Participation in occupational therapy in psychiatric care

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Paper I-II
Original papers

This licentiate thesis is based on the following two papers, referred to in the text by their Roman numerals:


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Introduction

Occupational therapy has a long and rich history, especially in terms of the role and function of the occupational therapist in mental health. Early thoughts in occupational therapy come from the moral treatment movement and they emphasize that mental disorders are a reaction to the environment and the degree of balance or rhythm in the person instead of diseases caused by some bacterium or damage. The principle of the treatment was that activities should inspire interest, courage and confidence through the quality of the activity and the therapist’s skills and interest in the activity. The therapy should be focused on health instead of ill-health and occupational therapy should help the person to organize daily occupations (Barris et al, 1998; Creek & Lougher, 2008).

Adolph Meyer, professor of psychiatry in 1922, suggested the view of mental disorders as the outcome of a person’s maladaptive interaction with the environment. The occupational therapist could provide opportunities for the patient to work, to plan, to create, and to learn to use tools and materials. The opportunities would assist patients in gaining pleasure and pride in achievement. Engagement in occupations, or doing, provides a sense of reality, achievement and temporal organization. Meyer suggested a clear relationship between the ability to perform daily occupations and one’s life satisfaction (Meyer, 1977).

Many patients in psychiatric care have lost their daily occupations; they have occupational deprivation since they have lost their daily contact with their natural environment. It is important that occupational therapists focus on occupational performance and support patients in becoming actively engaged in their life activities.

Related to the International Classification of Functioning Disability and Health (ICF) it is necessary that occupational therapists focus at the level of the person-environment interaction so that occupational performance issues can be assessed. Person-environment issues are addressed in the ICF-model at the activity, environmental and participation levels (Law et al, 2005).

In psychiatric care some of the most common disorders are “affective syndromes” and “schizophrenia and other psychotic syndromes” (American Psychiatric Association, 2000). The affective syndromes are either episodes of depression or episodes of mania. The depressive episode can be mild, moderate or major (American Psychiatric Association, 2000; Ottoson, 2009). When the patient has major depression it is common to have thoughts of
suicide. The mood is reduced and the patient gives a strong impression of being sad, resigned and in despair (Ottoson, 2009).

When the patient gets a diagnosis of schizophrenia he must have had symptoms for at least six months (American Psychiatric Association, 2000; Ottoson, 2009). The characteristic symptoms involve a range of cognitive and emotional dysfunctions. Almost half of the patients in psychiatric institutional care have schizophrenia and often compulsory treatment is necessary. Therefore many of the resources in psychiatric care are diverted towards this group of patients (Ottoson, 2009).

The goal for occupational therapy intervention is to enable the patient to achieve life satisfaction, manage daily occupations and relations to others in a context they find meaningful (Kielhofner 2008; Townsend & Polatajko, 2007; Wilcock, 2006). It is important that the occupational therapist takes the patients’ volitional choices into consideration and gives adequate support to achieving participation in occupations (Kielhofner, 2008). Occupational therapists in psychiatric care should support the patients in developing satisfying and valued daily occupations. This is strengthened when occupational therapy research proves that occupation promotes health and quality of life (Eklund & Leufstadius, 2007). Creek & Lougher (2008) established that “occupational therapists should continue to be mindful of the humanistic ideals on which the profession was founded: the belief in the therapeutic value of occupation, and the need for satisfying interpersonal relationships and balance in the daily routines of work, self-care and leisure” (p.14).

In Sweden the “psychiatric reform” was carried out in 1995. It was intended to ensure that local communities would provide housing and employment for people with mental disorders. But at that time in Sweden many communities and health care organisations had a lack of economic resources and many places which gave persons with mental disorders support in different ways had to shut down. As a result of this, institutional care was reduced. The treatment time in institutional care was also reduced. The institutional beds which were reduced first were those for people having voluntary care. In total, the compulsory care has been relatively unchanged under the last ten years (SOU, 2006). The statistics show that there has also been a continuous reduction in the number of occupational therapists in institutional psychiatric care since the “psychiatric-reform” and several occupational therapists are instead employed in non-institutional psychiatric care or in the community’s social services (FSA, 2009).
In psychiatric care the patients should be able to participate in their treatment and be seen as a resource. It is necessary to develop relevant methods and implementation strategies to let the patients influence their care (SOU, 2006).

**Participation**

One of the most important demands for health and medical care is that the treatment must be based on respect for the patient’s self determination and integrity. Another important factor is that the treatment will promote good contact between the patient and the professionals. The care and treatment should be established and carried out in collaboration with the patient. Different achievements for the patient should be coordinated in an appropriate way. The patient has the right to get individual information about his health condition and about the methods for examination, care and treatment that are available (SFS, 1982:763).

Sometimes when the patient has a serious mental disorder the chief physician decides that the patient must be committed under the Swedish Compulsory Institutional Psychiatric Act (LPT). A treatment plan must be established as soon as possible from the time the patient is admitted for compulsory care. The treatment plan states what kind of measures and other efforts that are needed to fulfil the aim of the compulsory care. As far as possible, the plan is established in cooperation with the patient, and if it this is not possible, with the relatives (SFS, 1991:1128). In 2008 the law of psychiatric compulsory care was changed and it is now possible for the patient to get non-institutional compulsory care (SFS, 2008:415). To be committed to compulsory care does not mean that the patient is deprived of all possibilities to make his own decisions. On the contrary, it is extra important that the patient’s integrity and self-determination are not prejudiced unnecessarily (SOU, 2006).

