Occupational performance in individuals with severe mental disorders

Assessment and family burden

BY

ANN-BRITT IVARSSON
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ABSTRACT

The overall aim of the present thesis was three-fold. The first was to study occupational performance in individuals with severe mental disorders and their experiences of occupational therapy, the second to study experienced burden of family caregivers and the third to test the validity and the homogeneity of assessment tools in this area. The samples consisted of individuals with severe mental disorders participating in organised occupations (n= 112), occupational therapy records (n=64), occupational therapists working in mental health care (n=7) and family caregivers of individuals with severe mental disorders (n=256). Data were collected by questionnaires, structured and narrative interviews, observations and occupational therapy records. Individuals with severe mental disorders reported problems related to leisure and work activities and the occupational therapists recorded problems concerning how to organise and structure occupational performance. Individuals functioning on a high cognitive level experienced problems related to work and productive activities. Participation in occupational therapy strengthened their confidence in their own ability. The “Experience of Occupational Performance Questionnaire” (EOPQ) was developed from data on the experiences of women participating in occupational therapy. A principal component analysis gave seven factors with acceptable homogeneity. There is a need for assessment tools to evaluate occupational therapy. The EOPQ represents an attempt to fulfil this need. Family caregivers experienced limitations of daily activities as a burden. The ability to perform daily activities was studied from three perspectives, the individuals’, the occupational therapists’, and the experienced burden of the family caregivers. These perspectives are complementary and thus necessary for planning and implementation of individually adapted occupational therapy as well as for the evaluation of outcomes.

Key word: Mental disorders, occupational performance, activities in daily life, factor analysis.

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To my family
This doctoral thesis consists of the present summary and the following papers, which are referred to by their Roman numerals.


V. Ivarsson, A., Sidenvall, B., Carlsson, M. Validation of the Burden Assessment Scale and family caregiving for individuals with severe mental disorders. Manuscript.

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INTRODUCTION

The present thesis focuses on individuals with severe mental disorders, their performance of activities in daily life and on occupation as a means in their treatment. The occupational therapy profession upholds the assumption that performance of activities is a basic human need that allows humans to act and master their environment (Kielhofner, 1995; Levine & Brayley, 1991; Wilcock, 1993). An additional assumption is that engagement in activities gives the person a sense of competence and knowledge about her/his own limitations (Fidler & Fidler, 1978; Wilcock, 1998a). The use of purposeful and meaningful occupations is also supposed to maintain and enhance health (McLaughlin Gray, 1998; Trombley, 1995). Studies support these assumptions but additional research is needed (Christiansen, Backman, Little, & Nguyen, 1998). Needs for lifelong care and support are common among individuals with severe mental disorders in domains such as activities in daily life (Bengtsson-Tops, 2001; Sandlund, 1991). The responsibility of the families has increased as a consequence of the deinstitutionalization of mental health care (Howard, 1994; Loukissa, 1995). More knowledge of how to reduce the family’s burden is still needed (Rose, 1998).

Individuals with severe mental disorders

In Sweden, approximately 9-18% of the inhabitants suffer from mental illness (SOU, 1992). It has been estimated that approximately 0.65% (40,000 to 46,000) of the adult population have a severe mental disorder (SOU, 1998). There are approximately equal numbers of men and women and half of them are under the age of 45. About 70% live in their own home and about a fifth is married or cohabitant (Widerlov, Stefanson, & Cullberg, 1992; SOU, 1998; Borga, ).

Various terms have been applied to describe individuals who do not recover from their mental illness. Concepts such as mentally disabled (Grunewald, 1999; SOU, 1998), chronic mentally ill (Minkoff, 1978) and individuals with severe mental disorders (Topor, 2001) are used in the literature. In this thesis the concept of severe mental disorders is used as a term to denote problems in important life areas like
personal care and leisure time and/or work activities due to a mental illness.

Regardless of the cause of the mental illness, many of these individuals have problems that diminish their ability to function in the community (Grunewald, 1999; SOU, 1993a) and they often become socially isolated (Halford & Hayes, 1995). They also have problems to perform activities in daily life (Boronow, 1986; Henry & Coster, 1996).

Cognitive impairments have been found to limit these individuals’ performance of daily activities (Allen, Erhart, & Blue, 1992; APA, 1994). In addition, individuals with severe mental disorders have been found to have lesser motor and process abilities when performing personal daily activities than do non-disabled individuals (Girard, Fisher, Short, & Duran, 1999; Pan & Fisher, 1994). It has been demonstrated that individuals with severe mental disorders have a restricted sense of themselves as active agents (Davidson & Strauss, 1992) and are less autonomous in leisure activities and socialization compared to a non-disabled sample (Weeder, 1986). Further, they have been found to have a small number of roles such as being a friend, worker and hobbyist (Dickerson & Oakley, 1994; Prusti & Brännholm, 2000).

**Daily activities and health**

When people have the ability to meet the challenges of daily activities, this contributes to the maintenance of their health (Christiansen et al., 1998; Wilcock, 1998a). In occupational therapy, the focus is on the individual’s ability and on the possibilities that the environment offers them to perform daily activities in spite of a disease or an injury (Christiansen & Baum, 1991; Rogers, 1981). Occupational therapy is thus described as a health oriented, rather than a medical discipline (Borell, 1993; Kielhofner, 1997; McLaughlin Gray, 2001).

Activities in daily life include things human do daily (Clark, Wood, & Larsson, 1998; Törnquist, 1995). Daily activities have been categorized and described in several ways in the occupational therapy literature (Mosey, 1986; Reed & Sanderson, 1992). The most common concepts used are daily living tasks, play and work (Kielhofner, 1995). The American Occupational Therapy Association (AOTA) has chosen the concepts Activities of Daily Living (ADL), Play and Leisure Activities
(PLA) and Work and Productive Activities (WPA) to categorize daily activities in human life (AOTA, 1994). No uniform terminology for the categorization of daily activities is available in Sweden (Persson, Erlandsson, Eklund, & Iwarsson, 2001).

In the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), the main focus is on components of health. The ICF consists of two main parts. The first part of the classification is Functioning and Disability, comprising the two components of Body Functions (physiological and psychological) and Structures (anatomical parts) and Activities and Participation. Activity is the individual’s execution of a task or an action. Participation is the individual’s involvement in life situations. The individual’s difficulties to execute a task or an action or problems that an individual may experience in a life situation are described as activity limitation or participation limitation. The second main part of the ICF is the contextual factors divided into the two components environmental (physical, social and attitudinal) and personal factors (the particular background of the individual’s life and living).

In the ICF, the focus on participation in various activities is an important component of health which has been found to correspond well with the main focus of occupational therapy (McLaughlin Gray, 2001).

**Occupational performance as a therapeutic mean**

In occupational therapy, the focus is on enabling occupational performance in individuals with activity limitations or participation restriction, using occupations as a therapeutic mean. The aim is to help individuals help themselves through their own active efforts (Nelson, 1996; Rebeiro & Miller Polgar, 1998; Wilcock, 1998b). Reilly (1962 p. 88) stated, “The man, through the use of his hands as energized by mind and will, can influence the state of his own health”.

The roots of the therapeutic use of occupation can be found in the history of treatment for individuals with mental illness. During the 19th century, physicians recognized that activities might be used as a form of treatment to establish daily routines in order to reintegrate these individuals into society (Palmborg, 1940; Pinel, 1948; Sondén, 1931). The moral treatment approach established by Turkey in Britain
was based on the belief that self-discipline and hard work were the keys to cure the insane (Bing, 1981; Peloquin, 1989). According to Stein and Cutler (1998), Kirkbride assumed that cure could be expected for the insane when highly structured activities were used. In the USA, Meyer (1921/1977) discovered that engagement in activities developed skills and habits of normal lifestyles and prevented faulty thinking among individuals with mental illness. In Sweden, Westlund stated that suitable activities cured patients, in contrast to idleness which had been a psychiatric treatment method during the first years of the 20th century (Palmborg, 1940).

Clark Slagle, one of the founders of occupational therapy, developed training programs for individuals with mental illness that focused on habit training, spanning 24 hours a day. The aims of these programs were to overcome, modify or construct daily habits and thus maintain health (Bing, 1981; Kielhofner & Burke, 1977).

In the second part of the 20th century, there was a growing interest to understand and explain the use of occupations as a therapeutic mean (Björklund, 2000; Borell, 1993; Reilly, 1962; Rogers, 1981). Several theories or approaches from related disciplines have been used to explain how occupations can be used as a mean in therapy (Kielhofner, 1997; Levine & Brayley, 1991). The psychoanalytical approach has been used as a conceptual model to describe the symbolic meaning of performing occupations (Azima & Azima, 1959; Azima & Wittkower, 1957; Fidler & Fidler, 1954; Mosey, 1981; Saint-Jean & Desrosiers, 1993). According to object relation therapy, occupations may be used to facilitate communication and thus reflect the individual’s problems nonverbally (Eklund, 1993; 2000). According to the behavioural approach, based on principles of learning theory, the occupation is analysed and broken down into isolated tasks, precise information about performance is given and the task is taught. Positive reinforcement from the occupational therapist is used to modify a previously specified behavioural performance (Hagedorn, 1997; Hickerson Crist, 1986). The cognitive behavioural approach is based on the assumption that thoughts are connected with emotions and influence behaviour. Activities such as diary writing and role-playing are used to replace ineffective
behaviours. Within this approach, the therapeutic process includes teaching positive and effective cognitive strategies (Bruce & Borg, 1987; Hagedorn, 1997).

Knowledge from other disciplines and assumptions and research on occupational therapy models have been used to develop occupational therapy (Allen, 1985; Eklund, 1993; Kielhofner, 1997). In the development of these models, such as A Model of Human Occupation (Kielhofner, 1995) the Canadian Model of Occupational Performance (CAOT, 1997) and the Life Style Performance Model (Fidler, 1996), an increasing interest has been noted in using occupation to influence health (Christiansen et al., 1998; Emerson, 1998; Wilcock, 1998a; 1998b; Yerxa, 1988). Knowledge in this area is built on assumptions and clinical experience but only on limited research (Gerhardsson & Jonsson, 1996; Law, Steinwender, & Leclair, 1998; Rebeiro, 1998; Rebeiro & Cook, 1999).

