Engagement in Occupations: a narrative study involving individuals who have a brain injury

"Getting the best out of life"

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Publication date:
2012

Document Version
Peer-review version

European Master of Science in Occupational Therapy

Accredited by the NVAO | Approved by the Dutch Ministry of Education and Science under CROHO nr. 69312

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Date: 20th of June 2012

Master of Science thesis in Occupational Therapy (30 ECTS)
Part of the European Master of Science in Occupational Therapy

Wordcount: 9961

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Part 1: Article to be submitted to Journal of Occupational Science

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Lone Elisabeth Andersen, 2012

Abstract

This study focuses on occupational engagement and describes experiences from three individuals with acquired brain injury and their views on the effects of engaging in occupations during home based rehabilitation. ***Aim.*** The aim was to develop knowledge from experiences on occupational engagement during a rehabilitation process among persons with acquired injuries; to explore relationships between occupation and engagement; to outline occupational engagement and its centrality in occupational therapy. Earlier research shows that occupational engagement have a positive effect on individual's health and sense of well-being, but there are also several barriers of patient engagement, that can result in occupational imbalance, and withdrawal from occupations. ***Setting of the research.*** Occupational narratives were gathered from 3 participants with acquired brain injury in their own context. ***Sampling method***. Three individuals were selected by purposeful sampling. **Data gathering**. Data was gathered with help of repeated narrative interviews and direct observation in combination with field notes. Narratives were used in order to capture occupational engagement from the participant's perspective. ***Data processing and analysis.*** The analysis of data was based on an interpretative hermeneutical tradition. **Findings**. The findings show that all participants have experienced an occupational change. A complexity emerged regarding their engagements in occupations and in regaining everyday life after acquired brain injury. It appeared that psychological factors highly impacted on the participants' level of engagement. Factors like despair, fear and decreased self-efficacy were indicating to which extent they were engaged. Facilitating occupational engagement was connected to well-known occupations and the importance of structure, and being in familiar and supportive environments while performing. This study shows identified plots from experiences, and is built upon narrative theory to advance our understanding of occupational change, engagement, and its relation to occupation. ***Potential use outcomes.*** Exploring the process of regaining occupations can lead to a more complete understanding of occupational engagement, as well as contributing to the theoretical development of the emerging occupational engagement.

Keywords: *Occupational engagement, acquired brain injury, rehabilitation process, narratives*

Introduction

This study aims to elucidate the resulting imperative to engage by focusing on the process of engaging in occupations, and regaining daily life after acquired brain injury. It is based upon three individuals' experiences and opinions about occupational engagement during home-based rehabilitation.

Acquired brain injury (ABI), or head injury, are terms used to describe all types of brain injury that have occurred after birth (Danish National Board of Health, 2011), and often involves significant disruptions in an individual's everyday life. ABI can affect every aspect of a person's life, and often leads to permanent changes that interfere with everyday living, and place limitations on the person's state of health (Townsend & Polatajko, 2007). Stroke and traumatic brain injury are the main causes of acquired brain injury. ABI affect each person differently, depending on which part of the brain has been affected and the amount of damage sustained, and the impairments people experience can be physical, cognitive or both and may be temporary or permanent in nature.

Rehabilitation

The treatment of ABI has been in focus both in Denmark and Europe for many years. More people survive serious trauma and diseases, which has resulted in more people living with or at risk of having complex negative health effects, after acquired brain injury (The Danish National Patient Registry, 2011). The objective of rehabilitation is to reduce the negative effects of the disease or trauma and to enable the person to achieve an independent and meaningful life by increasing the person's occupational engagement. The benefits of rehabilitation following ABI are all too often disrupted by lack of engagement due to various neurobehavioral dysfunctions (Kristensen et al., 2012) and the resulting difficulties relating to managing everyday life through engagement in occupation.

The concept of Occupational Engagement

Occupational therapy is based on the belief that people can influence the state of their health through what they do (Creek & Hughes, 2008; Townsend & polatajko, 2007). In the literature, occupational engagement is conceptualized as being occupied with doing an occupation and is viewed as a powerful determinant of a person's well-being (Townsend & Polatajko, 2007). In this study the broader term *engagement* is formulated and understood in line with involving

oneself or become occupied, to participate in occupations. (Houghton Mifflin Company, 2004 cited in Townsend & Polatajko, 2007).

Engaging in occupations is known to have a positive effect on an individual's health and sense of well-being. However, the mechanisms by which occupational engagement promotes health and well-being are still not fully understood (Reid, 2011). The revealed inconsistent definitions and uses of occupational engagement in relation to health and well-being, throughout the literature, illuminating the need to consider this concept's purpose within the profession of occupational therapy and occupational science.

Occupational engagement though occupation

It is important for occupational therapists to know about the occupational performance of persons with acquired brain injury and their involvement in different situations in their daily life (Ahlstrøm and Bernspång, 2003) as one of the main goals within the profession of occupational therapy is on enhancing occupational engagement though the use of occupation to improve individuals' independence and to support recovery (Ahlström & Bernspang, 2003). Occupational engagement is therefore a fundamental concept and essential skill in the discipline of occupational therapy when the domain of concern is occupation.

In order to gain knowledge about clients' involvement in their daily life and understand occupation as a whole, the occupation should be studied in relation to its context over time with the meaning the person has assigned to his or her engagement (Isaksson et al. 2007). Additional research is suggested to better understand and define the construct of engagement. The objective of this study is therefore to explore and understand the process in terms of the impact of engagement in occupations over a period of time by three persons with an acquired brain injury.

Literature review

With the emergence of occupational science, there has been renewed interest in the health benefits of occupational engagement and a call for more research into the occupational nature of humans (Creek & Hughes, 2008). There is a wealth of studies about occupational experiences in relation to their patterns of daily living and how to achieve occupational balance. Studies about experiences related to occupation, and forms of occupation are some examples. There is, however, a rather large body of research in that area, but few with a focus on the process of the emergent occupational engagement from the perspective of individuals with acquired brain injuries.

Wilcock defines occupational engagement, 2006 as "*Involvement for being, becoming and belonging, as well as for performing or doing occupations*". In occupational therapy literature engagement is directed towards the performance of an occupation, and according to Matthews, (2002) higher levels of engagement should be associated with increased involvement and participation in occupations. Occupation, for occupational therapists, means all the activities that people do in their daily lives that hold their attention, have meaning and purpose for them and are shaped by their environment and cultural context (American Occupational Therapy Association 2002, Christiansen and Townsend 2004, Lavin 2005, Iwama 2006, Wilcock 2006, Caulton and Dickson 2007).

Promoting health and well-being

The concept that a person's engagement in occupation is important for health was proposed to be occupational therapy's great hypothesis by Reilly (1962). It has been argued that engaging in occupations is known to have a positive effect on an individual's health and sense of wellbeing (Creek & Hughes, 2008; Townsend & Polatajko, 2007). Occupations are often performed to overcome physiological, psychological and social discomfort and to maintain the well-working of the organism (Christiansen 1994, Polatajko 1994, Wilcock 1998). As occupational therapists believe that engagement in occupation contributes to health, they have a role in promoting health by facilitating engagement in occupation.