The World Health Organization (2001) recognizes participation as a key indicator of human health and well-being. The WHO describes participation as “a person’s involvement in a life situation” (p.123) and it can be explained using the concept of “engagement”, which means to take part, to be involved, to be included, to be accepted and to have access to necessary resources. Involvement is a central component when participation is discussed in the ICF. The ICF takes into account the social aspects of disability and does not see disability only as a “medical” or “biological” dysfunction. By including contextual factors, which include
environmental factors, the ICF allows the impact of the environment on the person's functioning to be recorded (WHO, 2001).

Molin (2004) has made a concept analysis of participation. The analysis displays various forms of participation and begins to describe participation on micro and macro levels. The micro level is the person’s engagement and responsibility, and the macro level is the equality, influence and democracy. Engagement and responsibility can be related to one person but participation at the macro level assumes at least two persons. On macro level is the formal belonging and on micro level is the informal belonging. Formal belonging legitimates taking part and has objective and legal undertones. Often it is a person with authority that sanctions the formal belonging. The subjective dimension, a feeling of being accepted, is the informal belonging. The informal belonging is more like the daily interplay between people at the same level, for example between professionals in the team or between the patient and the occupational therapist. Further conditions for participation are described. Here the initiative and engagement from the person and the will to engagement are used. These conditions are related to an interpersonal interplay between the person and the social environment. Molin (2004) considered that the conditions of participation depend on the person’s will and ability to participate in relation to accessibility and opportunities for participation. Having total participation is something the person has in interplay with the environment and it will be characterized by acceptance and reciprocity.

Arvidsson et al (2008) conducted a systematic literature review to analyze different aspects of participation in relation to environmental factors or individual characteristics. In the environmental factors, social support is described as support that can come from a specific person, a specific group or the social network. Attitudes of staff persons, routines and formal meetings are included in social support. Individual characteristics such as adaptive skills including awareness of and the ability to handle the environment are described. Social skill, another individual characteristic, includes social competence in relating to other people. Furthermore, in the review, four aspects of participation were found: involvement, perceptions of self, self-determination and psychological well-being. In another literature review made by Vessby & Kjellberg (submitted) three dimensions of participation are described; client-centeredness, meaningfulness and involvement in the environment. In the dimension environment, the social environment is described as interaction with other individuals and can support or hinder participation.
The ICF describes actions from ability to opportunity aspects. The ICF also notices the person’s actual performance of an action but the will to perform is not taken into consideration. The ICF does not contain systematic studies of concepts such as will, purpose or interest. There is also a normalization perspective, stressing the belief that there is one normal way of performing the activity (Nordenfelt, 2004). The lack of a subjective dimension to assess participation related to occupation has also been noted by Hemmingsson and Jonsson (2005). Participation in the ICF only codes the observed performance. The person’s subjective experience of meaning of an occupation or the person’s experience of autonomy and self-determination are not included. However, when professionals code activity and participation in the ICF there are four different factors of assessment. The first is implementing, the second capacity, the third capacity with assistance, and the fourth implementing without assistance. A fifth factor of assessment in the ICF may be developed in the future, for example a factor of assessment for engagement and subjective satisfaction (WHO, 2001).

Arvidsson et al (2007) discuss the lack of methods to assess different aspects of functioning and disability. Often different factors in the ICF are assessed by professionals using interviews and observations. Self-rated participation can be a way to catch the actual participation reported by the subject.

Treatment planning in occupational therapy

In occupational therapy literature different terms are used for those persons who receive treatment or support from an occupational therapist. For example they are called clients, patients or customers. In Swedish health and medical care the term “patient” is used for “a person who receives or is registered for receiving health and medical care” (Socialstyrelsen, 2005). The ethical code is one of the foundations in the occupational therapy profession (FSA, 2005). In the code the term “patient” is used for those persons who receive occupational therapy; consequently this thesis also uses this term.

The ethical code also states that the occupational therapist has to respect the patient’s rights. The patient has a right to a dignified reception and self-determination. The treatment must be based on the patient’s desires and needs. The patient will be informed about alternative interventions and the treatment will begin after the patient gives consent. The ethical code
also establishes that the occupational therapist must respect the relatives’ rights on the basis of
the patient’s consent. This means the relatives should be informed about the interventions and
allowed to participate in the treatment (FSA, 2005).

Furthermore there are different ingredients which are important factors when meeting the
patient initially. The most important is respect for the patient, whatever the problems are. The
patient is a person first, and a patient only temporarily. It is also important that the therapist
empathise with most of the problems encountered and is honest about what occupational
therapy is about and what it can offer (Creek & Lougher, 2008).