Wilcock (1993) argued that humans have a biological need for occupations, and she stated that without engagement in occupations, human beings can not stay healthy. In a review of health and social science literature, Law et al. (1998) found moderate to strong evidence that occupation has an important influence on health. Most of the studies found had been completed with individuals without disabilities. These authors also found that removal of activities lead to increased stress, psychological changes and health deterioration. Among students, Lo (1996) found that active participation in daily activities had an effect on subjective well-being. In addition, Harris et al. (1992) found that active participation had a substantial influence on perceived health. In a study among 97 individuals discharged from rehabilitation centers, Osberg et al. (1987) found that participation in household and community activities was a significant predictor of self-reported quality of life.

The concepts purposeful activity and occupation

“Purposeful activity” and “occupation” have been used interchangeably to describe the unique focus of occupational therapy, but there is no consistency in their use (Darnell & Heather, 1994; Golledge, 1998). The concept of purposeful activity has been used interchangeably with the concept of occupation (Fidler, 1996) but the concept of occupation has been advocated by some authors (McLaughlin Gray, 1998;
Trombley, 1995). Golledge (1998) argued for this by distinguishing between activity, purposeful activity and occupation in the following way. Activities are those that do not have meaning and relevance to the individual’s life. Purposeful activity is a mean used with an expecting outcome such as enhancement or facilitation of performance in e.g. personal care (Golledge, 1998; Nelson, 1996). According to Golledge (1998), purposeful activities can be divided into two categories. The first is used in therapy programs on the ground that everyone needs to perform such activities, but they do not have real relevance for independent functioning in the life of a specific individual. The second category includes activities that can be regarded as purposeful but not necessarily as meaningful, because they have so far not been a part of the individual’s lifestyle. The characteristics of the concept of occupation is meaningfulness and purposefulness with a focus on the individual in her or his context. This agrees with Fisher (1998) who states that occupation is both purposeful and meaningful to the person who engages in it. Nelson (1988; 1996) on the other hand, describes the concept occupation as a relationship between occupational form and occupational performance. Occupational form is “the composition of objective physical and sociocultural circumstances external to the person that influences his or her occupational performance” (Nelson, 1996 p.776). Physical circumstances include e.g. material, environmental surroundings and human beings. The sociocultural circumstances include symbols, norms, roles and typical uses. Occupational performance is the doing, the action, the active behaviour, or the active responses exhibited in the context of an occupational form (Nelson, 1988; 1996).

Individual purposes and subjective experiences of meaning are essential when using occupation in therapy (Clark et al., 1997; Darnell & Heather, 1994). The meaningfulness aspect of occupation may be the emotional value that an interesting and creative experience offers individuals (Ayers, 1958). Meaningfulness may also stem from familiarity with the occupation or its power to arouse positive associations, or give approval from others who are respected and admired (Cynkin & Robinsson, 1990). A theoretical structure for describing the meaning of occupations has been presented by Persson et al (2001). The concept of occupational value was introduced as a prerequisite for meaning. The spectrum of occupational values can be
divided into concrete values, symbolic values and self-reward values. The meaningfulness of occupations is the integration of these value perspectives, presupposing that occupations are integrated parts of the individual’s occupational continuity (Persson et al., 2001). The theory of flow (Csikszentmihalyi, 1990) has been considered relevant by occupational therapists for exploring, describing and understanding how individuals experience the performance of occupations. If the proper challenges are inherent in an occupation and if it matches the individual’s own perception of her/his capabilities, it can be used in the individual’s therapy (Carlson & Clark, 1991; Emerson, 1998; Rebeiro & Miller Polgar, 1998).

**Studies of occupation as a therapeutic mean**

Occupational therapy practice is based upon the belief that the use of occupation can promote health of individuals with activity limitations. Occupational therapists analyze both the individuals’ ability to carry out various occupations and the demands that a particular occupation makes on the performer. Further s/he designs the occupational form together with the individual with the purpose to achieve a goal. The therapist provides the opportunity to engage in the potentially therapeutic occupation (Creighton, 1992; Nelson, 1996; Trombley, 1995).

Some studies support the assumption that the use of occupations for individuals with mental illness contributes to health. Eklund (2001) found that the number of valued roles, such as being a friend, a hobbyist and/or a worker increased significantly from admission to discharge and follow-up among individuals with mental illness who had participated in an occupational therapy group. Using an experimental design, DeCarlo and Mann (1985) found a significantly higher level of interpersonal communication skills among the individuals who participated in an occupational therapy group compared with a group that received verbal therapy. However, none of the groups differed significantly from a control group receiving milieu therapy. Webster and Schwartsberg (1992) performed a post intervention ranking of curative factors of occupational therapy groups using Yolam’s Q sort questionnaire. They hypothesized that there would be a differences in the evaluation of the therapeutic factors between an occupational group and psychotherapy groups.
The hypothesis was rejected. In a qualitative study of individuals with severe mental disorders (Eklund, 1997), occupational treatments were found to give feelings of being occupied, experiences of creativity and joy and new skills among individuals with mental illness. Other outcome factors found in qualitative studies are relaxation, increased motivation, development of self-identity and increased self-efficacy (Mee & Sumsion, 2001; Rebeiro & Allen, 1998; Rebeiro & Cook, 1999; Strong, 1997; Temple & Robson, 1991). Champney and Dzurec (1992) found significant associations between involvement in activities and satisfaction. Individuals with severe mental disorders who were involved in activities were found to have a greater increase of satisfaction compared to individuals having nothing to do. These findings can be summarized by a quotation of an individual with mental illness who participated in Rebeiro’s and Cook’s investigation (1999, p.178) “engaging in occupation provides a positive focus for one’s attention and thinking; provides a structure or balance and normalizes one’s sleep and wake cycles, provides a sense of purpose and meaning to one’s existence”. Findings in these descriptive studies indicate that occupations as a therapeutic mean and health aspects such as increased valued roles, skills, self-efficacy and wellbeing are related in individuals with severe mental disorders. But there is a lack of research examining the relationship between occupation as a therapeutic mean and health (Law et al., 1998) and also a lack of research using controlled designs examining the effects of occupation on health.

In Sweden, occupations are used as a means in the treatment of individuals with mental disorders both in psychiatric care organized by the county councils and in activity-settings arranged by local municipalities. The municipal social- and welfare authority should supply individuals with severe mental disorders, who no longer are in need of continuous care, with meaningful occupations to improve their living conditions (SOU, 1993a). To fulfil this responsibility, the municipalities arrange community-based activity settings. In a Swedish investigation (SOU, 1999), it was found that about 16,000 individuals with severe mental disorders attended these settings, but it was calculated that twice as many were in need of such organized activities arrangements (SOU, 1999). Other professionals such as nursing assistants
and social workers also use occupations in the treatment of individuals with severe mental disorders.

**Assessment and documentation of occupational performance**

Individual abilities and limitations may be viewed and described from the individual’s own perspective or as based on professionals’ observations and judgment.

Although several instruments have been developed to assess occupational performance, the majority of occupational therapists use informal interviews for such assessment (Neistadt, 1994; Stein & Cutler, 1998). Most of the instruments have been developed in the USA and Canada and some have been translated and validated for use in Sweden (Bernspång, 1999; Haglund & Henriksson, 1994; Wressle, Samuelsson, & Henriksson, 1999). There is a need for research concerning the reliability and validity of assessment instruments regarding occupational performance to be used among individuals with mental disorders (Haglund, 1997).

In order to develop effective occupational treatments of individuals with severe mental disorders, it is necessary to take their own perspective into consideration. (Lang, Davidson, Bailey, & Levine, 1999; Law, Baptiste, & Mills, 1995; McColl, 1994; Mosey, 1986). Several authors have stressed the need to regard individuals with severe mental disorders as key informants in their own treatment (Davidson & Strauss, 1992; Hansson et al., 2001; Tanzman, 1993). In occupational therapy, this has been called client-centered practice (Rebeiro, 2000). The individuals’ with severe mental disorders rediscovery and reconstruction of an enduring sense of self as an active and responsible agent has been found to provide an important aspect of improvement (Davidson & Strauss, 1992). It should be noted that staff and individuals with severe mental disorders differ in their judgment regarding the needs of the latter (Honkonen, 1995). Lang et al. (1999) and Hansson et al. (2001) found that individuals identified less self-care needs and more needs related to daytime activities compared to the staff. On the other hand, Slade et al. (1996) demonstrated similar ratings by these two groups. The discrepancies have been related to different perspectives, and different knowledge of available resources or to a lack of insight
among the individuals with mental disorders (Bengtsson-Tops, 2001; Dickerson, Boronow, Ringel, & Parente, 1997). In any case, dysfunction is an aspect of personal experience rather than an objective fact (McColl, 1994) and the individual’s own perspective on occupational performance should not be regarded as interchangeable with assessments by the staff (Hansson et al., 2001).

The professional perspective on patients’ occupational performance should be documented in their medical records (Foto, 1996). Care professionals in Sweden, including occupational therapists are required to document the treatment process for individuals participating in occupational therapy (SFS, 1985). The records should contain “details of the patient’s history, general indicators, diagnosis and reason for referral, and details of treatment interventions carried out and planned” (SOSFS, 1985 p.188). This parallels the occupational therapy treatment process including the goals of treatment, treatment intervention and outcome of treatment (Creek, 1997; Mosey, 1986; Reed & Sanderson, 1992; Söderback, 1991).

In order to meet the need for a comprehensive system to analyze occupational therapy documentation for individuals with severe mental disorders, the Template of Occupational Therapy (TOT) was constructed (Ivarsson, Söderback, & Stein, 1998) (See Appendix). This method will be employed in the present study.