Barriers or facilitators of engagement

When faced with illness, engagement in occupations can be diminished (Vrkljan & Miller-Polgar, 2001). Studies have shown that disability and lack of independence after a stroke can

be related to withdrawal from occupations (Vrkljan & Miller-Polgar, 2001). Withdrawal, disruption or changes in an individual's ability to engage in a chosen meaningful occupation may have a significant impact on an individual's perceived health and well-being (Vrkljan & Miller-Polgar, 2001). Furthermore, it has been shown in literature that anything that overextends a person's need to engage can result in occupational imbalance and negatively affect health, increase stress, and may actually result in depression (Duxbury et al., 1999, p.21 cited in Townsend & Polatajko, 2007).

Many individuals are required to rely on other people to assist in maintaining involvement in occupations that constituted their pre-stroke lifestyle (Lequerica AH et al., 2006). Earlier studies have shown different strategies to facilitate engagement. In a study about rehabilitation and acquired brain injury, making therapy tasks meaningful and explicitly related to personal goals of the patient was the most commonly reported practice for enhancing therapeutic engagement (Lequerica AH et al., 2006). It also appeared in literature that being able to make choices intentionally effect one's engagement positively in daily occupations (Borell et al., 2006).

Maintenance of self-efficacy was a very important factor regarding engagement. Self-efficacy has to do with 'the belief in one's capabilities' to organize and execute the courses of action required to manage and to succeed in a particular situation. According to Albert Bandura perceived self-efficacy is concerned with people's beliefs that they can exert control over their motivation and behavior and over their social environment. When people lack a sense of self-efficacy, they do not manage situations effectively, even though they know what to do and possess the requisite skills (Bandura, 1990). Therefore self-efficacy could be connected to the extent to which people are engaged in a particular situation.

Summarizing the literature review there are many limitations associated with engagement in occupations, and people with ABI do not possess the necessary skills and capacity to engage. In therapy, there are various treatment options and interventions to address those issues and to prevent occupational imbalance, e.g. by having a clear goal-setting based on the client's occupational needs and environmental context. Emotional changes and cognitive issues after ABI have been rated as the most frequently encountered barrier impacting client's engagement in occupation. Lack of independency has also shown to decrease client's

engagement, low feelings of self-efficacy and mood with consequences as withdrawal from occupations.

As engagement in literature is strongly connected and interrelated with health and well-being it is a relevant topic to rise. Consequently, it is important to better understand and gain knowledge about how occupational engagement is perceived in the occupational transition. This could enable occupational therapists to provide insight into the process of how people with acquired brain injury experience to engaging in daily occupation, and eventually which issues have contributed to reduced occupational engagement. An exploration of occupational engagement is therefore of significance for occupational therapists.

Knowledge of the topic may identify influences on occupational engagement by paying attention to different issues that are found to have a significant impact on clients' involvement in different situations. The aim is therefore to develop knowledge from experiences with engagement, and this leads to the following research question: ***How do some persons with acquired brain injury experience occupational engagement during their rehabilitation process?***

Method and design

This study is designed as a qualitative explorative study using a narrative methodology. This approach constrains the collection and analysis of narrative data on how people with ABI experience and make meaning from their engagements in daily occupation.

Narratives are used to understand the participants' experience over time with their unfolding actions. Narratives can show how things and people change over time (Mattingly, 2004), and found appropriate when focusing on the process of regaining daily occupations.

Furthermore, the concept of narrative is not seen as an outcome of daily activity informed by verbal storytelling, but rather narrative as embedded in the process of enacting daily activity (Clark, Carson, & Polkinghorne, 1987; Mattingly, 1998). Narratives are considered event-centered, as they concern action, and more specifically human interaction (Mattingly, 2004).

Using a narrative 'plot' to visualize the relationship between life events provides an understanding of a person's life as a whole. It is conceptualized as embedded in the process of enacting activities, which refers to 'emplotments' that are some kind of structure that involves actions. Narratives are created by linking together events and happenings, emplotted by the individual in the moment and circumstances under which the telling takes place (Mattingly, 1998; Ricoeur, 1984).

Meaning is embedded in the plots, and in line with narrative theory, plots of such stories will vary (Alsaker et al., 2009). In practice 'emplotment' is the process through which people create, understand or describe the relationship between unfolding events and significant moments in their life world. The narrative data in this study is seen as being in progress and requires participant observations in conjunction with interviewing (Jossephsson et al, 2006).

Participants

Participants were chosen by Purposive Sampling (Polit and Beck, 2008; Kielhofner, 2006) establishing specific inclusion criteria (table 1).

Specific inclusion criteria (table 1)

Table 1: Inclusion Criteria
Three adults (> 30 years). Danish participants with acquired brain injury – in juried for the first time in life.
People who have suffered a brain injury late in life
Ability to follow and respond to an interview
Ability to engage in daily occupation
Discharged from hospital or rehabilitation unit
Receiving home based rehabilitation

This purposive sampling was done by two occupational therapists involved in home-based rehabilitation for persons with brain injury, and who had detailed knowledge of the severity of the injuries, the persons and their situations.

Three participants (Table 2) were selected; the researcher asked for permission to participate in 'an occupation of each participant's own choice'. Subjects were contacted several times over a period of time (Polit & Beck, 2008; Kielhofner, 2006). These individuals were selected

because they were presumed to have experienced barriers to occupational engagement and thereby a change in their daily lives. It is important to note that this study focuses on experiences of occupational engagement rather than on the participants' impairments.

Table 2: Participants

Pseudonym	Tom	Ann	Liz
Age	55 years	63 years	61 years
Social status	Divorced Living on his own	Married	Divorced Living on her own
Time since injury	One year since injury	One and a half year since injury	2 years since injury
Diagnosis	Cerebral hemorrhage	Cerebral infarction – Stroke, facial palsy	Cerebral infarction – Stroke
Former employment	Electrician, Sailor	Cleaning	Speech therapist and Teacher
Family	One son, one daughter	One daugther, one son, one grand child	Two sons, one grand child
Observed activities during the study	Listening to music Making breakfast Going for a walk	Washing windows Playing cards Sewing	Knitting Computer

Two women (Liz & Ann) and one man (Tom) were initially contacted by the occupational therapists in the rehabilitation unit. To guarantee the persons' confidentiality, the participants received written information describing the aim and purpose of the study and verbal information about the project, and were given time to consider if they were willing to participate before verbal consent was obtained. They were assured that any information given would be treated in confidence and reported anonymously. Depending on each participant, two to three observation sessions were arranged with an additional interview after participant observation was finalized. Place and time were in convenience of the participants.

Data collection

The data collection was generated on two sources: Direct observations (Creswell, 2007; Green & Thorogood, 2004) and repeated unstructured interviews. A reflective field notes diary (Polit & Beck, 2008) was used for each participant right from the first meeting for recording all aspects of the project (Green & Thorogood, 2004).

The first source was chosen because within narrative research it is assumed that concrete action reveals meaning (Ricoeur, 1984). Unstructured interviews were conducted to resemble guided conversations (Kvale, 2009; Kielhofner, 2006) with focus on the particular topic (Kvale, 2009).

The interviews included a relatively short list of general open-ended questions built around *Occupational Engagement* (see appendix). The researcher was not entirely 'nondirective', through open questions the researcher leaded the subject, but respected how the interviewees framed and structured their responses because it was not meant to direct the respondents towards any particular value judgment, but rather to encourage them to reveal more specific information about their personal experiences and circumstances (Kvale & Brinkmann, 2009; Kielhofner, 2006). It was up to the subject to bring forth the dimensions he or she found important in the theme of inquiry (Kvale & Brinkmann, 2009).

