore ways in which individuals with traumatic brain injury make sense of their adaptation process and the performance of occupations within this process.

The narratives indicate that the adaptation process after traumatic brain injury is

1. a necessary struggle to gain a new identity;
2. facilitated by engagement in familiar occupations in familiar environments;
3. a protracted learning process that continues long after rehabilitation ends;
4. individual and situated.

Discussion

A necessary struggle to gain a new identity is also described by Christiansen (2), who reflects on several studies which have found that preserving and developing one’s identity is at the heart of adaptation strategies. The individuals’ identities were threatened when they found out that they were no longer able to perform meaningful activities or sustain important relationships. The experiences within occupations can be viewed as attempts to grasp a better understanding of their selves as they are now. This process is
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The adaptation process is facilitated by engagement in familiar occupations in familiar environments. The narratives demonstrate how the participants challenged themselves or how they were challenged by others to be engaged in occupation. In their home and work environments the participants had the opportunity to try and practise occupations on their own without having someone around looking over their shoulder. The home and workplace are crucial as these environments stimulated the participants to resume their old tasks and roles. They wanted to practise on their own because they had always done occupations on their own. This supports Tham’s findings (19) and Bontje’s study (17) as well as Toglia’s view (27) that individuals need time to practise on their own and to be active problem-solvers. The advice and encouragement provided to Mieke and Patrick by professionals, family members, and colleagues gave them confidence and helped them in practising occupations and finding solutions for problems. The studies of Gracey (28) and Strandberg (29) also describe the significant importance of informal and formal support for the changeover process.

Similarly, the four narratives show that the learning process of developing a new self-concept is a very long process that continues after rehabilitation. The narratives demonstrate how the process of discovering and learning to handle disabilities in everyday life takes place. Current research describing post-brain damage adaptation processes (4,12,28,29) offers interesting themes such as the study of Gracey et al. (28). For the participants in this study the personal meanings associated with activity and their personal reflections played an important role within their self-construction process. The studies, however, give little understanding of how the activities influenced the process and how the reflections developed over time. Strandberg (29) studied the experiences of adults with traumatic brain injury concerning the changeover process. His conclusion was that a narrative reconstruction of the course of injury is needed. The four narratives of this study give detailed information on how the individuals came from experiencing things as “strange”, “different”, “not totally OK”, or “frightening” to experiencing failures in their occupations and searching for explanations for their failures. Similarities and differences can be found with the discovery process described by Tham (19). The four women described in her study experienced something new and unfamiliar when they started to perform everyday tasks. After a while they began to compare what they could do now with what they could do prior to the stroke. Simon’s narrative shows that it took some time before he became aware of the fact that he was actually missing things. It was not until much later that he started to compare his current situation more critically with his previous one. Through experiences and confrontations with his wife, daughters, and a friend he became aware that, emotionally, he is a different person than he used to be. When applying the Occupational Adaptation framework (22) to the four narratives the prescribed steps can be followed: (1) producing a response, (2) evaluating a response, and (3) the learning takes place. Patrick only started to critically evaluate his responses after facing several occupational challenges. First, his colleagues decided that he had to stop working when he failed to meet the appropriate adaptive patterns. Second, a colleague advised Patrick to use a different method when repetition of his familiar method did not produce an effective and satisfying result. Third, Patrick himself evaluated his responses more critically by asking questions like: “Do I use the right method?” All the participants in this study tried other methods when their familiar methods failed, though not all participants understood their disabilities well before changing strategies. They achieved an understanding of their disabilities and realized the consequences for their life roles due to the learning that took place from different occupational challenges. This is different from the population of Tham’s study (19). The participants in her study did not use strategies to better handle occupational situations before they understood their disabilities. The stated examples show that the individuals themselves determine the discovery process or occupational adaptation process following traumatic brain injury.

Discovering that the adaptation process is a long-term learning process raises the question of whether...
the services we offer persons with traumatic brain injury are offered at the most suitable time. Currently intensive guidance is often offered in the rehabilitation phase and not offered at the time when there is a need for this. It could be a more useful path to spread professional support over time. Professionals can guide clients in using effective strategies after they have experienced their disabilities in their home environments. Sabari (30) argues that occupational therapy services have to be available for stroke survivors after rehabilitation, when changes in living environment, work, and/or personal interests present new performance challenges. This long-term availability of therapy services is also desirable for individuals with traumatic brain injury. A critical evaluation of the currently available healthcare services in different European countries shows the following problems: (1) after-care is not a regular part of the treatment of people with brain injury, and (2) the care of intramural and extramural services is not always linked and appropriate (31,32).