Assessment of cognitive problems in individuals with severe mental disorders

Cognitive problems are common among individuals with severe mental disorders (APA, 1994). Some, such problems are related to occupational performance and affect the individuals’ caring for themselves in everyday life (Allen et al., 1992; David & Riley, 1990; Velligen et al., 1995). Several methods have been developed to assess cognitive functioning. They usually concentrate on language skills or verbal responses such as the Mini-Mental Status Exam (Folstein, Folstein, & McHugh, 1995) or the Wechsler Adult Intelligence Scale (Wechsler, 1981). Allen (1985) stated that the ability to perform routine tasks is a reflection of the individual’s cognitive ability. She developed a cognitive approach, the Cognitive Disabilities Model (CDM) based on neuroscience elaborated by psychologists Vygotsky and Leontyev and influenced by Piaget’s developmental theory (Allen 1995). A hierarchy of six
cognitive levels is proposed in the model to describe progressively severe cognitive impairment (1 = severe cognitive impairment, 6 = normal cognition) (Allen, 1985; Allen et al., 1992; Allen & Allen, 1987). Each level reflects a person’s ability to perform familiar activities, type of assistance needed and treatment necessary to relearn tasks. Attention to motor actions, sensory cues and sensorimotor association are the main attributes of each cognitive level. Motor actions are observable activities, which are elicited by sensory cues and guided by sensorimotor association (Allen, 1995; David & Riley, 1990). At levels one and two, individuals are not able to handle objects and level six represents a theoretical norm for independence in performing activities for community living. The Allen Cognitive Level Test (ACLS) (Allen, 2000) is a brief tool based on the CDM. Levels three to five of the six CDM levels are represented in the ACLS. At level three, the individual performs manual actions spontaneously. These actions are often repetitive, not goal-directed and the individual needs guidance to complete a task successfully. At level four the individual’s behaviours are goal-directed. At this level the individual’s attention is captured by visual as well as tactile cues, but s/he needs situation-specific supervision. At level five the individual uses complex visual cues and exploratory actions. However, situations that require planning, organization and deductive reasoning are usually not handled effectively and the individual needs supervisory assistance (Allen, Erhart & Blue, 1992; Penny, Mueser & North, 1995). The ACLS is intended to give a quick estimate of the individual’s capability to follow verbal directions with demonstrations, and how s/he solves problems involving a progressively more elaborate task.

Caregiver burden and its assessment

The responsibility of families of individuals with mental illness has been recognized and studied during the last 50 years and found to affect several areas in the daily life of the families. Families must not only provide basic services but also handle disruptive symptoms (Howard, 1994; Loukissa, 1994; 1995; Rose, 1996; Tessler & Gamache, 1994). These effects have been called family or caregiver burden (Jones, Roth, & Jones, 1995; MacCartey et al., 1989). Two types of burden have been
distinguished: objective and subjective (Hoening & Hamilton, 1966; Platt, 1985; Schene, 1990). Objective burden refers to the costs for the family and includes aspects such as household routine, family relations and leisure time. Subjective burden refers to the distress experienced as a result of the caring, such as guilt, anger and feelings of loss (Loukissa, 1994; Schene, 1990).

Caregiving is complex and multifaceted and different intervention approaches aimed at reducing caregivers’ burden have been investigated (Jones, Roth & Jones, 1995; Rose, 1998). Psychoeducational programmes for caregivers have included information about communication and problem-solving strategies aimed at reducing expressed emotions, such as critical remarks, hostility and emotional overinvolvement. These interventions decreased the subjective burden but the objective burden was found to be unchanged (Orhagen & dElia, 1992). According to a study by Halford and Hayes (1995), social skills training improved social skills among individuals with severe mental disorders and reduced the family burden. Caregivers in a study by MacCartey et al (1989) reported that when the caretakers were offered day care, this helped the families to stop worrying during the day. They could pursue their own preferred activities and day care also helped the caretakers to structure their time.

There are number of tools for the assessment of caregiver burden (Loukissa, 1995). Some require interviewers (Platt, 1985), and some combine questions about burden with questions about caregiver’s physical and mental health (Hoening & Hamilton, 1966). The Burden Assessment Scale (BAS) was developed (Reinhard et al., 1994) to assess objective and subjective consequences of caring and the outcomes of support programs in terms of burden reduction. The content validity of the BAS was tested by a caregiver advisory group of six family members (Reinhard et al., 1994). Using data from two samples, the factor structure of the BAS was found to be fairly stable (Reinhard et al., 1994). The two samples yielded substantially the same factors: Disrupted Activities, Personal Distress, Time Perspective and Guilt. A distinction was found in one factor. In the first sample, the factor Basic Social Functioning was identified but in the second, the analysis identified the factor Worry. No Swedish studies have been carried out of the validity of the BAS.
RATIONALE FOR THE STUDY

Studies have shown that mental illness results in problems to perform daily activities. However, the experience of performance of daily activities has rarely been studied. To encourage an active role for individuals with severe mental disorders in treatment, it is important to take their perspective in consideration in research as well as clinical practice. Thus, the present thesis aims to elucidate that perspective on the performance of activities.

The content of occupational therapy is routinely assessed by occupational therapists but their documentation of such information has seldom been studied systematically. Knowledge about the content of such documentation should contribute insight into professionals’ perspective on occupational therapy practice.

Occupation has been found to contribute to health in individuals with severe mental disorders. However, there is still lack of empirical data to support this notion. Also most of the occupation therapy literature in this area concerns assumptions based on occupational therapy theory. The present thesis aims to contribute knowledge on the experiences of participation in occupational therapy of individuals with severe mental disorders.

Also, there is very little research on family caregiver burden. The present thesis aims to evaluate a Swedish version of an instrument for assessment of family burden and to study that type of burden in families of individuals with severe mental disorders.
AIMS

The overall aim of the present thesis is three-fold. The first is to study occupational performance in individuals with severe mental disorders and their experiences of occupational therapy. The second is to study the experienced burden of family caregivers of such individuals. The third is to develop and test psychometrically some assessment tools in this area.

The specific aims are:
To describe self-perceived capability to perform daily activities and functional cognitive ability. (Study I)

To relate differences in self-perceived capability to the demographic variables gender, educational level, age, civil status and living conditions and to functional cognitive ability (Study I)

To analyze the content of occupational therapy records documenting treatment goals, interventions and outcomes for individuals with severe mental disorders (Study II).

To investigate the experience of occupational therapy among individuals with severe mental disorders (Study III).

To develop an instrument for assessment of experienced occupational performance and to test the construct and content validity and homogeneity of this tool (Study IV).

To test the construct validity and the homogeneity of the Swedish version of the Burden Assessment Scale (BAS) and study perceived burden in daily life among family caregivers of individuals with severe mental disorders (Study V).
METHODS

An overview of the periods of data, collection, samples, methods of data collection and analysis of data in Studies I-V is presented in Table 1.

<table>
<thead>
<tr>
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<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
<th>Study V</th>
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<tr>
<td><strong>Design</strong></td>
<td>Correlational</td>
<td>Explorative</td>
<td>Explorative</td>
<td>Correlational</td>
<td>Correlational</td>
</tr>
<tr>
<td><strong>Participants/Documentation</strong></td>
<td>Individuals with severe mental disorders</td>
<td>Occupational therapy records</td>
<td>Women with severe mental disorders</td>
<td>1) Individuals with severe mental disorders 2) Occupational therapists</td>
<td>Caregivers of individuals with severe mental disorders</td>
</tr>
<tr>
<td><strong>Samples (Number of participants/Documentations)</strong></td>
<td>51</td>
<td>64</td>
<td>6</td>
<td>1) 106 2) 7</td>
<td>256</td>
</tr>
<tr>
<td><strong>Methods of data collection</strong></td>
<td>Questionnaires Interviews Observations</td>
<td>Collection of occupational therapy records</td>
<td>Interviews</td>
<td>Questionnaires</td>
<td>Questionnaires</td>
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<td><strong>Methods of data analysis</strong></td>
<td>Wilcoxon-Mann-Whitney-Test Kruskal-Wallis-One-Way Analysis of Variance</td>
<td>Coding Content analysis</td>
<td>Phenomenological analysis</td>
<td>Principal Component Analysis Cronbach’s alpha coefficient Student’s t-test Index of Content Validity</td>
<td>Principal Component Analysis Cronbach’s alpha coefficient Wilcoxon-Mann-Whitney-Test Kruskal-Wallis-One-Way Analysis of Variance</td>
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**Samples**

Four samples were included in the studies;

1. Individuals with severe mental disorders participating in organized occupations (Studies I, III and IV),
2. Occupational therapy records (Study II),
3. Occupational therapists working with individuals with severe mental disorders (Study IV),
4. Caregivers of individuals with severe mental disorders (Study V).

*Individuals with severe mental disorders*

The criteria for inclusion to individuals in Studies I, III and IV were severe mental disorder and participation in occupations outside home. Each respondent received information about the specific study and that it concerned their experiences of consequences of having a mental disorder.

In Study I, participants were recruited by the staff in 13 of 17 identified activity settings in five municipalities in a county council in central Sweden. In four settings, the staff declined participation, in three they did not want to give the individuals information about the study because they thought they did not want to answer questions about their situation, and in one case the staff reported that the individuals had recently participated in another investigation. About 200 individuals with mental disorders took part in occupations in included activity settings and 54 of these were willing to participate. No information concerning age, gender, civil status, living situation or diagnosis was available regarding the individuals who declined participation. Three respondents interrupted their participation why 51 participated in the study.

In Study III, participants were recruited by occupational therapists in psychiatric care in a county council in central Sweden. Six women participating in occupational therapy took part.

In Study IV, 106 participants were included, and 51 of these also participated in Study I. The remaining 55 participants, out of 110 eligible respondents, were recruited by their relatives who took part in Study V (see below). A comparison between the participants included by the staff and by the relatives showed some differences. Fewer were married or lived with a partner ($\chi^2 = 6.119; \text{df} = 1; p = 0.013$) among those who were included by their relatives compared to the group recruited by the staff. There were no gender differences, or differences in educational levels or living conditions.
The age of the participants was 20-69 years in Study I, 28-42 years in Study III and 18-69 years in Study IV. An overview of the demographic characteristics of the participants in Studies I, III and IV is presented in Table 2.