The interviews were conducted in Danish, tape recorded and transcribed verbatim (Kvale & Brinkmann, 2009).

Data analysis

Since engagement in occupation can constitute a possible source of understanding experiences, it is the unit of analysis for this study. The analysis is based on an interpretative hermeneutical tradition drawing on Riceour and Mattingly as additional sources. The purpose of hermeneutical interpretation is to obtain a valid and common understanding of the meaning of a text (Kvale & Brinkmann, 2009). Ricoeur (1981) broadened this notion of text to include not just the written text but also any human action or situation. Emplotments involving actions and experiences was identified with possible interpretations.

The process of analysis started by reading the transcripts to define plots that described changes or significant events within the participants experienced process. Each participant's data was treated independently. All defined plots were then sorted to get an overview of the plots and describe possible emplotments for each participant as a result of interaction and consideration of several possible interpretations.

The analysis then continued with searching for changes over time and formulating possible interpretations in relation to meanings, contradictions, turning points or significant events (Mattingly, 2004). This procedure continued several times aiming at a plausible emplotted story.

Reliability and credibility

Through a dynamic dialogue, by looking for new nuances, richer interpretations and a deeper understanding of the material, the use of two sources of data contributed to more reliable material and richer responses. As narratives are considered linked to actions (Joseppson, 2011), it is assumed that direct observation from occupations of the participants own choice, was an appropriate and complementary source to gather narratives. The interviews were conducted and transcribed in Danish, and an English/Danish speaker was consulted for the accuracy of the participants' words.

Ethical considerations

The study was approved by the Danish Data Protection Agency and received j.no. 2011 – 41 - 6292. Ethical issues were considered such as an informed consent, anonymity, guarantee of confidentiality to the participant, chance to withdraw from the study (Creswell, 2009; Kvale & Brinkmann, 2009) and awareness of the potential of each participant. The participants were informed about the study both orally and in writing (see appendix) using a simple language and to avoid technical terms whenever possible. Special attention was taken during the contact period, to handle some critical moments with empathy, also considering the special needs of a vulnerable populations (Creswell, 2009), in this case persons with neurological impairments.

Findings

The findings describe how the participants experienced the occupational transition from the time of injury until the present. This section presents three narrations involving actions in the participants' own context: (1) Liz's, (2) Ann's and (3) Tom's. Each part is followed by possible interpretations. The narratives are about the participants' experienced process of engagement during their rehabilitation and how engagement might possibly be related to occupations:

Could have jumped into the harbour (1)

The researcher met Liz for the first time in her small apartment. Just before the injury her husband of 42 years left her, and she was clearly emotionally marked by this event. In between the lines she thought it was because of the divorce that she got stressed and had the injury. She had two grown up sons and grandchildren. Liz was a teacher and speech therapist and due to her injury she had decided to retire. Liz's occupational therapist relates that Liz was emotionally affected, and that she needed support to engage in occupations because she was nervous. Her process from time of injury went from thinking about committing suicide to enjoying life and going on a trip to Cuba.

"It's all about feelings that pop up in situations you used to manage without any particular problem. Things I have experienced right after the brain injury….I get sad, is it really so bad that I can't find my way around anymore? I wanted to take the No. 40 bus, but the sign at the bus stop only referred to No.10. I had to ask for help. This makes me really sad; is it really so bad that I can't get on the right bus? How could you be so wrong, I ask myself".

The researcher asked if Liz experienced situations where she must withdraw from the occupation. Liz answers: *"Yes, you try to avoid the situation because it hurts so much".*

As can be seen by the above quotes Liz expressed a sadness, a sadness not being able to do things the same way as before the injury. She found it hard to admit and realize that even small things cause problems. This is seen in the analysis as grief when it is realized, because it is so unexpected; never before had she had to struggle to engage. The experience of not being able to engage resulted in withdrawal from occupations. The higher the demands on Liz' abilities the more difficult life became.

A possible emplotment of these events had led to low feelings of low self-efficacy, because of Liz' negative beliefs about her own capabilities in the face of difficulties. People who experience repeated failure may develop a negative view of self and little confidence in their ability to influence events (Christiansen & Baum, 1997).

"Things I couldn't imagine were a problem, it was first when I met them I realized that they were a problem. It's something were used to doing, but suddenly the brain is cuts out – it's scary…now I have a new hotplate and it causes me trouble, but my old hotplate in my summer house is no problem, I know it very well.

"I had some problems finding my way in a shopping centre, but I wasn't conspicuous, you know. Things are not as they use to be". "Then someone reminds me that I can't do something". Liz stops talking for a while and says with tears in her eyes***:*** *"I can tell you; I could have jumped into the harbour at that".*

One emplotment making sense of the above quote could be that Liz tried so hard to cope with her situation, and to act normally even though things were not as they used to be. She felt alone because no one supported or said "well done, Liz" to her. Her children expected her to be able to perform just as before, because it was two years since she had been injured, and in their view she should have recovered by now. The powerful narrative: "I could have jumped into the harbour", she mentioned several times. A possible interpretation could be that Liz had been at the edge and thought of committing suicide.

"There it is again, this mechanism; if I have to do a little too much I won't do it. It is hard work, and it just takes such a long time. The more things I have to remember, the more my memory is challenged, and then life becomes difficult".

This narrative above could illustrate that Liz actually withdrawals from occupations when the demands were too high.

Knitting was one of her great passions, and this occupation formed part of her identity. "*I can knit, and I went down town to buy a knitting recipe for a sweater to my little grandchild, but when I came home I realized; I couldn't figure it out".* The experience of not being able to knit like before the injury affects her identity and life significantly: *"I did not know I had problems with practical things, it was first when I performed again I realized it. At that moment… I could have jumped….and I thought; now you are totally insane Liz".*

The fact that occupations take longer, and the fatigue due to her injury, were limitations on engagement in occupation. She mentioned that she had memory loss, and that life unexpectedly became difficult when challenged, which meant that if the occupation got too complicated her level of engagement decreased automatically.

Liz tried to regain everyday life occupations in spite of her disabilities by finding new compensating strategies and using personal resources: *"One of my strengths is that I have a strong will, but I cannot compensate always of course. The black holes in my memory will still be there even with the power of will. It is about finding a strategy or a detour".*

Liz explained that her surroundings considered the extent of her injury as insignificant. A possible plot could be an expression of lack of understanding from her social environments and relations: *"I know, the severity of my injury is moderate, even though it is pretty tough. People who know me says: 'Oh, your injury must be minor'. But a stroke more than two centimeters is not in the category, 'minor'".*

Liz still had several problems engaging in different occupations, even though she said she had a strong will and had been able to develop throughout the rehabilitation process. In spite of everything, her everyday life had become much better since the time of her injury.

When Liz was in rehabilitation, she had experienced how social relations impacted on her engagement when baking cakes with the other clients on her own initiative, helping each other to compensate for their different and complex injuries: *"…together with other patients we did it on our own, together we were strong, were attentive to each other, it was so natural, we were having fun, laughing"*

The above quote could represent a plot within a social context, where Liz was influenced by the values, beliefs, and experiences of the social group. Occupational engagement is also affected by our social group in terms of how we experience the occupation as well as why we participate (Townsend & Polatajko, 2007). The motivation and reason to engage in an occupation is thought to be affected by an interplay of social dynamic experiences and shared meanings. It was clear that Liz profited from having a community with the other clients and how social relationships and environmental elements were facilitating resources and occupational engagement.