As the narratives provided here demonstrate, the adaptation process after traumatic brain injury is individual and situated and therefore must be approached within its personal context. Each required specific occupations to develop a new self-awareness; occupations that were meaningful to them personally, such as social occupations and household tasks. Meaningfulness is related to the occupational form (33); the person makes sense of the situation, within the physical and sociocultural circumstances in which the occupational performance will take place. The situation is meaningful when it has relevance to the person’s life. With the current marketing of the healthcare the focus is more and more on the training of skills and activities with the end goal of independent living. However, from the client’s point of view, the need to focus on meaning and activity together might be more important in rehabilitation (28). Competence in occupation or mastery should be the goal of rehabilitation. Mastery is more than the ability to perform a discrete task; it is a reflection of the client’s experience as an occupational being. In order to be able to evaluate the person’s self-reflection parameters like competence and satisfaction are needed.

Similarly, different patterns of the adaptation process are visible within the four narratives. The content and the order of important phases within the learning process differ between the four persons. Before actively creating a solution, Dirk sought an explanation for his inability to perform small tasks. Patrick, on the other hand, attempted tasks time and again before he asked himself why it was he could not succeed in erecting a crane. Simon needed information from others like his boss to realize that he could not do his work any more. Mieke’s evaluation of progress is vital to her story as it provided her with information on her abilities and disabilities and, as such, helped her develop a new concept of herself.

Implications

It is important that healthcare professionals including occupational therapists provide environments that help their clients with traumatic brain injury learn about their new selves. It is important for individuals that they have opportunities to test and practise their abilities within their home environments. Individuals with traumatic brain injury also need space to practise on their own. In the current clinical rehabilitation programme there is little space and time to practise alone and weekends are needed for rest.

This study shows that persons with traumatic brain injury might not always learn immediately from the occupations that are offered to them within therapy. They might need multiple occupational challenges and relevant information on the individual situations. Through this they can better learn how to evaluate, understand, and solve problems. Healthcare professionals should guide individuals with traumatic brain injury in using old or new strategies in an efficient and satisfying way.

Therapy must be process orientated rather than only performance driven. Occupational therapists must offer their clients meaningful occupations if their goal is to guide them in resuming the roles that are of importance within their unfolding life story. Therapists have to make efforts to understand the client’s unfolding life story and personality in order to be able to create meaningful occupations because personality influences our behaviour (2). Professionals can support individuals to reflect on their selves by asking questions about meaning, e.g. “To what extent does this activity reinforce you or help you to feel part of things?” (28) and satisfaction, e.g. “Are you satisfied with your performance level?” The satisfaction score of the Canadian Occupational Performance Measure can give insight in the clients’ strivings and feeling of mastery.

Limitations

Narratives are individual stories influenced by one’s personality, history, impairments, and environment and cannot be generalized. Generalization demands a different research question and research approach. A larger sample with more differentiation such as participants from different age groups and a relatively equal amount of women and men would have enhanced the results.
Also a longitudinal design might give a deeper understanding of the experiences participants describe at certain moments in their process of change. In this study the participants were asked to reflect on events in the past. Their ability to remember those events in the past might have been affected by the brain injury and by time.

Member checking is not used throughout all the stages of the research process, which can be seen as a limitation concerning this study’s credibility. A second interview was used to check perspectives, verify indistinct information, and achieve understanding of the participant’s story. The participants were not asked to do member checks within or after the analysis phase. In this stage of the research a member check might be difficult for informants due to the necessity of higher conceptual analysis (34). Ethically, a member check would have been necessary after data analysis in order to involve the participants throughout the whole research process. This is necessary in order to give the participants the possibility to withdraw from the study at any time.

The dual position of the researcher in the research setting—researcher and occupational therapist—could have influenced the research process. It is possible that participants withheld stories about experiences that did not advance their adaptation, due to poor guidance by the rehabilitation team. On the other hand, the participants in this study were no longer dependent on the centre for their treatment, which encouraged them to talk freely and openly about their experiences there. The dual role of the doctor and psychologist—being a member of the rehabilitation team and selecting the participants—could have had a negative influence on the selection process. Their past professional relationship with clients could have influenced them in including or excluding clients as participants.

Future research

It is obvious from the four narratives that a variety of occupations plus informal and professional support helps the individual persons in building a new identity. The results of the study of Fleming (34), who investigated the effect of an occupation-based intervention programme on the self-awareness of people after traumatic brain injury, indicated preliminary support for the effectiveness of the programme. However, studies with more controlled programmes and larger numbers of participants could be a necessary supplement.

One important finding of this study is that the adaptation process after traumatic brain injury is a long-term learning process that continues after rehabilitation in its usual form. The data suggest that professional guidance is spread over time because those with traumatic brain injury need time to learn and time for their adaptation process. Is it helpful, then, that professional guidance is spread over time? Is it helpful to support them professionally in the phase after the rehabilitation, precisely in the phase in which they are trying to establish a meaningful life despite their disabilities? And would such support facilitate or speed up the adjustment process? These are questions that need to be answered with greater and more detailed research on the subject.

Conclusion

Narrative was a suitable research strategy to reveal the adaptation process over time and provide understanding of how and why the persons with traumatic brain injury adapted in a certain way. The four narratives share common traits, including how engagement in occupations helped in building a new identity. This knowledge enhances occupational therapists’ understanding of the experiences that helped individuals with traumatic brain injury to resume an active and meaningful life.

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