Table 2. Demographic characteristics of participants in Studies I, III and IV.

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Study I n=51</th>
<th>Study III n=6</th>
<th>Study IV n=106</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>18</td>
<td>6</td>
<td>32</td>
</tr>
<tr>
<td>Men</td>
<td>33</td>
<td>-</td>
<td>73</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>21</td>
<td>-</td>
<td>26</td>
</tr>
<tr>
<td>Senior high school</td>
<td>20</td>
<td>6</td>
<td>49</td>
</tr>
<tr>
<td>University level</td>
<td>9</td>
<td>-</td>
<td>29</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Civil status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or cohabitant</td>
<td>13</td>
<td>-</td>
<td>17</td>
</tr>
<tr>
<td>Single</td>
<td>38</td>
<td>6</td>
<td>87</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Living condition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living in own home</td>
<td>47</td>
<td>3</td>
<td>84</td>
</tr>
<tr>
<td>With parent</td>
<td>2</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Group home or nursing home</td>
<td>2</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>4</td>
</tr>
</tbody>
</table>

Participants in Study I were asked about whether they were aware that they had any psychiatric diagnosis. Thirty-two reported diagnosis and at least one stated it as schizophrenia, psychosis, anxiety, depression or neurosis. Nineteen, reported no diagnosis. In Study III, all participants had a documented diagnosis of psychosis. In Study IV, 51 of the participants were the same as in Study I. For the remaining 55 participants, there is no information about their diagnosis, but they all suffered from a severe mental disorder.

Occupational therapy records

Study II concerned occupational therapy records regarding individuals with psychosis. Occupational therapists provided 64 printouts of occupational therapy records.

A random selection of 250 occupational therapists from the register of the Swedish Association of Occupational Therapists were asked to send printouts of occupational
therapy records for individuals with psychosis. They were asked to send in an occupational therapy record regarding a treatment process that was terminated at least one month before they were asked to participate in the study. Fifty-seven occupational therapists consented to provide records. However, 32 did not send in the documentation because no suitable patient was found (n = 4), the patient refused (n = 1), the physician responsible to the case refused (n = 4), there was no replay from the physician (n = 8), the occupational therapist left her job (n = 1), or the occupational therapists did not supply records (n = 14). Thus, a total of 25 occupational therapists mailed 64 printouts of occupational therapy records.

*Occupational therapists*
In Study IV included occupational therapists working in mental health care. Twelve of fifteen eligible occupational therapists in a mental health care district were asked to participate as experts on using occupation as a mean in therapy for individuals with mental disorders. Three occupational therapists did not work during the data collection period. Seven occupational therapists who had worked between 1.5 and 26 years in mental health care chose to participated, and the remaining six occupational therapists refrained due to a lack of time.

*Family caregivers*
In Study IV, the inclusion criteria were family caregivers of individuals with severe mental disorders. The caregivers were recruited by ten local presidents of the Swedish Schizophrenia Fellowship. A written invitation was sent to 750 caregivers. After one reminder, 295 (39 %) responded. Twenty-four were excluded because they had not completed a questionnaire that accompanied the invitation. Thirteen were not family members and two caretakers were deceased. Consequently, 256 caregivers took part in the study.
Data collection methods and procedures

An overview of the data collection methods and samples in Studies I-V is provided in Table 3.

Table 3. Overview of data collection methods and samples in Studies I-V

<table>
<thead>
<tr>
<th>Methods</th>
<th>Study</th>
<th>Samples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capability to Perform Daily Occupation (CPDO)</td>
<td>I</td>
<td>51 individuals with severe mental disorders</td>
</tr>
<tr>
<td>Allen Cognitive Level Test (ACLS)</td>
<td>I</td>
<td>51 individuals with severe mental disorders</td>
</tr>
<tr>
<td>Template of Occupational Therapy (TOT)</td>
<td>II</td>
<td>64 occupational therapy records</td>
</tr>
<tr>
<td>Narrative interviews</td>
<td>III</td>
<td>6 individuals with severe mental disorders</td>
</tr>
<tr>
<td>Experience of Occupational Performance Questionnaire (EOPQ)</td>
<td>IV</td>
<td>106 individuals with severe mental disorders</td>
</tr>
<tr>
<td>Index of Content Validity (CVI)</td>
<td>IV</td>
<td>7 occupational therapists</td>
</tr>
<tr>
<td>Burden Assessment Scale (BAS)</td>
<td>V</td>
<td>256 caregivers of individuals with severe mental disorders</td>
</tr>
</tbody>
</table>

Questionnaires

Three questionnaires were used: Capability to Perform Daily Occupations (CPDO) (Schult, Söderback & Jacobs, 2000) (Study I), Experiences of Occupational Performance Questionnaire (EOPQ) (Study V) and Burden Assessment Scale (BAS) (Study III) (Bogren, 1996; Reinhard et al., 1994).

Capability to Perform Daily Occupations (CPDO)

The Capability to Perform Daily Occupations (CPDO) (Schult, Söderback, & Jacobs, 2000) was used to assess perceived occupational performance in individuals with severe mental disorders (Study I). The CPDO was developed in Sweden for assessment of self-perceived capability to perform daily occupations among individuals with chronic pain. The CPDO is a computer-based self-administering tool. It includes 27 daily occupations shown as short films on a computer screen. The occupations included in the CPDO are well known and performed by most individuals in Sweden. They represent occupations performed during the entire lifespan by both women and men (Schult, Söderback, & Jacobs, 2000). If a shown
daily occupation is assessed by the participant as not applicable, it is deleted. The participants are asked to rate six questions following each film based on their experiences. The six questions are: Do you interrupt the occupation while you are performing it? Do you avoid this occupation? How much exertion do you feel during or after you have performed the occupation? How much inconvenience do you feel during the occupation? How satisfied are you after having completed the occupation? How often do you usually perform the occupation? Each question has a nine-degree ordinal scale ranging between zero and eight. Zero means never interrupt, never avoid, no effort at all, no inconvenience, very satisfied, and very often for the respective questions. Eight means always interrupt, always avoid, very, very much effort, very, very much inconvenience, not at all satisfied, and never perform.

The CPDO was used as a structured interview tool and the participants were asked to rate to what extent they interrupted, avoided, felt exertion, perceived inconvenience, were satisfied when performing the occupation and how often they performed each occupation illustrated on the screen. The interviews were performed in the activity settings where participants took part in organized activities. Questions about the participant’s demographic data and awareness of diagnosis were posed at the same session. The interviews lasted between 20 minutes and one hour.

Experience of Occupational Performance Questionnaire (EOPQ)
The EOPQ was used to assess the experience of occupation as a means in therapy (Study IV). The EOPQ was constructed on the basis of 49 transformed statements of women’s experiences of performing occupations” (Study III). These forty-nine transformed statements were reformulated as items of the EOPQ. Each statement describes experiences associated with performing occupations. An ordinal rating scale ranging from 1 to 7 (1 means agreement, 4 no opinion, 7 disagreement) is used for each item.

Fifty-one of the respondents completed the EOPQ in a structured interview and fifty-five as a mailed questionnaire. The interviews were performed at the activity settings and lasted 15 to 30 minutes. The EOPQ questionnaire was distributed to the family caregivers by the local presidents of the Swedish Schizophrenia Fellowship.
The caregivers were asked to hand out the EOPQ to the caretakers. The caregivers were asked to return the completed EOPQ in the same envelope as the BAS (see below, Study V).

**Index of Content Validity (CVI)**

The Index of Content Validity (CVI) (Lynn, 1986) was used to address the content relevance of the EOPQ (Study IV). The CVI is a tool for quantification and judgment of the content validity of an instrument. This entails a judgment by experts of the extent of which the items have a sufficient content validity. A minimum of five experts is recommended to provide a sufficient level of control for chance agreement (Lynn, 1986). To quantify content validity, the experts are instructed to rate the content relevance of each item using a 4-point rating scale (1 = not relevant; 2 = unable to assess relevance; 3 = relevant but needs minor alteration; 4 = very relevant and succinct). The CVI score is defined as the proportion of items that receive a rating of 3 or 4 (Waltz & Bausell, 1981).

The occupational therapist experts received the questionnaire. They were asked to rate each item of the EOPQ concerning its relevance to occupation as a mean in therapy for individuals with severe mental disorders. They returned the questionnaire by mail.

**Burden Assessment Scale (BAS)**

The Swedish version of the Burden Assessment Scale (BAS) (Bogren, 1996) was used to assess perceived burden in daily life among family caregivers (Study V). The BAS was developed by Reinhard et al (1994) to assess family burden related to individuals with severe mental disorders. The BAS is a 19 item scale that focuses on specific objective and subjective caregiver consequences. Ten items assess objective burden and refer to observable behavioral effects of caregiving, observable by the caregivers, such as financial problems, limitations of personal activity, household disruptions, and social interactions. Nine items assess subjective aspects of burden such as feelings, attitudes, and emotional experiences. Each item has a 4-point scale (1 means not at all and 4 means a lot). The respondents are asked to state to what
extent they had experienced burden in each of the 19 areas covered. The homogeneity of the BAS has been reported in two samples to be $x = 0.91$ and $x = 0.89$ respectively in two separate sample. It has also been found to have a stable factor structure, whether self administered or interview (Reinhard et al., 1994).

The BAS and a questionnaire about demographic data and occupation outside the home concerning the caretakers were distributed to the caregivers by the local presidents of the Swedish Schizophrenia Fellowship. The caregivers were asked to complete the questionnaire and return it in a pre-paid envelope.