Everything as it was (2)

Ann lived with her husband and two children on an old farm where she had been living for most of her life. She was discharged from hospital six month ago. The researcher met her for the first time when she was receiving rehabilitation in her own house. Her diagnosis said cerebral infarction with significant unilateral body and facial palsy. Her occupational therapist informed the researcher about Ann's lack of insight into her disease and lack of initiative. Ann's process went from sitting in a wheel chair, having given up, to being more aware and trusting in her own abilities, and walking round without a wheel chair.

While washing windows (using a rollator) Ann said suddenly: *"My husband will very soon have been married for 50 years"*. The interviewer looked at her and said supportively: "Oh that's a lot of years together". Ann answers: *"Yes it is"*, and continued washing windows**.** *"Round here we don't change things very much"*.

This narrative above might suggest that she must have gone through a huge change since her injury, because almost everything had changed in her life since her injury. A possible understanding of this emplotment may suggest that she just wanted everything to be like before.

When playing cards on the computer Ann said: *"I try to see if this can be completed, even though it is not always a success". "Sometimes you can do it, but sometimes you can't, but maybe it doesn't always have to be like that."*

One emplotment that makes sense of the above quotes could be the link between the occupation, the actual doing and her condition. Ann's lived experience from the time of her injury until the present was that it had been a struggle to get better, because it was difficult to engage in almost every occupation.

But when Ann thought back to the time when she was discharged from hospital sitting in a wheelchair, she could see a change; she was able to do several occupations in a better way. For instance, she could stand up when doing several occupations, whereas before she had to sit down to do almost everything. So there had been a change, but the researcher asked her several times, and she hesitated because she still had difficulties managing daily life. She doubted whether she would ever improve, and cried several times during the interview. She seemed very despairing and sad, and did not had the courage to take any initiative on her own in terms of engaging in new occupations.

In her mind, everything had to be as before, but a possible plot in this narrative from the card-playing situation, referring to her actual condition, may indicate that she really hoped that *it did not had to be like this*. She was very dependent on her therapist, standing on the sideline while performing, and her level of involvement was very low.

She continued to play cards on the computer, and the researcher asked her about her experiences in terms of regaining occupations, she replied: *"I knew somehow that somehow I could, but it just takes a long time...and there is nothing to be done about it".*

As can be seen by the above quotes, Ann felt blocked in her own life and was not satisfied if things could not be as they were before the injury. Accordingly, she did not find any new strategies on her own to tackle and engage in occupations. Another possible interpretation could be that Ann was in a crisis due to her situation, and simply didn't know what to do about it. She expressed no pleasure in engaging in daily occupations anymore.

I am struggling everyday to do my best (3)

The researcher meet Tom in his apartment with music instruments hanging on the wall and a lot of old records on the shell. It was sure that music was a great part of his life. He lost his job 55 years old due to the injury. There were also pictures of his children and grand child,

whom he spoke a lot about. Tom's process went from not knowing where and how to do simple things when he was discharged, to being able to manage his daily life on his own using compensating strategies.

People from the local authority were visiting Tom to assess his application for a disability pension. Tom says with tears in his eyes: *"They thought that I was an alcoholic, that I have been drinking, because I was stumbling with words and looked very tired. That was not the case, but they mistrusted me and called my OT, who was able to point out that if so I must have been quick of the mark, because she just got back from training with me. Mistrust is the worst thing..., I am struggling everyday to do my best".* Then he leaves the room to pull himself together again emotionally.

One emplotment making sense of the above quote could reflect how Tom felt about himself in terms of managing daily life in general – that it was a struggle to engage in social relations and even worse to be misunderstood due to the symptoms of his disability. Tom described: "*They (people from the local authority) ask you after a week if one has recovered – Recovered!? a brain certainly does not get well within a week".* This powerful narrative was told with a sense of humour, expressing that in spite of his difficulties within daily living he also possessed energy. The local authorities had estimated that Tom would recover at the point of taking care of himself without any help, but Tom felt that he still needed help and support.

Tom described how he used a lot of energy just to be present in a social context, and that he lost self confidence when people did not understand his condition. *"It makes me feel empty inside...and frustrated".*

"The neurologist compared me to a mobile phone .....green/red need to recharge". The fact that the doctor compared Tom to an uncharged phone low on battery made Tom feel that his condition was rather static, being unable to do anything if he did not rest during the day. *"I need to rest otherwise I can't make it through the day".* To engage in occupations Tom needed rest, otherwise he would have to reduce elements of the occupation or use more time. *"If I don't sleep or rest I can't do anything of what I need to do or wish to do".*

When the researcher met Tom for the third time, he was inviting to listen to music in his home. He had an enormous collection of old records and some pictures with his famous musicians and instruments hanging on the walls. One could tell from the decorations on the walls that music was a great part of Tom's life. We agreed that he should pick out two musicians or groups that he liked most and play them. He found this was a hard choice because he had plenty he liked. It was impressive to observe that Tom knew exactly where he could find the records he was looking for on the shelves. There were shelves all over the wall containing only records and some books about music.

Normally, in other situations he had a problem with structure, but when it came to his great passion he had a better overview than when doing other occupations. This points in the direction that meaningful occupation made a better performance. Observing him and hearing him talk about his great passion for music, it was very clear that this occupation had his attention and the highest level of engagement:

"I have been playing the drums and guitar for many years now, but when I practice with the band sometimes, suddenly I play something wrong, and then I have to stop playing"..."That is actually very annoying, I can't concentrate that long, but the old lads they know what has happened to me, so we just have a break".

One emplotment making sense of the above quote could illustrate that Tom's occupational engagement was limited by lack of concentration amongst other disabilities. Even though he experienced limitations in his performance, he was still engaged to the extent of his ability to participate in his favourite artistic occupation.

The first favourite band he plays is a band from the late sixties called: 'Grateful dead'. The researcher asked if this name *grateful dead* meant anything to him? He came up with powerful narratives: *"When you die you have to have lived your life to the edge...I mean have lived your life completely, doing the things you really want to do, and wish to do"*. He takes a reflective moment and suddenly he says loudly: *"I could have been dead"*.

Tom and the researcher then went out for a walk in the garden and Tom says: *"Have to get the best out of life, it is no use to sit and cry"*

The identified plots were connections between what he was actually doing and his inner constructions of feelings in relation to his present situation and process experienced from time of his injury until now.

Within narrative theory (Ricoeur, 1984) an important role is played by agents who carry out the actions and this also includes the social dimension of doing, which can be narrated only because it is symbolically mediated, articulated by signs. A possible interpretation could be that Tom's symbolic meaning was mediated by the title of the band, 'Grateful dead'. He created meaning by playing his record, and realized while doing this that he had to get the best out of a life shaped by what he had experienced while ill and disabled. Another layer could be that the title of the band symbolizes the opposite: that Tom was really grateful for life itself, for the fact that that he did not die, but at the same time he also felt limited, due to the negative effects of the disease involving difficulties in managing everyday life.