In occupational therapy literature many different treatment planning processes are described.
In some ways they differ, but mostly they are very equal. The aim of the treatment planning is
collaboration between the occupational therapist and the patient. Some basic ideas in all
treatment planning processes are: to gather information and identify strengths and weaknesses
of the data, formulate short and long-term goals, generate strategies for intervention,
implement intervention, and determine outcomes of the treatment (Creek & Lougher 2008;
Fisher & Nyman, 2007; Kielhofner, 2008; Pelland, 1987; Socialstyrelsen, 2001; Stein &
Cutler, 2002).

The occupational therapist can gather information and identify strengths and weaknesses
about the patient using structured or unstructured approaches. Structured assessments have a
definite procedure to collect information about the patient and they have been systematically
developed and studied. The structured assessments should feature certain characteristics such
as: protocol or guidelines for use, and evidence that the assessment is dependable and a
formal basis for interpreting the information they gather. The assessment methods can be
observational, self-reported or can collect the information through interview (Kielhofner,
2008; Kielhofner, 2006).

One form of interview is the semi-structured interview. The semi-structured interview often
has a number of questions to ask or specific set of topics, which are written in the manual. It is
often acceptable to take brief notes during the interview (Creek & Lougher, 2008; Polit &
Beck, 2008). In an interview the therapist can also observe the patient’s ability at
communication, cognitive functioning or mood (Creek & Lougher, 2008).

The occupational therapist can also let the patient use self-assessment which can help the
patient to clarify his own thoughts and feelings about his circumstances. The assessments can
be used to facilitate the dialogue between the therapist and the patient, which leads to a deeper understanding of the patient’s circumstances (Kielhofner, 2008).

For an assessment to be applicable three things must be fulfilled. The first is if the assessment is reliable. It is important to know if the assessment elicits accurate information (Creek & Lougher, 2008). The reliability is the consistency with which it measures the target attribute. Reliability also concerns the degree of accuracy (Polit & Beck, 2008). Another factor which is important to consider is the validity of an assessment, which means if the procedure measures what it is supposed to measure (Creek & Lougher, 2008; Polit & Beck, 2008). Also the usefulness of the assessment, its utility, is important in regard to whether it can be used in clinical practice (Innes & Straker, 2001). Utility is about the assessment’s relevance, availability, time effectiveness and cost. The assessment should also be easy to learn, administer and interpret (Law et al, 2005).

The next step in the treatment planning process is to use the collected information to formulate short and long-term goals with the patient. Communication and collaboration with the patient is central in order to reach success in the treatment. Also, to generate strategies for intervention and to implement intervention require continued collaboration with the patient. During the intervention process the treatment plan has to be reviewed constantly because new circumstances and information may emerge.

One way to determine outcomes of the treatment is to compare the results of ongoing or final assessments with the result of the baseline assessment. To measure outcomes of an intervention helps the therapist and the patient to clarify changes of condition and improvement in reaching treatment goals (Creek & Lougher, 2008).
**Aims of the thesis**

The overall aim of the thesis was to investigate and describe how patients in psychiatric care perceive participation, and how existing assessments support participation.

**Study I**
The purpose of this study was to describe how patients in psychiatric institutional care perceived their opportunities to be active in and to participate in their own treatment.

**Study II**
One aim of this study was to investigate if there is harmony between the Comprehensive Psychopathological Rating Scale (CPRS-S-A), the Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS-S) and the Occupational Self Assessment (OSA) and if they can replace each other when the occupational therapist collects information about the patient. Another aim was to investigate how the occupational therapist uses the collected information in the treatment planning process.
Methods

Participants
In Study I, 115 patients were asked to participate. A questionnaire was sent out 1-5 days after the patients had left the ward, and the reply rate was 53%. Ten patients were selected for an interview based on their reply that they were willing to take part. A strategic sample was made according to sex, age, experience of different wards and voluntary/compulsory treatment. In Study II, 45 patients were asked to participate in the first week at the ward and 14 accepted and completed the study. Nine of the patients were randomly selected for occupational therapy treatment. There was a wide age of range in both studies. Concerning sex there was a majority of women in Study I while the division between women and men was more equal in Study II (Table 2).

<table>
<thead>
<tr>
<th>Table 2. Description of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study I</strong></td>
</tr>
<tr>
<td>Participants</td>
</tr>
<tr>
<td>Women</td>
</tr>
<tr>
<td>Men</td>
</tr>
<tr>
<td>Age range</td>
</tr>
<tr>
<td>Mean age</td>
</tr>
<tr>
<td>Diagnosis of the participants</td>
</tr>
<tr>
<td>Time of treatment</td>
</tr>
</tbody>
</table>

Study contexts
In Study I the patients had experience of institutional care at two different wards. One ward was mostly for patients with affective disorders and the other ward was mostly for patients with psychotic disorders. The study was made in a 6-month period and during that time the two different wards had been united for some weeks because the staff had a vacation. Nine patients were committed to the Swedish Compulsory Institutional Psychiatric Act (LPT).

In Study II the patients were being treated in psychiatric institutional care at two different hospitals in Sweden. The patients were treated at wards for affective disorders. When the patient was discharged from the ward but was still on the sick-list, the treatment was continued with non-institutional care, so the patient was living at home, by himself or with relatives.
Questionnaire, assessments and data collection
In Study I a questionnaire was developed inspired by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). Seventeen statements in the questionnaire were constructed to describe how patients with experience of institutional care valued their opportunities to be active and to participate during their stay in the ward. Four of the statements dealt with the “Psychiatric care”, seven with “Environmental factors” and six with “Activities and Participation” (Table 1).