Observations

Allen Cognitive Level Screen (ACLS)

The Allen Cognitive Level Screen (ACLS) was used to assess observed cognitive ability among individuals with severe mental disorders (Study I). The ACLS (Allen, 2000) is a brief screening instrument developed to measure and predict the individual’s performance in routine daily occupations. The ACLS is based on the Cognitive Disability Model (CDM) (Allen, 1985; Allen & Allen, 1987).

The ACLS is intended to give a quick estimate of the individual’s capability to follow verbal instructions with demonstrations, and to solve problems involving a progressively more elaborate task. The individuals are observed during their performance of a standardised leather-lacing task and assigned a score on a 25-point scale. Scoring guidelines (Allen, 2000) are used to assess the individuals with regard to error frequency and type, ability to recognize and correct errors and the level of assistance required. This is done on the basis of her or his ability to imitate and perform three progressively difficult leather-lacing stitches. The test yields an ordinal score.

The ACLS scores have been found to predict ability to perform basic activities of daily living in individuals with schizophrenia (Velligen et al., 1995). Findings in a study by David and Riley (1990) indicated that the ACLS is a valid measure of cognitive functioning especially related to tasks of visual-motor speed and concentration. Further, Penny et al (1995) found that individuals with greater
cognitive disability assessed by the ACLS had poorer social skills. Good interrater reliability (ICC=. 98) has been demonstrated (Velligen et al., 1995).

The observation was performed by the author at the activity settings of each of the participants. They were observed during performance of the standardized leather-lacing task and assigned a score on the 25-point scale (Allen, 2000). The observations lasted 5 to 10 minutes.

**Interviews**

**Narrative interviews (Study IV)**

Personal narrative interviews were performed to illuminate how individuals with severe mental disorders experience occupational therapy (Study III). This type of interview was chosen in order to gain access to the participants’ lived experiences of occupational therapy (Bengtsson, 1999; Giorgi, 1993; Kvale, 1989).

Tape-recorded interviews were conducted by the author twice with each participant, with a two or three week interval. The interviews were conducted immediately after a session in which the women participated in occupational therapy. They were asked to narrate what they had done during the session and what experiences they had had when performing the occupation. The interviews were conducted as a conversation with complementary questions such as “can you describe what you did after that?”, and “can you describe what you felt about that?”. The interviews lasted 15 to 30 minutes and were transcribed verbatim.

**Documents**

**Template of Occupational Therapy (TOT)**

The Template of Occupational Therapy (TOT) (Ivarsson, Söderback & Stein, 1998) was used to study occupational therapists’ descriptions of the goals of treatment, treatment intervention and outcome in occupational therapy records (Study II). The TOT is a coding scheme and covers the main elements of the occupational therapy process “treatment goal”, “treatment intervention” and “outcome”, organized into components and subcomponents. The subcomponents are presented in the coding scheme as questions. Each question in the TOT starts with “What is documented
about…”, such as “What is documented about the patient’s restriction of occupational performance?” (see Appendix).

All questions were related to each of the 64 patient charts. Identified key sentences, terms or words served as answers to the TOT questions and constituted the coding statements.

Data analysis
The methods used for analysis are presented in Table 1 page 15.

Statistical analysis
Frequencies were used for overall description of the data (Studies I, IV and V).

The 27 daily occupations assessed by the CPDO were categorized into activities of daily living (ADL), play and leisure (PLA) and work and productive activities (WPA) following the Uniform Terminology of The American Occupational Therapy Association (AOTA) (Christiansen & Baum, 1997).

The statistical methods used in Studies I, IV and V are presented in Table 4 and described in detail in the respective studies.

Principal Component Analysis with varimax rotation was used in Studies IV and V. Eigenvalue above 1 was used as a criterion to include the factors and items with factor loadings of more than 0.40 were included in further analysis in accordance with Tabachnick and Fidell (2001).

The level of significance was set at p<0.05 in all studies. The Statistical Package for the Social Science software (SPSS, 2000) was used for the statistical analyses.
Table 4. Statistical methods used for each of the assessment instrument in Studies I, IV and V.

<table>
<thead>
<tr>
<th></th>
<th>CPDO Study I</th>
<th>ACLS Study I</th>
<th>EOPQ Study V</th>
<th>BAS Study III</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wilcoxon-Mann-Whitney Test</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Age group</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Awareness of diagnosis</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Civil status</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Kruskal-Wallis One-Way Analysis of Variance of Ranks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age group</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational level</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Daily occupation outside home</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>ACLS scores</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student’s t-test</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Principal Components Analysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Determination of structure</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Cronbach Alpha</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal consistency</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>The index of Content Validity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Content validity</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

**Content analysis**

The occupational therapy records were analyzed by a content analysis approach (Downe-Wamboldt, 1992; Waltz, Strickland, & Lenz, 1991) (Study II).

To prepare for the content analysis a four step procedure was undertaken. First, the tree main areas of the Template of Occupational Therapy (TOT) (goals, treatment, and outcomes) were applied to the 64 medical records identifying key sentences, terms and words belonging to each area. Second, the identified material was entered into separate text files according to the TOT areas. Third, the material was checked to determine whether it was put in the right text file. Then finally, compound description were separated into single units which generated 2992 statements. They constituted the material for the content analysis.

In the content analysis a search was first performed for themes within each text area. Some themes represented questions in the TOT scheme, such as “measuring the goal: in terms of time, others emerged through the analysis. The texts belonging to the areas were transcribed in several stages. In the next stage, all statements were categorized under the themes that emerged and these themes were named. This was followed by a search for dimensions within each theme. Dimensions were designated
a summarizing term and illustrated with statements. When only one theme appeared, these were confirmed with statements as quotations.

**Phenomenological analysis**

The narrative interviews were analyzed by a phenomenological approach (Study IV). The analysis procedure was inspired by Giorgi (1993) and performed in six steps. The verbatim transcribed tape-recorded interviews were read through to get a sense of the whole. The text was then re-read from the beginning and divided into meaning units. These meaning units were transformed into general terms and then transformed into occupational therapy terms (exemplified in Table 5). In a further transformation, the content was further condensed into statements. Invariations and variations were sought for and similar kinds of invariation in the interviews were adopted as key constituents. The integration of the key constituents formed two structures.

**Table 5.** Examples of dividing the text into meaning units and transforming it into occupational therapy terms.

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Transformation into general terms</th>
<th>Transformation into occupational therapy language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, a little bit, but kind of nice, you know, and thinking too, maybe - but it’s hard to relax, have something else to think about, for a bit, what you have to do</td>
<td>S explains that when she take part in an activity she has something else to think about for a while</td>
<td>Participation in an activity gives something else to occupy the mind</td>
</tr>
<tr>
<td>That’s feels worthwhile doing, something that feels worth doing, sort of what you do, I think</td>
<td>S explains that it feels worthwhile to take in an activity</td>
<td>Participation in an activity is meaningful</td>
</tr>
<tr>
<td>Somebody that sees</td>
<td>S explains that she take part in the activity someone sees her</td>
<td>Participation in an activity gives confirmation</td>
</tr>
<tr>
<td>Get on with it that it’s done</td>
<td>S explains that when she take part in the activity it gets done</td>
<td>Participation in an activity results in the completion of the activity</td>
</tr>
</tbody>
</table>

An inter-judge comparison was performed to investigate the trustworthiness of the first authors analysis. The second and third author’s of Study III independently checked the transformation into occupational therapy language. Unclear transformations were discussed with the first author and checked against the original text until consensus was reached.
ETHICAL CONSIDERATIONS

All studies were approved by the Research Ethics Committee at the Faculty of Medicine, Uppsala University (Dnr 97141, 98099, 99299, 99294)

Written and oral information about the purpose of the study and on voluntary participation consent was given to the respondents first by the staff in Studies I, III and IV. Before the data collection, the respondents were informed again. It was also stressed that all information gained would be treated with confidentiality and that participants could terminate their participation without any explanation at any time they wished.

In Studies IV and V, written information about the purpose of the study, on voluntary participation and that all information gained would be treated with confidentiality were given to the caregivers and caretakers separately.

In Study II, written information about the purpose of the study and on voluntary participation were given to the occupational therapists that were asked to provide printouts of occupational therapy records. Before sending the printouts of the records, the patients’ referring physicians were asked to give their consent. The occupational therapists were asked to remove the personal identification in the printouts of the occupational therapy records.

In Study IV, written and oral information were given about the purpose of the study, on voluntary participation and that all information gained would be treated with confidentiality.
RESULTS

Occupational performance in individuals with severe mental disorders

Occupational performance according to the CPDO

As shown in Table 6, all the participants in Study I (n=51) reported that they transferred from bed, dressed and took care of personal hygiene. Only six and four of the participants assessed the activities “home maintenance/ repair work” and “take care of dishes/use of dishwasher” as applicable to them. These two items were therefore excluded from further analysis. At least 15 of the 51 participants assessed the remaining activities as applicable to them. The categorization of the CPDO and the number of the participants who assessed the daily activities as applicable to them are presented in Table 6.

Table 6. The number (%) of participants assessing categories of daily occupations in the CPDO as applicable to them (Study I).