The injury has led to permanent changes that he has to cope with, but as he said it is all about to *getting the best out of life*. This way of understanding the emplotment is somewhat contradictory, but certainly he had to find a way to explore and enact this duality in himself within different scenarios and different actions.

The process of the occupational engagement

This section is summarises the findings and describes how the participants had developed throughout the rehabilitation process. They had all registered a *change* in the way they engage in occupations and needed to make more effort. In this part of the analysis, a complexity emerged regarding how the participants regained everyday life and struggled to engage in different occupations with different difficulties caused by their injury.

Common to all were the experience of frustration and feelings of depression. They were frustrated about the physical and psycho-social limitations that impacted their desired lifestyle.

The rest of the narrative analysis presented a picture of how emotions, depressive feelings, self-esteem, self-efficacy and identity were strongly related to engagement in occupations, and were more often the cause of withdrawal from occupations than the disability itself.

One of the participants described her process as "it is all about feelings". Acquired brain injury leads to permanent changes and they had all experienced significant disruptions in their everyday life in many ways. Determining to what degree they were engaged depended on how psychological and mental factors like (a) sadness, (b) despair, (c) anger, (d) fatigue, (e) insecurity, (f) fear and (g) negative thoughts affected them and influenced their daily lives.

All participants had a special need to regain and try out different occupations after they were discharged this was linked with feelings of, for example, fear and insecurity. Both successful and unsuccessful experiences were connected to the performance of an occupation, and it was very important to them to know their own capacities and abilities and return to the same occupations as before their injury.

One significant finding was that self-efficacy tended to be connected to their level of motivation for engagements. Participants with insight into their ability appeared more motivated and able to effectively problem solve barriers to accomplish a desired task. This led to enhanced feelings of independence and choice, which assisted in the maintenance of a positive self-efficacy.

One participant (Tom) clearly described having a renewed sense of what was important in life after having come so close to death. Tom reflected: *"When you die you have to have lived your life to the edge...I mean to have lived your life completely, doing the things you really want to do, and wish to do"*.

Heavy demands placed by an occupation seemed also to have a significant impact on the respondents' self-efficacy and identity. All participants had experienced different factors that are barriers to occupational engagement, but also factors which can promote and facilitate occupational engagement. Common to all participants were factors improving occupational engagement, mainly related to structure in their daily lives, social relationships, and familiar occupations and supportive environments. On the other hand, they all felt alone with their

emotions during the time of rehabilitation, and that was an important cause of decreased levels of engagement.

Lack of understanding from their surroundings had an significant impact on their mood and self-efficacy, and this was further connected to a reduced level of engagement in occupations.

Discussion

Could the findings of this study be seen as empirical examples about how occupational engagement works in actual daily living for this group of people? The participants had experienced three different journeys from the time of injury until the present; all had developed throughout the process and experienced a change, but in different ways. There were also a lot of similarities in terms of the consequences of their injuries.

Common to all participants were that they wished to return to their pre-stroke occupations. Ann especially had a hard time accepting the things were not as they were before. She saw no potential for change in her circumstances, the result was a feeling of disempowerment. There appeared to be an emerging pattern whereby she felt unable to undertake tasks and had lost confidence. This was linked to further withdrawal from occupations.

The other two participants had gained more insight into their situations and were more self-confident, believing in their own abilities. Research has shown that people who perceive themselves as competent tend to view their overall well-being as more favourable and more likely to continue working on tasks despite setbacks (Gage & Polatajko, 1994, cited in Christiansen & Baum, 1997).

The majority of the approaches used to date in occupational therapy are concerned with occupational challenges related to personal capacity, paying attention to the potential of the clients' resources, but very often the first emphasis in occupational therapy intervention is focused on impairment reduction and occupational problems.

The findings in this study show that the participants focused primarily on reframing their sense of self and identity in the process, and this might suggest that greater use should be made of establishing priorities concerning the patient's process as experienced, by addressing psychological aspects of the client in occupational therapy intervention.

Self-efficacy is an important concept for occupational therapists because a person's feelings of competence can be influenced by success in task-related experiences (Christiansen & Baum, 1997). This study have shown the importance of receiving rehabilitation designed to improve the participants sense of competence, because it was highly the belief in oneself as an effective, competent person that provided the motivation to engage in occupations that led to later success. One example of believing in oneself as an effective, competent person was Liz performing a group occupation: "*...together with other patients we did it on our own, together we were strong, were attentive to each other, it was so natural, we were having fun, laughing"*. But when she was performing occupations on her own, she was less motivated and had feelings of anger and frustration and the occupation was often perceived as difficult.

Conclusion

This study contributes three emplotted stories as empirical data towards understanding the process of occupational engagement as experienced by individuals with acquired brain injury. Overall, the results of this study suggest that despite good functional recovery and a positive occupational change, the participants experienced ongoing barriers to occupational engagement.

Changes in self-efficacy were a notable finding and maintenance of self-efficacy was linked to the ability of participants to exercise choice and sustain participation in meaningful occupations. The level of engagement was dependent on the participants' self confidence, feelings of self-efficacy and emotions, rather than on their physical impairments.
Thus, it was not the impairment or the performance itself, but rather what it did to them as they experienced not being able to do things as they could before.

Participants expressed an ongoing wish to return to those occupations undertaken before their injury. The extent to which this was achieved varied between participants, depending of course on the amount of residual disability, but also on how they felt about their situation.

Performance strategies were mostly discovered by a need to try out different occupations, configuring alternative possibilities for engagement in occupations.

For participants who saw no potential for change in their circumstances, the result was feelings of disempowerment and withdrawal from occupations.

These multiple emplotment alternatives of enacted narratives might contribute to developing resources that would pay attention to psychological features, helping in this way to increase the participants' level of engagement within a forward-moving and changeable process.

References

Ahlström, S., & Bernspang, B. (2003) *Occupational Performance of persons who have suffered a stroke: a follow-up study..* Scandinavian Journal of Occupational Therapy, 10: 88-94

Alsaker S., Bongaardt R., Josephsson S. (2009) *Studying Narrative-in-Action in Women With Chronic Rheumatic Conditions.* Qualitative Health Research Volume 19 Number 8 Aug. 1154-1161. Sage Publications

Bandura A. (1990) *Perceived self-efficacy in the exercise of control over AIDS infection. Evaluation and Program Planning*. vol. 13, pp. 9-17, Stanford: Pergamon Press

Borell L., Asaba E., Rosenberg L., Schult ML., Townsend E. (2006) *Exploring experiences of Participation among individuals living with chronic pain.* Scandinavian journal of occupational therapy, 13: 76-85 Taylor & Francis

Bowling A. 3rd edt;(2005) *Measuring health – A review of quality of life measurement scales.* Berkshire: Bell & Bain

Bruner J. (2002) *Making stories: Law, literature, life.* Cambridge, MA: Harvard University Press

Christiansen C., & Baum C., 2nd edt;(1997) *Enabling Function and Well-Being.* Thorofare: SLACK Incorporated

Creek J., & Hughes KJ. (2008) *Occupation and health: a review of selected literature.* British Journal of Occupational Therapy, Nov 2008

Creswell J.W. 3rd edt;(2009) *Research Design – Qualitative, Quantitative, and Mixed Methods Approaches*. Thousand Oaks: Sage Publications