Two of the assessments used in Study II had a theoretical base in the Model of Human Occupation (MOHO) (Kielhofner, 2008). This is a conceptual practice model in everyday practice for occupational therapists. MOHO describes how volition, habituation and performance capacity integrate with the environment in order to understand daily occupation. The volition describes the process of choosing things to do in everyday life, and it includes concepts such as personal causation, interest and values, and habituation, referring to habits and roles. The concept of performance capacity describes ability for doing and comprehending subjective experience and objective physical and mental components. Skills are observable, goal-directed actions and are a function of the interaction between the personal components (volition, habituation, performance capacity) and the environment. The dimensions affecting the doing referring to the model are physical and social, cultural, economical and political conditions (Kielhofner, 2008). One of the assessments used is the Occupational Circumstances Assessment Interview and Rating Scale (OCAIR-S) (Deshpande et al, 2002; Henriksson & Haglund, 2005) and OSA (Occupational Self Assessment) (Hellsvik, 2000).

The original OCAIRS-S was developed for use in acute psychiatric settings and support discharge planning (Kielhofner, 2008). The OCAIRS-S is a semi-structured interview and can be used as an initial interview to determine whether the patient needs occupational therapy or not (Deshpande et al, 2002; Henriksson & Haglund, 2005). It collects information about the patient’s participation and ability to manage daily activities. On the rating form the occupational therapist is free to comment on the reason for the given rating on each item explaining why such a rating was made. Since the development of the OCAIRS, studies have been completed to examine its quality and these studies provide evidence of reliability and concurrent validity (Haglund & Henriksson, 1994; Lai et al, 1999) (Table 1).

The other assessment used is Occupational Self Assessment (OSA), which is a self-rating assessment and is designed to be a client-centred assessment. OSA gives information about
the patients’ perception of their occupational competence and which occupations they consider important to manage. The assessment has a two-part rating form; one where the patient responds to a statement about his occupational competence and one where he responds to the same statement indicating the importance of the statement. OSA also includes a rating of what statement the patient would most like to change; however this study does not use that rating. International studies confirm that the statements and ratings (competence and value) in OSA can be used as a valid and reliable measure of the patient’s occupational competence and the value of the occupation (Baron et al, 2006; Hellsvik, 2000) (Table 1).

The third assessment used in Study II was Comprehensive Psychopathological Rating Scale-Self-Assessment (CPRS-S-A). This is a self-rating scale for affective syndromes and covers depression, anxiety and obsessional symptoms. The assessment was developed on the basis of the original CPRS from 1978 (Åsberg et al, 1978) to a self-rating format, CPRS-S-A (Svanborg & Åsberg, 1994). The purpose of the assessment is to give a picture of the patient’s present sense of his condition over the previous three days. The CPRS-S-A has been developed since the end of the 1970s and further development has shown good values concerning reliability and clinical usefulness (Holmstrand et al, 2008) (Table 1).
### Table 1. Summary of the questionnaire and assessments

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Questionnaire inspired by ICF</th>
<th>OCAIRS-S</th>
<th>OSA</th>
<th>CPRS-S-A</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Collect information about how the patients valued their opportunities to be active and to participate in institutional care</td>
<td>Collect information about the patients’ participation and ability to manage daily activities.</td>
<td>Collect information about the patients’ occupational competence and importance of occupations they manage.</td>
<td>Collect information about the patients’ affective syndromes, such as depression, anxiety and obsession</td>
</tr>
<tr>
<td>Method</td>
<td>Self-assessment</td>
<td>Semi-structured interview</td>
<td>Self-assessment</td>
<td>Self-assessment</td>
</tr>
<tr>
<td>Number of items</td>
<td>17</td>
<td>14</td>
<td>29</td>
<td>27</td>
</tr>
<tr>
<td>Scale</td>
<td>4-point rating scale</td>
<td>4-point rating scale and column for comments</td>
<td>2-part rating form with a 3-point rating scale</td>
<td>7-point rating continuum</td>
</tr>
<tr>
<td>Validity</td>
<td>Evidence of concurrent validity</td>
<td></td>
<td>Valid measure</td>
<td>Good validity</td>
</tr>
<tr>
<td>Reliability</td>
<td>Evidence of reliability</td>
<td>Reliable measure</td>
<td></td>
<td>Good values on reliability</td>
</tr>
</tbody>
</table>

2. OCAIRS-S (Occupational Circumstances-Interview and Rating Scale) (Deshpande et al, 2002; Henriksson & Haglund, 2005).
3. OSA (Occupational Self Assessment) (Hellsvik, 2000).

The data collection in **Study I** consists of the questionnaire inspired by the ICF and developed for this study, and a semi-structured interview. The interview was based on an interview-guide also inspired by the ICF. The interview-guide was a more detailed version of the questionnaire and provided the possibility for the patient to verbally describe thoughts and opinions of the statements. The patients decided if they wanted to be interviewed at the psychiatric clinic or at home. At the end of the interview an activity schedule was used to sum up and confirm that the interviewer had collected information about the patients’ activities and participation during an ordinary day at the ward.