<table>
<thead>
<tr>
<th>OCCUPATION</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activities of Daily Living (ADL)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer from bed</td>
<td>51</td>
<td>100</td>
</tr>
<tr>
<td>Dress</td>
<td>51</td>
<td>100</td>
</tr>
<tr>
<td>Take care of personal hygiene</td>
<td>51</td>
<td>100</td>
</tr>
<tr>
<td>Climbing stairs</td>
<td>50</td>
<td>98</td>
</tr>
<tr>
<td>Preparing meals</td>
<td>45</td>
<td>88.2</td>
</tr>
<tr>
<td>Read</td>
<td>42</td>
<td>82.4</td>
</tr>
<tr>
<td>Go for a walk</td>
<td>40</td>
<td>78.4</td>
</tr>
<tr>
<td>Write</td>
<td>38</td>
<td>74.5</td>
</tr>
<tr>
<td>Using public transportation</td>
<td>34</td>
<td>66.7</td>
</tr>
<tr>
<td>Lift and carry grocery bags</td>
<td>32</td>
<td>62.7</td>
</tr>
<tr>
<td>Take care of children</td>
<td>25</td>
<td>49.0</td>
</tr>
<tr>
<td>Drive a car</td>
<td>16</td>
<td>31.4</td>
</tr>
<tr>
<td><strong>Physical exercise/training</strong></td>
<td>15</td>
<td>29.4</td>
</tr>
<tr>
<td><strong>Play and Leisure Activities (PLA)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch TV</td>
<td>49</td>
<td>96.1</td>
</tr>
<tr>
<td>Social activities</td>
<td>40</td>
<td>78.4</td>
</tr>
<tr>
<td><strong>Work and Productive Activities (WPA)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dusting and vacuum cleaning</td>
<td>43</td>
<td>84.3</td>
</tr>
<tr>
<td>Clean the bathroom</td>
<td>42</td>
<td>82.4</td>
</tr>
<tr>
<td>Supplementary grocery shopping</td>
<td>41</td>
<td>80.4</td>
</tr>
<tr>
<td>Make the bed</td>
<td>40</td>
<td>78.4</td>
</tr>
<tr>
<td>Wash the laundry</td>
<td>38</td>
<td>74.5</td>
</tr>
<tr>
<td>Do an errand at post, bank, shop</td>
<td>36</td>
<td>70.6</td>
</tr>
<tr>
<td>Grocery shopping</td>
<td>32</td>
<td>62.7</td>
</tr>
<tr>
<td>Ironing</td>
<td>23</td>
<td>45.1</td>
</tr>
<tr>
<td>Garden work</td>
<td>15</td>
<td>29.4</td>
</tr>
<tr>
<td>Home maintenance/repair work</td>
<td>6</td>
<td>11.8</td>
</tr>
<tr>
<td>Use the dishwasher</td>
<td>4</td>
<td>7.8</td>
</tr>
</tbody>
</table>

* Categorisation of daily occupations according to the Uniform Terminology for Occupational Therapy (Christiansen, 1997).
Activities of Daily Living (ADL) seemed to give the participants some problems of occupational performance. They reported that they interrupted and avoided ADL occasionally and experienced some exertion and inconveniences when performing these. They reported that they performed ADL often and were satisfied after performing them (see Table 7). Ten of thirteen of the ADL activities were applicable to more than half of the group (Table 6). There were no significant differences with regard to ADL between groups formed on the basis of age, sexes, educational levels, civil status and those who reported their diagnosis or not.

Table 7. Means and standard deviations of responses to the CPDO questions concerning the daily occupations assessed by the CPDO.

<table>
<thead>
<tr>
<th>Daily occupations</th>
<th>Interruption/Break off Mean (SD)</th>
<th>Avoid Mean (SD)</th>
<th>Exertion Mean (SD)</th>
<th>Inconvenience Mean (SD)</th>
<th>Satisfaction Mean (SD)</th>
<th>Frequency Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>1.77 (1.06)</td>
<td>1.52 (1.08)</td>
<td>1.79 (1.06)</td>
<td>1.57 (1.76)</td>
<td>1.76 (0.99)</td>
<td>1.66 (0.95)</td>
</tr>
<tr>
<td>PLA</td>
<td>2.72 (2.14)</td>
<td>2.72 (2.16)</td>
<td>2.58 (2.16)</td>
<td>2.23 (1.83)</td>
<td>1.76 (2.07)</td>
<td>1.95 (2.00)</td>
</tr>
<tr>
<td>WPA</td>
<td>1.43 (1.22)</td>
<td>1.89 (2.00)</td>
<td>1.77 (1.26)</td>
<td>2.12 (1.32)</td>
<td>1.68 (1.43)</td>
<td>1.66 (1.02)</td>
</tr>
</tbody>
</table>

The Play and Leisure Activities (PLA) seemed more problematic to the participants. They reported that they interrupted and avoided PLA sometimes and experienced rather much exertion and moderate inconvenience when performing these. However, they reported that they were satisfied after performing PLA and performed these often (Table 7). Most of the participants reported that they watched TV but less than half of them stated that they did not attend performances at a cinema/theatre (Table 6). Comparisons were made of PLA performance between age groups, sexes, educational levels, civil status groups and groups that reported their diagnosis or not. Men stated that they performed PLA less frequently \((z = -2.02; p = 0.043)\) than women. Participants with a lower educational level reported that they performed PLA less frequently \((\text{Chi}^2 = 11.10; \text{df} = 2; p = 0.004)\) and experienced more inconvenience \((\text{Chi}^2 = 6.67; \text{df} = 2; p = 0.036)\) than those with a higher educational level. On the other hand, those with a lower educational level \((\text{Chi}^2 = 6.66; \text{df} = 2; p = 0.036)\) and those who reported a diagnosis \((z = 22.66; p = 0.008)\) were more satisfied than their comparison groups.
Men, participants who reported a diagnosis and those who lived alone experienced Work and Productive Activities (WPA) as more problematic than their comparison groups. Men reported that they interrupted (z = 2.73; p = 0.006) and avoided (z = 2.23; p = 0.022) WPA more often than did the women. On the other hand they reported that they performed WPA less frequently (z = 2.13; p = 0.034) and were more satisfied after performing WPA (z = 2.23; p = 0.026) than the women. Participants who lived alone reported more inconvenience (z = 2.29; p = 0.22) compared with participants living with a partner. Participants who reported a diagnosis interrupted more often (z = 2.66; p = 0.008), avoided more (z = 2.43; p = 0.015), experienced more exertion (z = 5.56; p = 0.011) and more inconvenience (z = 2.25; p = 0.032) compared with participants who did not report a diagnosis. On the other hand they reported that they performed WPA less frequently (z = 2.88; p = 0.004) but reported a higher degree of satisfaction (z = 2.23; p = 0.026) after performing WPA than did the comparison group.

These findings show that the participants interrupted and avoided ADL occasionally and perceived some exertion and inconvenience when performing ADL. The PLA seemed more problematic. They interrupted and avoided PLA sometimes and perceived rather much exertion and moderate inconvenience. Participants with a lower educational level experienced more inconvenience when performing PLA compared with those who had a higher educational level. Men, participants who reported a diagnosis and those who lived alone perceived WPA as more problematic than the comparison groups. Participants reported that they were satisfied after performing ADL, PLA and WPA.

*Occupational performance according to the ACLS*

Eight of the fifty-one participants in Study I were assessed to be at cognitive level 3 in the ACLS, which means that they could perform manual actions spontaneously but needed guidance to complete a task successfully. Twenty were assessed at level 4, which means that their attention is captured by visual and tactile cues but she/he needs situation-specific supervision. Twenty-three of the participants were assessed at level 5, which means that these participants uses complex visual and exploratory
but needs individual supervisory assistance in situations that require planning and organization.

Comparisons were made of cognitive levels between age groups, sexes, educational levels, civil status groups and groups that reported their diagnosis or not. Participants with a higher educational level ($\chi^2 = 10.00; df = 2; p = 0.007$) and those who lived alone ($z = 2.25; p = 0.024$) had higher ACLS scores compared to those with a lower educational level and those who cohabitated, respectively.

There were no significant differences between the cognitive levels with regard to ADL and PLA. Participants assigned to level 5 seems to perceive problems with their performance of WPA. These individuals reported that they more often interrupted ($\chi^2 = 6.44; df = 2; p = 0.040$), experienced exertion ($\chi^2 = 6.96; df = 2; p = 0.031$) and inconvenience ($\chi^2 = 7.05; df = 2; p = 0.029$) than did participants at levels 3 or 4. In addition, they reported that they performed these occupations less frequently ($\chi^2 = 10.05; df = 2; p = 0.007$) than did participants at level 3.

These findings indicate that more than half of the participants assigned to level 3 ($n = 8$) or 4 ($n = 20$) were in need of assistance in performing occupations. Also less than half of those at level 5 ($n = 23$) were in need of supervisory assistance in situations that require planning and organization. Participants’ cognitive level, seems to correlate with their performance of WPA.

The content of occupational therapy records
The results are reported according the structure of the TOT (see Appendix).

Occupational therapy goals
Documentation within the area of “occupational therapy goal” contained 57 % of the total 2992 statements reported in the records. The area contained 31 themes. One theme, the theme Ability or impaired ability, included dimensions such as Solving problems, Choosing, Organizing and structure routines, and Performing dimensions in relation to motivation, initiative, concentration, use of time and endurance.

The other themes lack dimensions. They were named Relationship with therapist and other patients, Environmental support and Roles. The patient’s and occupational
therapist’s cooperation and the patient’s involvement in the planning goal process were documented in terms how the occupational therapist acted, in terms how the patient acted, and how they planned together.

Health goals were documented in the themes Developing own personal abilities and relation to others, and Independent living. Other themes were the patient’s attempts to increase abilities, to have confidence in themselves and giving structure and continuity to daily life and preventing relapses or recurrence of symptoms. Further, Preparing to work in the open labour market. Leading to daily occupation were other important themes.

**Occupational therapy treatment**

The documentation in the area of “occupational therapy intervention” contained 38% of the total 2992 statements reported in the records. The area contained 37 themes. Two themes contained dimensions. The theme Discussion had four dimensions, Confront, Advise, Support and Information. The theme Designation of group activities contained different group activities related to ADL, creative and social activities. Remaining themes had no dimensions and reflected theoretical background, assessment forms and different types of planning. Eight themes reflected how different activities were used in therapy and how activities were carried out together with single individual or a group. Support in activity, Opportunities in connection with the activity, Working together with the patient in the activity, Performing the activity, Activating and training and Discussion were themes that reflected how the occupational therapy acted. Other themes were named Residential, Community resources and Trying of aids.

**Effect or outcome of occupational therapy**

The effect or outcome of occupational therapy was documented in 5% of the total 2992 statements reported in the records. The area contained 9 themes and no dimensions. Important themes reflected affected ability to manage daily activities, increased ability to handle behaviour and emotions and also relations to others. One theme illustrated reduction of psychotic symptoms. These themes reflected the
individuals experiences and remaining themes concerning effects on activities and emotions and methods used for assessment reflected the occupational therapist’s perspective.