Creswell J.W, 2nd edt;(2011) *Designing and conducting Mixed Methods research.* Thousand Oaks, California, U.S.A: Sage publications

Goldstein K., Kielhofner G., Paul-Ward A. (2004) *Occupational narratives and the therapeutic process.* Australian Occupational Therapy Journal, 51, 119-124

Green J., & Thorogood N. (2004) *Qualitative Methods for Health Research*. Thousand Oaks: Sage Publications California

Isaksson G., Josephsson S., Lexell J. Skär L (2007) *To regain participation in occupations though human encounters – narratives from woman with spinal cord injury.* Disability and Rehabilitation, 29(22): 1679-1688 : Informa UK

Johnsson H., Kielhofner G., Borell L. (1997) *Anticipating retirement: The formation of narratives concerning an occupational transition.* American journal of occupational therapy, 51, 49-56

Josepsson S., Asaba E., Johnsson H., Alsaker S. (2006) *Creativity and order in communication: Implications from philosophy to narrative research concerning human occupation.* Scandinavian Journal of Occupational Therapy, 2006; 13: 86-93

Kielhofner G. (2006) *Research in Occupational Therapy – Methods of Inquiry for Enhancing Practice*. Philadelphia: F.A. Davis Company

Kristensen H.K., Borg T., Hounsgaard L. (2012) *Aspects affecting occupational therapists' reasoning when implementing research-based evidence in stroke rehabilitation.* Scandinavian Journal of Occupational Therapy, 19: 118-131

Kvale S., & Brinkmann S, 2nd edt;(2009) *Interviews-Learning the Craft of Qualitative Research Interviewing*. Thousand Oaks: Sage Publications

Lequerica A.H., Whitman R., Millis S., Hanks R., Axelrod B. (2006) *Psychometric Properties of the Rehabilitation Therapy Engagement Scale: when Used Among Individuals With Acquired Brain Injury*. Rehabilitation Psychology, Vol. 51, No. 4, 331–337

Mattingly C. (1998) *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge: Cambridge University Press

Mattingly C., & Garro LC. (2000) *Narrative and the Cultural Construction of Illness and Healing.* Berkely: University of California Press

Polit D. & Beck C., 8edt:(2008) *Nursing Research – Genrating and Assessing Evidence for Nursing Practice.* Lippincott: Williams and Williams

Ricoeur P. (1985) *Time and narrative.* Vols 1-lll. Chicago: Chicago University Press

Ricoeur P. (2002) Red. by Hermansen M., Rendtorff J. *En Hermeneutisk Brobygger: Tekster af Paul Ricoeur*. Århus: Forlaget Klim

Reid D. (2011) *Mindfulness and flow in occupational engagement: Presence in doing*. Canadian journal of Occupational Therapy, 78, 50-56, CAOT Publications

Townsend E. & Polatajko H. (2007) *Enabling Occupation ll – Advancing an Occupational Therapy Vision for Health, Well-being, & Justice through Occupations.* Ottawa: CAOT

Vrkljan B. & Miller-Pollgar J. (2001) *Enabling occupation: an occupational therapy perspective*. Ottawa, ON: CAOT Publications ACE

Wilcock A. (1999) *Reflections on doing, being and becoming*. Australian Occupational Therapy Journal 46, 1-11

On line sources:

World Health organization: www.who.com

Danish National Board of Health: www.sst.dk

Part II: Extended Part

Extended Literature Review

The concept of occupational engagement among persons with ABI are further developed in this section in dialog with occupational therapy. The search strategy in this part is based upon further evaluation and support of the findings. Five databases were searched: Cinahl, PsycInfo, Embase, Amed, and Science direct with advanced search in the resources of Brighton University with the following search terms: "Self-efficacy", "acquired brain injury", "rehabilitation", "changes", "occupational engagement", "occupational therapy".

Stroke and traumatic brain injury and other types of acquired brain injury are the main causes of acquired brain injury. Acute stroke is one of the main factors for morbidity and mortality worldwide. Stroke is the most important cause of morbidity and long-term disability in Europe and imposes an enormous economic burden (European stroke organisation, 2009). In Denmark it is estimated that approximately 80.000 people live with disabilities following acquired brain injury (Danish national board of health, 2011) and every year 15000 – 16000 people will get injuried.

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 (Seibert et al., 2002).
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 (Hoogerdijk et al., 2010).

At the time of the research there were few studies documenting acquired brain injury in relation to the individual's perspective on the process of occupational engagement. The stroke studies gave little understanding regarding the development of the process of occupational engagement. But in a study about the "adaptation process" and "identity" in relation to acquired brain injury, it is claimed that the process is an individual and ongoing occupational struggle to gain a new identity (Hoogerdijk et al., 2010). The results indicates that the experienced process is facilitated by engagement in familiar occupations and familiar

environments. The participant in this study also lived though a long adaptation process to adjust to their disabilities facing a different everyday life.
Studies also found that engagement in occupation is a powerful force in recovery (Brown et al., 2006; Blair, 2000). That study explored the pertinent ways in which people manage and adapt to change. Among the conclusions from those experiences is the acknowledgement of the centrality and personal meaning of occupation at the point of transition.

The onset of illness combined with the resultant disruption in occupational routines challenges a person's identity as a capable and healthy individual. However in literature it remains unclear how individuals regain a sense of health and well-being in the period following acquired brain injury. Occupational engagement has been linked to health and well-being (Wilcock, 2006; Townsend & Polatajko, 2007; Reid, 2008). Although one of the basic premises of occupational therapy is to improve health and well-being though occupation (Law, 2002; Wilcock, 2001), there exists no consensus as to how these concepts are interrelated, and the mechanisms by which occupational engagement promotes health and well-being are still not fully understood. However, in a study about stroke rehabilitation health and well-being were regarded as influenced by having choice, control, and the ability to engage in everyday life activities (Kristensen HK. Et al., 2012).

According to the World Health Organization (2001), engagement is an important component of participation, and refers to a person's involvement in life situation. Therefore, occupational engagement is more than just performing a task because it also incorporates on element of motivation for the actual doing (Yerxa, 1998).

Occupational engagement does not represent an absolute quality, and this is why individuals report having different experiences of being engaged in an occupation (Reid, 2010). There are different ways to be engaged, different experiences, and different prerequisites engaging in occupations, therefore the subjective experiences of clients should be underpinned by interventions aiming to promote engagements in occupations.

Some of the findings in this study showed that lack of sense of self-efficacy, clearly affected the participants' level of engagement. The participants' self-efficacy; beliefs about their capabilities affected what they chose to do, and how much effort they were able to mobilize in

the face of difficulties. Numerous studies have been conducted, linking perceived self-efficacy to health-promoting and health impairing behavior (Bandura, 1986, 1989; O'Leary, 1985). The results show that perceived efficacy can affect every phase of personal change, whether people even consider changing their health habits, how hard they try, how much they change, and how well they maintain the changes they have achieved (Bandura, 1990).

How occupation and engagement are interrelated needs to be further addressed in the occupational therapy intervention, to be able to claim that by enhancing occupational engagement clients automatically achieve well-being. If occupational therapists are to take seriously their espoused commitment to enabling equitable access to clients' engagement in occupation, the inequitable condition of people's lives will need to be addressed. It is acknowledged that well-being cannot be achieved solely by enhancing individuals' abilities to engage, and that consequently endeavors also address the conditions of people's lives (Hammell & Iwama, 2011).