In **Study II** an occupational therapist interviewed the patient with the Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS-S) (Henriksson & Haglund, 2005) and then the patient filled in the self-rating assessments; the Occupational Self Assessment (OSA) (Hellsvik, 2000) and the Comprehensive Psychopathological Rating Scale (CPRS-S-A) (Svanborg & Åsberg, 1994).
Then, every fortnight after that the patients filled in the two self-assessments and the interview with the OCAIRS-S was repeated every month until the patient was discharged. The interviews were done at the hospital or in the patient’s home or, in exceptional cases, by telephone. In all there were 46 interviews with the OCAIRS-S, 75 self-assessments with OSA and 73 self-assessments with CPRS-S-A.

If the patient was offered occupational therapy treatment, the occupational therapist belonging to the ward was present during the OCAIRS-S interviews. The occupational therapists had the responsibility for developing a treatment plan and it was included in the case record. The treatment plans and the comments on the rating forms of the OCAIRS-S amounted to 109 pages.

**Data analysis**
The data of the questionnaire in Study I were evaluated with Stat View and Fischer’s exact test was used in the statistical analysis (Petrie & Sabin, 2005). The four-point rating scale (Totally agree, Partly agree, Partly disagree and Totally disagree) were dichotomized in two values; agree and disagree. The statistical tests were two-sided and the rejection limit for the null-hypothesis was set to $\alpha=0.05$.

The analysis of the interview started with transcription. Every interview was then read several times before the data analysis process started. The structure of the interview-guide inspired by the ICF was: personal factors, environmental factors and activity and participation, which became the basis for sorting and organizing the meaning units into aspects of these different areas. The analysis process continued with a refinement of the aspects and with comparison of the different statements from the patients on each aspect. Consensus was reached between the authors regarding the identified aspects. This was accomplished by continuous discussions between the authors (Polit & Beck, 2008).

To be able to compare the different assessments in Study II each item from CPRS-S-A was examined in order to identify which components in MOHO the item corresponded to and was most equal to. Two of the authors (Å.D. and L.H.) performed this stage. After discussion, agreement was reached and this resulted in a list, describing the items from CPRS-S-A in the components of MOHO. To increase accuracy in this process, triangulation was used as a technique (Kielhofner, 2006). An experienced occupational therapist with genuine knowledge of psychiatric care and MOHO independently examined and validated the list. There was
agreement on all items apart from one (“obsessive thoughts”). After discussion consensus was reached between the two authors and the third person regarding which component of MOHO the item corresponded to and was most equal to.

As mentioned earlier, the theoretical framework of the OCAIRS-S and OSA is the MOHO, and in their manuals it is specified which component of the MOHO each question or statement belongs to. Furthermore to be able to compare the OCAIRS-S, OSA and CPRS-S-A and see if there was harmony between them and if they could replace each other, the scale of the different assessments also had to be changed. They were dichotomized into “Resources” or “Problems”. In the four rating scales in the OCAIRS-S the two ratings “Competent” and “Some difficulties/challenges” was classified as resources, and in OSA “I do it well” and “I manage it”. In the CPRS-S-A grades 0 and 1 from the seven-point continuum were classified as resources.

Content analysis was used to analyze the written notes in the treatment plan and in the comments column on the rating form of the OCAIRS-S (Graneheim & Lundman, 2004; Polit & Beck, 2008). The focus in the material was on the manifest content; on what the text said, the visible and obvious component (Graneheim & Lundman, 2004).

A deductive approach in content analysis is based on an earlier theory or model (Elo & Kyngäš, 2007) and in this study it was the MOHO (Kielhofner, 2008). When using an existing theory or model the researcher identifies key concepts or variables such as initial coding categories and then operational definitions for each category are determined using the theory (Hsieh & Shannon, 2005). In this study the predetermined codes were volition, habituation, skills, performance capacity and environment.

The 109 pages of material from the written notes in the treatment plan and the notes in the comments column on the rating form of the OCAIRS-S were read several times to make sense of the data. Meaning units regarding problems and goals for each patient were highlighted. There were 98 different problems and 38 different goals presented in the treatment plans and on the rating forms of the OCAIRS. Using a template guide with the predetermined codes from the MOHO the next step was to code all highlighted passages.
Ethical considerations

Study I was approved by the Ethics Committee of the Faculty of Health Sciences in Linköping, Sweden (Dnr. 03-166), and Study II was approved by the Regional Ethical Review Board in Linköping, Sweden, (Dnr. M116-04).
Results

Study I, Activity and participation in psychiatric institutional care

Based on the predetermined aspects in ICF, the following results came up. According to personal factors those patients who were treated according to compulsory care (LPT) were generally more dissatisfied and valued institutional care less than the patients who had experienced voluntary care (HSL). The younger patients were also more dissatisfied and placed less value on the treatment they were offered.

In relation to the environmental factors the values of the working place influence the staff; from the methods of working to the attitudes in meetings with the patients. The results indicate that the reception from the staff was sometimes rather cold and patients experienced a feeling that they were insignificant, especially patients who had been treated at the ward many times and were treated according to LPT. The patients experienced a broad lack of continuity of the staff, especially when it came to the doctors. They were given different information from the staff about their treatment plan and the purpose of the care, which caused confusion for the patient. When the patient had a contact person from the ward or the collaboration with the doctor went well it influenced the feeling of support they had. They felt that someone was taking a real interest in their care. Many patients received support from people outside the ward and from their relatives during their institutional care, and 93.4% were satisfied with the support from their relatives.