In summary these findings showed that documentation in the area of “occupational therapy goal” ranged from goals referring to the patient’s inner life, e.g. expressing one’s own feelings and choosing occupation, to goals relating to the patient’s practical ability to structure daily life. The documentation in the area of “occupational therapy interventions” concerned mainly the occupations that were used as a mean in occupational therapy. Included in these statements were creative occupations, but also documented was the use of activities of daily living. It was evident that that current use of occupations was combined with the occupational therapist use of self. Furthermore, the findings showed that the documentation concerning “treatment outcome” was related to patient’s experiences and how they were able to manage the occupations.

Women’s experiences of participation in occupational therapy
Two structures called “Meaning of occupational therapy” and “Form of occupational therapy” emerged from the phenomenological analysis of the interviews (Study III). The two structures with their key constituents are presented in Table 8.

<table>
<thead>
<tr>
<th>Structures</th>
<th>Meaning of occupational therapy</th>
<th>Form of occupational therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key constituents</td>
<td>Reliefe</td>
<td>Environment</td>
</tr>
<tr>
<td></td>
<td>Belief in the future</td>
<td>Guidance</td>
</tr>
<tr>
<td></td>
<td>Self-knowledge</td>
<td>Voluntariness</td>
</tr>
<tr>
<td></td>
<td>Capability</td>
<td>Collaboration</td>
</tr>
<tr>
<td></td>
<td>Resistance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td></td>
</tr>
</tbody>
</table>

The first structure, “Meaning of occupational therapy” describes the women’s experiences of how the treatment affected them. Participating in occupational therapy helped the women to relax and become calm. It gave them something else to think about and dark thoughts could be held at bay for a while (Relief). They started to
think about how things learnt could be used on a future job and generated a desire to be able to manage a complete activity without help (Belief in the future). When they performed the occupations they became aware of what they could do and what they could not. They could also compare themselves with others and learned by watching their performance. They also got opportunities to state their own wishes and make their own choices in consultation with others (Self-knowledge). The women learned to handle tools and materials and to do a variety of new activities. Participation in the occupations made it easier for the women to take part in a conversation and they had something to say when they started (Capability). Participating in occupational therapy took energy and the women reported that it could be hard to think during the performance of the occupation (Resistance). They experienced that time had passed quickly during the session, which was stated to be a measure of enjoyment. Participation gave the women feelings of togetherness, generated a feeling of managing to do something on one’s own and something meaningful, of being useful and like other people (Satisfaction).

The second structure, “Form of occupational therapy” describes the women’s experiences of the arrangement of the occupations. They reported that the participation in the planned occupation was scheduled and the occupation was divided into items that were carried out according to a distinct time frame. The termination of the occupation was described as being deliberate (Time). The occupations took place in a specially arranged environment in a room adapted for the occupation or in the community. The environment was reported as agreeable and homelike (Environment). The women described the occupational therapist as practical and that she explained and demonstrated what to do. The occupational therapists were reported to give support by individualizing the occupation, in this way enabling it’s completion (Guidance). The women also reported that their participation was voluntary, and initiated by questions about what the women wished to do. Continued participation presupposed that the women accepted responsibility for their own decisions. The choice of activity was adapted to the interests, wishes, needs of the women and what was available. The manner in which the occupation was performed was prepared jointly before the occasion (Voluntariness).
Participation in the occupation could be either only with the therapist or with other patients as well. The occupation was commenced when all had gathered and different tasks were allocated in collaboration (Collaboration).

The main findings are the key constituents integrated in two structures. The meaning of occupational therapy as expressed in the key constituents relief, self-knowledge, belief in the future, capability, resistance and satisfaction formed one structure. The form of occupational therapy as expressed in the key constituents time, environment, guidance, voluntariness and collaboration represented the other.

Development and psychometric characteristics of the Experiences of Occupational Performance Questionnaire (EOPQ)

The main findings from the analysis of women’s experiences of occupational therapy constituted the two structures “Meaning of occupational therapy” and “Form of occupational therapy”. The structure “Meaning of occupational therapy” contained 49 transformed statements describing the experiences associated with performing occupations (Study III).

Forty-six of these 49 items were determined by the occupational therapists to have a content relevant to occupation as a therapeutic mean by the occupational therapists (Study IV). The three items “Didn’t think about distressing things” (item 4) (CVI=0.71), “Started to think about own living” (item 12) (CVI=0.71), and “Learned how to live by myself” (item 17) (CVI=0.57) were not found to be relevant.

Factor analysis yielded a six-factor solution providing an explanation of 58% of the variance of the responses of the 46 items (Study IV). These six factors were named: “Satisfaction and confidence in own ability”, “Capability to perform”, “Challenge”, “Ability to handle difficult situations”, “Forgetting time and self”, and “Identification with others”. The variance proportions were 30.28 (Factor I), 10.45 (Factor II), 5.24 (Factor III), 4.46 (Factor IV), 3.83 (Factor V) and 3.44 (Factor VI).

The intercorrelations between the 19 items in the first factor indicated an underlying structure. A separate factor analysis of the first factor yielded two factors. These were named “Satisfaction with own ability” and “Confidence in own ability”. The results are presented in terms of the seven-factor structure (Table 9).
Table 9. The seven factors with related items in the EOPQ and Cronbach $\alpha$ values for the factors.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Items</th>
<th>$\alpha$ coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with own ability</td>
<td>5. Was rewarded</td>
<td>0.91</td>
</tr>
<tr>
<td></td>
<td>6. Was allowed to do what I could</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10. Could express what I wanted</td>
<td></td>
</tr>
<tr>
<td></td>
<td>14. Learned social behaviour that would help me in the future</td>
<td></td>
</tr>
<tr>
<td></td>
<td>35. To take responsibility</td>
<td></td>
</tr>
<tr>
<td></td>
<td>43. I was kept busy and that’s better than not having anything to do</td>
<td></td>
</tr>
<tr>
<td></td>
<td>45. Gave sensory stimuli</td>
<td></td>
</tr>
<tr>
<td></td>
<td>46. Gave feelings of joy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>47. Gave feelings of satisfaction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>48. Gave feelings of pleasure</td>
<td></td>
</tr>
<tr>
<td></td>
<td>49. Gave feelings of being useful</td>
<td></td>
</tr>
<tr>
<td>Confidence in own ability</td>
<td>24. Exercise to improve my health</td>
<td>0.88</td>
</tr>
<tr>
<td></td>
<td>25. To choose</td>
<td></td>
</tr>
<tr>
<td></td>
<td>28 To gain a sense of belonging and get know others</td>
<td></td>
</tr>
<tr>
<td></td>
<td>29. To cooperate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>30. To take initiative</td>
<td></td>
</tr>
<tr>
<td></td>
<td>31. To start doing something</td>
<td></td>
</tr>
<tr>
<td></td>
<td>32. To structure my time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>33. To add variety to my day</td>
<td></td>
</tr>
<tr>
<td>Capability to perform</td>
<td>15. Learned things and had experiences that I could use in similar</td>
<td>0.83</td>
</tr>
<tr>
<td></td>
<td>situations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>16. Learned how to do things</td>
<td></td>
</tr>
<tr>
<td></td>
<td>19. Learned to use tools</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20. Learned to handle materials</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22. My imagination was awakened</td>
<td></td>
</tr>
<tr>
<td></td>
<td>23. My memories came back to me</td>
<td></td>
</tr>
<tr>
<td>Challenge</td>
<td>7. Discovered my own limitations</td>
<td>0.71</td>
</tr>
<tr>
<td></td>
<td>36. Took a lot of energy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>37. It was hard to think and I became confused</td>
<td></td>
</tr>
<tr>
<td></td>
<td>38. I was forced to be considerate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>39. It was difficult</td>
<td></td>
</tr>
<tr>
<td></td>
<td>40. It was not meaningful</td>
<td></td>
</tr>
<tr>
<td></td>
<td>41. I was forced to concentrate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>42. I was forced to endure</td>
<td></td>
</tr>
<tr>
<td>Ability to handle difficult</td>
<td>4. Could handle my hallucinations</td>
<td>0.67</td>
</tr>
<tr>
<td>situations</td>
<td>11. Stared to think about the future</td>
<td></td>
</tr>
<tr>
<td></td>
<td>26. To make decisions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>27. To decide the subject to conversations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>34. To manage a conversation</td>
<td></td>
</tr>
<tr>
<td>Forgetting time and self</td>
<td>1. Relaxed and became calm</td>
<td>0.70</td>
</tr>
<tr>
<td></td>
<td>2. Had something else to think about</td>
<td></td>
</tr>
<tr>
<td></td>
<td>18. Learned things I thought I could not possible learn</td>
<td></td>
</tr>
<tr>
<td></td>
<td>44. Time went by quickly</td>
<td></td>
</tr>
<tr>
<td>Identification with others</td>
<td>8. Could see how others performed</td>
<td>0.63</td>
</tr>
<tr>
<td></td>
<td>13. Started to think about working</td>
<td></td>
</tr>
<tr>
<td></td>
<td>21. Learned to consider others</td>
<td></td>
</tr>
</tbody>
</table>

The factor “Satisfaction with own ability” reflects feelings of being satisfied when performing an occupation. “Confidence in own ability” concern feelings of confidence in the individual’s own ability to perform occupations. The factor “Capability to perform” reflects the individual’s experiences of her/his own
capability to perform an occupation. The factor “Challenge” mirrors the experiences that the occupation may take much energy and be difficult to perform. This factor may be seen as the challenge of performing the occupation despite it being difficult and taking energy from the individual. The factor “Ability to handle difficult situations” reflects experiences of being able to handle hallucinations and manage a conversation. The factor “Forgetting time and self” mirrors experiences of being relaxed and calm. The last factor, “Identification with others” reflects a social dimension consisting of identification with others, and with several social roles.

The EOPQ factors were tested for internal consistency and were found to have \( \alpha \) coefficients between 0.63 and 0.91 (Table 9).