Extended professional and personal reflections

This Master education and conducting the research project was quite a journey, but also it embraces my passion for the core values of Occupational Therapy and Occupational Science, both as a former practitioner and now as a teacher. My experience with brain injury was useful in the data gathering process, emphatic to handle and understand some critical moments. But it also made me face with humble to enter the multilayered world of narrative, and experience how rich and powerful material was behind the participants' personal narratives.

One of the benefits of the study was the identification of the circumstances around occupational engagement and the linking to health-related issues like well-being. It has opened up a broader perspective on the experienced rehabilitation process and occupational engagement from the participants' point of view.

This study can lead to the optimization of the rehabilitation process by providing knowledge about the process of occupational engagement and its meaning to individuals following an acquired brain injury. This might enable occupational therapists and other professionals to better assist persons with acquired brain injury to adapt to their new situations. The

knowledge gained can also be of use to rehabilitation professionals in treating patients who are difficult to get engaged. Thus, it is also of importance to occupational therapy to identify variations in engagement in order to adjust the intervention and assist the client in achieving occupational balance. To include psychological factors and work with feelings of self-efficacy could be useful, as a way of determining and to increase client's occupational engagement.

Furthermore, it is also my hope that this study can contribute more specifically to clarifying the concept of occupational engagement within occupational science.

Reflection on Methodology

It is recognized that the greatest strength in qualitative studies utilizing observation and participation is that they provide very rich and detailed data in settings and situations in which subjects are observed (Polit & Bech, 2008; Kielhofner, 2006).

Narrative approach

The narrative approach brought the object more sharply into focus in this study. The narrative approach was fundamental to this study, and in combination with participant observation and within a context of occupation, the researcher was informed at several levels about the participants' life and opinions, which also made the process rich in understanding and easier to interpret. It gave a detailed description of the phenomenon under study.

To probe the specific meanings of participants' actions and behaviours, the data was supplemented by other methods such as interviews and field notes (Polit & Beck, 2008; Kvale & Brinkmann, 2009).

The researcher was interested in focusing on the uniqueness of each patient and learn about their opinions and experiences with occupational engagement. Within theory of narratives (Ricoeur, 1984) an important role is given to the complexity of how the meaning-making process is dependent on the context. The real-time situatedness, the process quality of everyday action, and the concrete connection to meaning were more propositional and ongoing than the interview setting could encompass (Alsaker et al., 2009).

Because narratives are about meaning-making, it is according to Ricoeur an ongoing form of negotiating meaning through acts (Ricoeur, 1985). Ricoeur, 1985 describes this as the concept: 'mimesis'. This way of using acts in the data collection by observing the participants in occupation gave multiple material and several possibilities interpreting and to understand experience.

Furthermore the researcher choose this approach because of possible limited capacity of the participants due to cognitive impairments. For example, some research participants may not be able to provide full and complete information about their experiences owing to the nature of their disability or health condition (Kielhofner, 2006). As the study focused in people with a brain damage, the researcher's intentions were to address methodologically their presumed difficulties in expressing themselves due to their injury, and the selected approach initially was enacted narratives (Ricoeur, 1990) about meaning construction in relation to significant events (Mattingly, 2004; Josepsson, 2011).

Gathering the situated context of the participant in combination with interviewing, provided an open atmosphere with the participants and at the same time rich material. It was especially interesting to experience how fruitful and reflective the narratives became while the participant was performing. It is now clear that the enacted narratives are a very powerful way to gather data. However, the findings are possible understandings, and might be controversial.

Participants and recruitment

Purposive sampling (Polit & Beck, 2008; Kielhofner, 2006) was used as sampling strategy for this study. The sampling method was a judgmental sampling (Polit & Beck, 2008) and based on the clinicians knowledge about the participants and their personal judgment about which ones will be most informative.

Data gathering

Data was gathered through participant observation (Polit & Beck, 2008) and unstructured interviews (Kvale & Brinkmann, 2009), and fieldnotes (Kvale & Brinkmann, 2009). The relevance of fieldnotes (Polit & Beck, 2008) within this design was a key element to gain a deeper understanding of the participants' life worlds and to supply the interpretative process.

Additionally, participant observations presented a less threatening alternative to present occupational engagement.

Most importantly, however, the unstructured interview conveys the attitude that the participant's views are valuable and useful (Kvale & Brinkmann, 2009; Kielhofner, 2006), and the task of the researcher was to capture these views and meanings as completely and accurately as possible.

Data Analysis

Analysis in narrative studies opens up forms of telling about experience, not simply the content to which language refers. Analysis of personal narratives can illuminate 'individual and collective action and meanings', as well as the social processes by which social life and human relationships are made and changed' (Laslette, 1999, cited in Riessman, 2000). By using narrative analysis, 'the change' for each participant appeared clearly, but it was still a challenge to interpret.

An additional challenge was to present the findings in a conventional research article, where narratives wants to have space, but at the same time is supposed to fulfil the research requirements, losing in this way some of its richness.

Credibility and transferability

Qualitative researchers should consider the transferability of the findings and demonstrate the credibility of their interpretations, and ensure that analysis is done rigorously and thoroughly (Polit & Beck, 2008). Additionally supervision and peer debriefing (Polit & Beck, 2008; Kvale & Brinkmann, 2009) with a senior researcher and expert in the narratives, was essential regarding credibility of possible interpretations.

To ensure the accuracy in the translations from one language to another, an English speaker was consulted.

To what extent are the findings transferable to other settings? Answering this question some of the findings are context specific and cannot be generalized, others like changes in perceived self-efficacy and experiences of ongoing barriers to occupational engagement

despite of good functional recovery are more widely applicable (Green & Thorogood, 2004) and characteristic for this group of people.

Limitations of the study

The findings are presented as possible understandings and not as factual true, which might constitute a limitation within traditional paradigmatic research or might be controversial regarding its validity. Another limitation of the study is about transferability, because firstly it is a qualitative study and secondly it is about a very specific group of people. However the study provided a better understanding of the participants under study. As one of the limitation of this study is its transferability and the small amount of patients involved, further research about the process of occupational engagement is needed. Finally, participants were aware of the focus of the research, which might had influenced the way they informed the researcher about occupational engagement.

Ethical Considerations

Researchers have a duty to protect the life, health, privacy and dignity of the human subject and to seek ethical review for all research protocols (Green & Thorogood, 2004). Informed consent was obtained, which implies both that all pertinent aspects of what will happen are disclosed to the participant, and that they are able to comprehend the information. Consent implies that the participant is capable of making a rational judgement about whether to participate, and that their agreement should be voluntary rather than the result of influence (Green & Thorogood, 2004). However, with attention to this vulnerable group of people, the researcher needed to probe into the psychological state of the participants at a vulnerable time in lives; such probing could turn out to be painful (Polit & Beck, 2008). A qualitative study like this involves highly personal areas (Polit & Beck, 2008), but the participants were not subjected to unnecessary risks for harm or discomfort. The researcher felt confident about her experience as an occupational therapy practitioner during the contact period. The fact that the research involved observations within occupations, meant that the context was natural for capturing their narratives. It was up to the participants how they linked their current occupation with experiences of engagement or which information they were willing to share.