Concerning activities and participation in the ward the patients thought it was important to have agreement on the reason for their institutional care. The patients’ expectations on the treatment disappeared since they never had a serious dialogue with the staff about the goals and intentions of their care and therefore they lost their motivation to be active in the treatment. The lowest rated item in the questionnaire was “the environment has stimulated activities”. Furthermore, the staff told the patients about activities that should take place soon, without any individual distinction, and this resulted in some patients feeling that they did not have the opportunity to take responsibility and participate in their own treatment.

In total a significant difference appeared in seven of 17 questions in the questionnaire for patients who were treated according to compulsory care. They were more dissatisfied with their opportunities to be active in and to participate in their own treatment. There was a significant difference in three questions between younger patients (aged 18-29) and the others. The younger ones were also more dissatisfied.
The study resulted in a checklist describing the patient’s perceptions of facilitators and barriers regarding activity and participation in the institutional ward. This checklist can be used for evaluating the care, and by extension result in treatment being offered that is more appropriate to the patient’s condition.

**Study II, Values of different assessments when measuring occupational performance in mental health**

All three assessments used in this study showed improvements for the patient during the treatment period, and the CPRS-S-A showed the highest improvement. Different symptoms related to depression disorder were reduced in the last measure, but the OSA and OCAIRS-S showed that the patients still had problems related to occupational performance. This indicates the importance of using both assessments for measuring occupational performance and assessments for measuring medical symptoms since they cannot replace each other or are not in full harmony with each other.

The CPRS-S-A and OSA, the self-assessments, showed more improvements for the patient than when using the OCAIRS-S interview. In order to get a broad picture of the patient’s occupational performance it is important to apply self-assessment, not only interviews. “Habituation” and “Volition” are the components in MOHO that the patients described as giving them the most problems and which at the same time were most important for them to manage in the first measure with OSA. “Skills” and “Performance capacity” were those components the patients had least problems with or which were not so important for them to manage. This supported the results of the CPRS-S-A in which the patients reported great improvement in both “Skills” and “Performance capacity”.

For those patients who were offered occupational therapy there were 98 different problems and 38 different goals described in their treatment plans. “Performance capacity” was the component that was most equal in numbers between identified problems and goals, and “Skills” was the component that included the most problems and had the fewest goals. There were also few goals related to the “Environment”.

In the written notes in the treatment plans and the notes in the comments column in the OCAIRS-S, problems related to self-confidence and lack of interest in different activities were reported. In addition, balance in everyday life was difficult for many patients and there were often goals related to obtaining balance in everyday life. The patients also identified
problems in the social environment; difficulties in asking for support from relatives or friends, little understanding, or getting criticism from their relatives or friends. In the treatment plans there were few identified goals related to the social environment. Several goals in the treatment plan were long-term goals.
Discussion

Patients treated according to compulsory care were generally more dissatisfied with the treatments they were offered than the patients who had experienced voluntary care. Even if the patient is committed to compulsory care or/and has a severe psychiatric disorder it is possible for the professions in psychiatric care to take into consideration the patient’s subjective experience of the situation. The occupational therapist has knowledge about the symptoms of the disorder. Based on the patient’s experience and the symptoms a rich dialogue can start about the goal of the treatment, and the patient can feel that the professional is showing interest in his experience. In Study I the patients who were committed to compulsory care felt that they were satisfied with the support outside the ward, such as that from the professionals in the community services. These professionals knew the patient in normal life and had built up a relationship and could treat him with respect.

When the patient has been committed to compulsory care it does not mean that he is deprived of all opportunities to make his own decisions. The psychiatric care should create the possibility for the patient to feel autonomy and give an opportunity for him to participate in the treatment plan (SOU, 2006). Molin (2004) describes formal belonging as a concept of participation. It has legal undertones and is something that can be sanctioned from a person with authority. In this case it is the chef physician who decides if the patients must be committed to compulsory care. The patient’s power to decide for himself outweighed by the law of compulsory treatment. O’Donoghue et al (2009) interviewed eighty-one people who had been admitted involuntarily to psychiatric care at a hospital in Dublin. That study showed that 72% of the patients believed that their involuntary admission was necessary at the time and this was associated with greater insight into their illness. Nearly 78% of the patients felt that the treatment they received had been beneficial. The patients included in Studies I and II were not investigated regarding their perceptions concerning their involuntary care after admission. This can be regarded as a limitation since a patient’s dissatisfaction may change after admission. Topor (2004) discusses the situation when patients are committed to compulsory care and they appraise to be dangerous to themselves or for other persons and they need extra staff to watch over them. This situation is often characterized by a passive attitude and the opportunity to build up a relationship with the patient is ignored.