Further reflections on the Findings

This thesis has argued that a philosophical approach to the concept of occupational engagement requires a critical practice of occupational therapy; innovative practice that acts on the knowledge that occupational engagement cannot be achieved solely by enhancing individuals' abilities. Several conditions of people's lives need to be addressed to be able to enhance occupational engagement. Based on the findings of this study it is necessary to include the clients' life factors, specifically the psychological consequences of the injury, when aiming to improve clients' occupational engagement.

There was an explicit link between self-efficacy and negative emotions observed throughout the study and many participants expressed having a negative view of themselves since their injury. This further diminished feelings of self-efficacy. A call for commitment to enhance occupational engagement though addressing the conditions of people's lives is needed.

Based on the findings of this study and throughout the literature, building on current theoretical trends, the author advocates a more nuanced and considered use of occupational engagement with attention to the clients' experienced process, acknowledging the uncertainty of occupational engagement in relation to health and well-being faced by occupational therapists, occupational scientists, and the people with whom they practice or do research. Further research needs to be done in order to support the clients 'occupational change', and the emergent occupational engagement.

Acknowledgments

Thanks to my dear family and friends for all the support, space and especially patience; A special thanks to my supervisor Staffan Josephsson for encouragement, respect and generosity, and for sharing his great knowledge as a specialist into narrative methodology; to my dear colleague, friend and English teacher Michael Cain for his support and resources all along the way of this Master education; his great insight and interest in my thesis and expertise in professional reading of the English accuracy. To my colleagues for listening as I talked about all my ideas and thoughts. I owe a special gratitude for the openness of the informants, for inviting me into their lives, opening their homes and their hearts.

References

Bandura A. (1990) *Perceived self-efficacy in the exercise of control over AIDS infection - Evaluation and Program Planning*. vol. 13, pp. 9-17, Stanford: Pergamon Press

Blair S.E.E. (2000) *The centrality of Occupation during life transitions.* British Journal of Occupational Therapy, 63:231-6

Brown D., Lyons E., Rose D. (2006) *Recovery from brain injury: Finding the missing bits of the puzzle.* Scandinavian Journal of Occupational Therapy, 20: 937-46

Christiansen C. & Baum C., 2nd edt;(1997) *Enabling Function and Well-Being.* Thorofare: SLACK Incorporated

Creswell J.W., 3rd edt;(2009) *Research Design – Qualitative, Quantitative, and Mixed Methods Approaches*. Thousand Oaks: Sage Publications

Creswell J.W 2nd edt;(2011) *Designing and conducting Mixed Methods research.* Thousand Oaks: Sage publications

European Stroke Organisation. Available at: http://www.esostroke.org. (September 25th , 2009)

Green J. & Thorogood N. (2004) *Qualitative Methods for Health Research*. Thousand Oaks: Sage Publications California

Hammell K.W. & Iwama M. (2011) *Well-being and Occupational rights: An imperative for critical occupational therapy***.** Scandinavian Journal of Occupational Therapy. Early Online, 1-10.

Kielhofner G. (2006) *Research in Occupational Therapy – Methods of Inquiry for Enhancing Practice*. Philadelphia: F.A. Davis Company

Kristensen H.K., Borg T., Hounsgaard L. (2012) *Aspects affecting occupational therapists' reasoning when implementing research-based evidence in stroke rehabilitation.* Scandinavian Journal of Occupational Therapy, 19: 118-131

Kvale S. & Brinkmann S., 2nd edt;(2009) *Interviews-Learning the Craft of Qualitative Research Interviewing*. Thousand Oaks: Sage Publications

Mattingly C. (1998) *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge: Cambridge University Press

Polit D. & Beck C., 8edt:(2008) *Nursing Research – Genrating and Assessing Evidence for Nursing Practice.* Lippincott: Williams and Williams

Ricoeur P. (1985) *Time and narrative.* Vols 1-lll. Chicago: Chicago University Press

Ricoeur P. (2002) Red. by Hermansen M., Rendtorff J. *En Hermeneutisk Brobygger: Tekster af Paul Ricoeur*. Århus: Forlaget Klim

Riessman C.K. (2000) *Analysis of personal narratives: Handbook of interviewing.* Boston university: Sage Publications

Seibert P.S., Reedy D.P., Hash J. et al. (2002*) Brain injury: Quality of Life's greatest challenge.* Brain injury, 16: 837-48

Townsend E. & Polatajko H. (2007) *Enabling Occupation ll – Advancing an Occupational Therapy Vision for Health, Well-being, & Justice through Occupations.* Ottawa: CAOT

Yerxa, E.J. (1998) Occupation: *The keystone of a curriculum for a self-defined profession*. American Journal of Occupational Therapy, 52, 365-372

Appendixes

Participant Information Letter:

Information to respondents concerning participation in a project contributing to a master thesis:
Engagement in occupations after an acquired brain injury

Esbjerg 15/8/2011

Introduction

This study will describe the experiences of several people with acquired brain injury and their views on resuming and engaging in occupations during rehabilitation. The focus will be on the process of engaging in occupations, and I am interested in exploring what happens when you engage in an occupation which did not pose a problem before your injury, but now requires training: for example, what are the decisive factors that make engaging in the occupation a good experience; what other factors influence you if you have to learn new ways of doing things?

Aims of the study: to develop knowledge from people's experiences of occupational engagement during a rehabilitation process.

Occupations: this means everything you do in the course of a day. Daily activities such as taking a bath, making coffee, shopping, visiting family and friends, etc. And also leisure activities such as knitting, swimming, cycling, gardening, etc.

Data gathering: I hope to be able to see you engage in an occupation several times; perhaps something we could do together. After this I would like to interview you; 30 minutes at the most. As I would like to trace any changes in the way you perform and engage in occupations, we shall have to meet several times with a few weeks in between. The collection of data will take place over a period of five weeks, during which we shall meet 2-3 times.

Discretion and ethical considerations: this study has been approved by the Danish Data Protection Agency, which means that the information you provide will be handled with full discretion and the way I collect and manage the data you provide has been judged in advance to be ethically acceptable. You are assured of remaining anonymous and the results of the investigation will be treated with caution and respect. Finally, you have the right to withdraw from the whole process whenever you like.

Background: engaging in occupations is known to have a positive effect on an individual's health and sense of wellbeing, but after an injury there are various things that can prevent people performing daily occupations, which may mean that they stop doing it, even though it would be beneficial to do so.

Outcomes: this study can help to optimise training programmes for people who have an acquired brain injury, helping to improve their everyday performance. Researching the process from the point of view of the

participants will enable us to plan training so as to comply with their needs and wishes in terms of engaging in occupations. I want to identify those factors that promote your engagement in occupations, and those that may hinder it.

I hope you will accept my invitation to contribute your knowledge to my study, which will form part of my master thesis. I am studying an International Master in the Science of Occupational Therapy.

Lone Elisabeth Andersen, Lecturer in Occupational Therapy
University College South Denmark
Degnevej 16
DK-6705 Esbjerg Ø
Telefon: +45 24256801

Interview Guideline:

1. Can you tell me about the occupations you have been performing during your rehabilitation?

2. I would like to learn more about your experiences of engagement in occupations, could you please tell me about a situation/event where you felt engaged?

3. Can you describe more in detail your engagement in these occupations?

4. Has your level of engagement changed?