The checklist that is described in Study I give a description of the patient’s perception of facilitators and barriers regarding activity and participation in the psychiatric institutional
ward. Generally, in health and medical care, perception of good care is when the patient’s dignity is respected, which also is included in the checklist. It is also important that one is believed and treated with sympathy. The patients want to have better information on their health condition, the diagnosis, the treatment and the consequences of treatment so they can participate more in the care (Schröder, 2006; Spri-rapport, 1999). Schön et al (2009) also describes which factors patients with mental disorders regard as decisive to their own recovery and what makes them beneficial. Cooperation with the professionals in psychiatric care played an important role in their recovery. The professionals who showed an interest and involvement in the individual and went beyond merely diagnosing the patient were those who were most helpful from the patients’ viewpoint. They did more for the patient than was regarded as standard practice, or they did other things apart from what was customary or expected.

Arvidsson et al (2008) discuss self-determination as one aspect of participation and recommend self-assessments to identify the subjective experience of the patient. One example of this in this thesis is the self-assessment OSA. In Sweden, OSA is translated as “Min mening”, i.e. the subjects meaning of occupational performance (Hellsvik, 2000). The OSA captures the patients’ perceptions of their own occupational competence, the occupations they consider important, and which occupations the patient wants to have treatment goals related to. How the occupational therapist uses the results from the self-assessment is of interest. Does the occupational therapist really use this subjective information to let the patient participate in the treatment planning process? It is crucial that these self-assessments are used as “living documents” to help the occupational therapist identify strengths and weaknesses of the patient, formulate short and long-term goals together with the patient, and determine outcomes of the treatment.

The social support from the relatives and professions outside the ward was very important for patients in the recovery process (Study I). In Study II the patients sometimes said that there were problems getting good support from the relatives. The relatives sometimes had limited knowledge about the symptoms of the disease and what kind of demands it placed on the patient. Recovery from mental illness is a social process and the supporting factors have to do with the quality of the social relationships (Schön et al, 2009). Social support is one aspect of participation and it includes support and helpfulness from one specific, significant person in the social network (Arvidsson et al, 2008). This thesis shows that relatives play a valuable
role in the recovery from a severe psychiatric disorder. When the relation is helpful and supportive it promotes the patient’s recovery but the relation can also be negative and invalidating for the patient. It is essential to discuss who has the preferential right of interpretation of the patient’s condition and what kind of demands should be made on occupational performance in daily life. Vessby and Kjellberg (submitted) maintain that “involvement in environment” is one dimension of participation and is where the social support can compensate for the effect of functional limitations. Related to Topor (2004) the relatives know that the person has not been a “patient” or “disabled” for ever. They can see the real person instead of the patient, and the most valuable forms of help from relatives in the patient’s recovery process are practical help, and emotional and social support.

The European Society for Quality in Healthcare (2009) has made a manifesto to accelerate patient participation in health and medical care. The strategies and tools which are discussed in the paper include the importance of education for both the patient and the relatives. One way to achieve this could be if the occupational therapists together with the patient invited the relatives to become involved in the treatment, to get information, to formulate goals and plan interventions. Sometimes the relatives may need support themselves to be able to be there and inspire hope in the patient.

For the occupational therapist in psychiatric care it is important to have knowledge of the occupational performance in relation to the medical symptoms of the disorder. These different perspectives are necessary when observing problems and deciding goals in the treatment plan. A study made by Skärsäter et al (2006) analyzed the level of severity of major depression and its relation to functioning and health-related quality of life. In that study the OCAIRS-S was used in relation to assessment for symptoms of depression with MADRS (Montgomery Åsbergs Depression Scale). The patients experienced that the depression caused a break in the structure of their lives and they questioned their old values and life-goals. Many everyday activities were affected. Their occupational functioning changed in a positive direction but when recovery was defined as remission, the functional capacity of the recovered patients was not fully restored. In Study II the patients rated item “Structure in daily activities” as one they had a “problem with” and which at the same time was “very important” for them. Study II and the study performed by Skärsäter et al (2006) showed that even if the symptoms of the depression were improved from the acute phase it took time for the patient to resume earlier habits and roles in their daily life.
Methodological considerations

Mixed method design is used in both Studies I and II. The questionnaire in Study I was combined with interviews and in Study II the self-assessments were combined with interviews. In Study I it was important to do the interviews related to the questionnaire to get a deeper understanding of the different aspects of participation in psychiatric care. The descriptions from the interviews of the different factors in the ICF and the quotations from the patients gave more detailed information. In the interview in Study I some patients said that the study gave them an opportunity to influence future care. It was important for them to make statements about the care and be interviewed regarding their experiences of the care. Thirty-three of 61 patients in Study I agreed to be interviewed. In Study II it was obviously important to combine the OCAIRS-S interviews with the self-assessments (OSA and CPRS-S-A). The patients rated more improvement with self-assessments than the occupational therapist recorded when she was interviewing the patients.

The activity schedule was a part of the interview in Study I and the purpose of it was to summarize what an ordinary day at the ward was like. The activity schedule was not described separately in the result of Study I. The information from the activity schedules was included in the result concerning engagement and responsibility in activity and participation. Because the interview was done after the patients had left the ward it was not a detailed version of an ordinary day the patient described. It was more like describing different kinds of activities they were offered during the treatment period.

Mixed methods research is becoming increasingly common in the social sciences and in the health care field but there are still no standard protocols on how to combine qualitative and quantitative analysis methods in a successful way (Creek, & Lougher, 2008; Mendlinger & Cwikel, 2008; Polit & Beck, 2008).

When using content analysis it is common to talk about transferability of the study, which means whether the findings can be transferred to other settings or groups (Graneheim & Lundman, 2004). In Study I, patients committed to compulsory care were included. This thesis shows important factors for participation, namely the possibility to use self-assessment of both symptoms of the disease and occupational performance, which creates opportunities for the patient to influence the treatment plan. Since it was possible to use self-assessments and interviewing patients with severe psychiatric disorders the findings may be transferable to other contexts, for
example non-institutional care, social psychiatry, and with other groups of psychiatric patients.

In Study I the interviews were analyzed qualitatively. In the article there is no mention of what kind of qualitative approach was used. It can be discussed if the approach could have been labelled as latent content analysis. The focus was on the relationship between the aspects and an interpretation of the underlying meaning of the text in the interviews (Graneheim & Lundman, 2004).

Concerning the instruments used in Study II, they were well tested and commonly used in the area of concern, especially the OCAIRS-S and CPRS-S-A. The CPRS-S-A has been developed over about 30 years and covers symptoms for patients with depression. Nowadays, it is also possible to have CPRS-S-A administrated by computer and the results of the test are summarized for the patient and therapist. It is easy to learn how to do this and does not take long to do. The MOHO-based instruments (OCAIRS-S and OSA) demand that the occupational therapist is familiar with the Model of Human Occupation (Kielhofner, 2008). According to Haglund et al. (2000) the occupational therapists in psychiatric care most frequently use the Model of Human Occupation (MOHO) as a practical model in their daily work and therefore many are familiar with it. There is also much research based on the MOHO, which constitutes useful evidence concerning the model (Kielhofner, 2008). The OCAIRS-S interview in Study II took nearly an hour to perform, and the occupational therapist must have time after the interview to conduct the assessment. However, the results of the assessments gave the occupational therapist broad information about the patient’s strengths and weakness, which was necessary for the treatment planning process. The OSA did not take too long to complete. The patients could fill in the assessments by themselves at home and take it back to the therapist.

To interpret the result of the OSA and the OCAIRS-S and establish the priority of different goals demands a dialogue between the patient and the occupational therapist, which promotes participation in the treatment planning process. Investigating the assessments used in Study II is important to improve evidence-based practice in psychiatric care.
Implications for practice
The purpose of the compulsory care is to influence the patient to voluntary care and obtain the support he needs. Regardless of what kind of law the patient is treated under, the occupational therapist should meet each patient and find out what kind of problems, goals and values in occupational choices he has. It is important to capture the subjective dimension of participation, which can be done with self-assessments and interviews.

It is vital to use different kinds of assessments in psychiatric care. The occupational therapist must get an understanding of occupational performance for each patient and combine this information with an understanding of the medical symptoms. It seems to be useful with self-assessments to get an understanding of the patient’s need of support, but the most important factor in getting participation for the patient in the treatment plan is how to use the information gathered from the self-assessments to formulate goals and determine outcomes of the treatment.

In Study I a checklist is developed with factors for facilitating participation in psychiatric institutional care. Professionals in psychiatric care can use this checklist to evaluate if the ward facilitates or hinders participation.

Implications for further research
It is important to investigate further dimensions of participation for patients in psychiatric institutional care. In Study I some factors in institutional care were found to describe how the patient experiences the opportunity to participate in his own care. The study has resulted in a proposal for a checklist which is built on the patients’ subjective experience. This is a first step in building a checklist inspired by the ICF for evaluation of participation in psychiatric institutional care at a local level, but further research must be carried out in order to identify the scientific standard of the list.

Patients in need of support from psychiatric care appreciate and are dependent on their relatives to a great extent. Research on recovering from psychiatric disorders has established that the social process, the quality of social relationships, is crucial in the treatment. How occupational therapists inform the relatives about the patient’s condition and let them participate in the treatment is a question for further research, and by extension, for evidence based practice.
Conclusion

This thesis clarifies the importance of identifying the subjective experience of participation with self-assessments and interviews in the treatment planning process. It is also valuable for the occupational therapist to use assessment for both occupational performance and medical symptoms to get an overall picture of the patient’s daily activities. This thesis shows a discrepancy between the occupational performance and symptoms of the disease. It is obvious that the patients medical symptoms are reduced earlier than perceived problems in occupational performance.

Participation can be considered as a process, and different degrees of participation can be described. Participation for some patients in psychiatric care was about having control and goals for the near future, and for other patients it involved participating in formulating goals for the future. Regardless of what kind of law the patients are treated under or the degree of the disorder, all patients have the right to participate in their own treatment plan.

The social environment is important for participation. Support from relatives and other professionals outside the ward are important factors for the patient’s participation in the treatment. With self-assessments and interviews the occupational therapist can identify the value of the relatives’ support in the recovery process but can also discover difficulties such as when patients say that the relatives do not have enough knowledge about the disorder. It is necessary that the occupational therapist involve the relatives to a greater extent. Nevertheless it is crucial that relatives involvement in the treatment occurs according to the patient’s condition.
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