There were no significant gender differences in any of the factors and only four individual items showed such differences. Women reported less reward (item 5) \((t=0.46; \text{df}=103; \ p=0.029)\) when performing the occupation than did men. Further, they reported that the performance of the occupation took more energy (item 36) \((t=2.65; \text{df}=102; \ p=0.019)\) and gave less sensory stimulation (item 45) \((t=1.15; \text{df}=103; \ p=0.008)\) than did men. On the other hand, men reported fewer opportunities to make decisions (item 26) \((t=1.66; \text{df}=103, \ p=0.040)\) compared with the women.

In summary, the EOPQ was developed on the basis of experiences of women participating in occupational therapy. A principal component analysis gave seven factors with acceptable homogeneity. There were no significant gender differences in any of the factors.

**Psychometric test of the Burden Assessment Scale (BAS)**

Factor analysis yielded a three-factor solution providing an explanation of 52 % of the variance of the responses of the 19 BAS items (Study V). These three factors were named: “Activity limitation”, “Feelings of worry and guilt” and “Social influence”. The eigenvalues were 6.60 (Factor I), 1.83 (Factor II) and 1.25 (Factor III). The variance proportions were 36.29 (Factor I), 9.62 (Factor II) and 6.56 % (Factor III). The factors were tested for internal consistency resulting in \( \alpha \) coefficients of 0.88, 0.73 and 0.75, respectively.
The first factor, “Activity limitation” reflects aspects of daily activities such as caregivers missing work or school, upset household routines or changed personal plans. The second factor, “Feelings of worry and guilt” reflects feelings of not helping the caretakers enough, upset about changes in the caretaker and worry about their future. The third factor, “Social strain” reflects the caregiver’s feeling of friction among the family members and among people around the family. It should be noted that the first factor reflects the objective burden and the second and third factors two types of subjective burden.

In summary, the BAS was found to have an underlying structure consisting of the three factors “Activity limitation”, “Feelings of worry and guilt” and “Social influence”. The BAS was also found to distinguish between objective and subjective burden.

**Perceived burden among caregivers**

The caregivers reported the greatest perceived average to be burden from their worry about the future (mean = 3.65) whereas friction with others (mean = 1.28) was least burdensome.

Comparisons were made of the scores of the three BAS factors between groups formed on the basis of gender, age, civil status, educational level and occupation outside home or not. The caregivers experienced more “Activity limitation” related to the youngest caretakers (< 38 years) (Chi$^2$ = 9.28; df = 2; p = 0.010), to those who had an elementary educational level (Chi$^2$ = 6.37; df = 2; p = 0.041), and to those who lived with a partner than was true for the comparison groups. The caregivers also experienced more “Feelings of worry and guilt” in relation to the youngest caretakers (Chi$^2$ = 8.45; df = 2; p = 0.015) than to the older. In addition, caregivers experienced more “Social strain” in relation to female caretakers (z = 2.28, p = 0.23), and to those who had an elementary educational level (Chi$^2$ = 6.83; df = 2; p = 0.033) than they did for comparison groups.

There were no significant differences between the caregivers in relation to the caretakers daily occupation outside home or in relation to the caretakers frequency of daily occupation outside home.
The findings indicated that caregivers experienced more “Activity limitation” and “Social strain” in relation to the youngest caretakers and to those who had an elementary educational level than they did to corresponding comparison groups.
DISCUSSION

**Occupational performance in individuals with severe mental disorders**

The individuals with severe mental disorders experienced that performance of Activities of Daily Living (ADL) gave them some trouble, they interrupted and avoided ADL occasionally and perceived some exertion and inconvenience when performing these activities (Study I). However, they experienced the performance of Play and Leisure Activities (PLA) as more problematic. This was true particularly for the men and participants with a high educational level. The Work and Productive Activities (WPA) were more problematic to the men, the participants who reported a diagnosis and those who lived alone than was true for corresponding comparison groups. More than half (55%) of the participants were in need of assistance in performing occupations. Less than half (45%) were assigned to cognitive level 5, which indicate that they were in need of supervisory assistance in situations that require planning and organization. According to the documentation in the occupational therapy records (Study II), to remember, to absorb, to solve problems, to take initiatives and to use time seemed to give problems in the performance of occupations. Emotions such as worry, anxiety, irritation, passivity and motor-related conditions also seemed to be problematic.

With regard to daily activities, the present findings are in line with results by Honkonen (1995) who reported that 75% of schizophrenic participants had no problems in basic self-care skills. Those who reported problems with self-care skills were hospitalised or lived with a relative who was doing such tasks for the individual. It should also be noted that participants in a study by Lang et al (1999) reported fewer difficulties with skills for daily living compared to clinicians’ reports. The present results indicate that participants’ problems were related to areas in which they cooperated with other people, such as leisure and work activities. The problems to perform leisure activities agree with Weeder’s (1986) findings that individuals with mental illness saw themselves as not active in leisure activities. Social isolation and a small number of roles may limit their social skills repertoire and influence the
individuals’ performance of leisure activities (Halford & Hayes, 1995; Prusti & Bränholm, 2000).

There were no gender or age differences in the assessment of cognitive level according to the ACLS (Study I). The absence of a gender difference is consistent with previous studies (Mueser et al., 1990; Penny et al., 1995; Wykes & Dunn, 1992).

Participants assigned to level 5 in the ACLS experienced the WPA as more problematic compared to those who were assigned a lower ACLS score. It can be speculated if these individuals were familiar with abilities that were needed for them to perform WPA. The results of Studies III and IV showed that the participants became aware of what they were able to do and not to do when they performed the occupation. In occupational therapy, the WPA represents not only paid work, but includes unpaid work, caregiving and household management. Work is not only a source of income, it also helps to develop self-esteem and enables individuals to be active members in society (Champney & Dzurec, 1992; Rebeiro & Allen, 1998). Eklund, Hansson and Bejerholm (2001) found that satisfaction with employment status was related to health among individuals with schizophrenia. In Sweden, About 70 percent of the individuals with severe mental illness are deemed not to have the ability to perform work on the open market and 15 percent are fit for work but unemployed (SOU, 1998). Despite difficulties to perform work, these individuals have the right to be given opportunities to participate in occupations outside the home. These opportunities should be organized by the society (SOU, 1993a). The results of Studies III and IV showed that participants were given opportunities to learn how to perform occupations despite their inability. This generated a sense of being capable. These feelings may elicit a more functional sense of self and encourage the individual to a more active role (Davison & Strauss, 1992).

In the occupational therapy records (Study II), the individuals’ limited ability to perform occupation was described e.g. in relation to taking initiatives, to solving problems and to using time. Inabilities in these respects seem to influence these individuals and give them problems to perform occupations. The occupational therapists documented disorders and behaviour-related problems such as worry,
anxiety and passivity which also seem to have a negative influence on the individuals’ occupational performance. These findings suggest that both the limited abilities, disorders and psychological status influence occupational performance.

The present findings showed that identification of problems from several perspectives gave complementary information about the individuals’ limited ability to perform occupations. The occupational therapist perspective described the conditions for occupational performance, the individuals’ own experiences of problems in daily life and assessed needs of assistance in daily living. The structured tool CPDO illuminated the individuals’ own perspective on occupational performance ability in several areas of daily life. These findings may serve as a foundation for the development of collaborative treatments aimed to support the individual’s ability or reduce the individual’s limited ability to perform occupations.

**Occupational performance as a therapeutic mean**

The documentation in the occupational therapy records (Study III) in the area of “Treatment intervention” was characterized by descriptions of the occupations used. A wide range was found, including structured everyday activities such as taking care of clothes and cooking, and using creative occupations like videotaping, photography and pottery. It was evident that the current use of these occupations was combined with how the occupational therapists acted. Here, a continuum was implied, from the individual choosing and carrying out the occupation independently, to the occupational therapist helping the individual perform the occupation. This cooperation emerged in statements regarding both goal planning and intervention.

The fewest statements of the occupational therapy records (5 %) concerned the area of “Outcome”. There was a limited number of statements showing the individuals’ improvement after participation in occupational therapy. This indicates that there is a need for development of valid methods for evaluating occupational therapy outcome for individuals with severe mental disorders.

The participants in Study III reported that participation in occupations gave relief of symptoms. Similar results can be found in a study by Webster and Schwartsberg (1992) who reported that participants valued occupational therapy as relaxing. It has
always been a central assumption in occupational therapy that the use of occupation provides a mean of diverting mental energies from worrisome thoughts into more positive channels (Creek, 1997; MacRae, 1991; Meyer, 1921/1977). The participating women also stated that occupations enabled them to find out what they could manage on their own and where they needed practice, how to co-operate with others and how to make a decision and follow it. These experiences of performing occupations may have served as a means to define and redefine one self, as in the findings of Webster and Schwartsberg (1992) and Rebeiro and Cook (1999). The main goal of occupational therapy is stated to be its contribution to the individuals’ abilities to perform daily occupations (Kielhofner, 1995; Reitz, 1992; Stein & Cutler, 1998). In the present study, the participants reported that the occupation gave them opportunities to learn daily activities despite their limited ability, which generated a sense of being capable.

The occupational performance gave thoughts about the future, e.g. the participants began to think about and long to live on their own and to cope with daily life unaided. These findings indicate that occupational performance may improve temporal orientation. Suto and Frank (1993) stated that occupational therapy must address temporal orientation in planning, sequencing, visualising and enacting goal-directed occupations.

The women described how they had to concentrate and persevere when performing the occupation, which made them tired. In a study by Pejlert et al (1995), some patients reported lack of energy for activities. These findings suggest that when using occupation as a therapeutic means, the therapists must be aware of individuals’ limitations and the demands the chosen occupation makes on them (Nelson, 1996).

It was obvious that the women’s influence on their own participation was considerable. The participation in the occupation was voluntary and performed in cooperation. These findings are in line with current assumptions about using individual, meaningful and purposeful occupations (Christiansen et al., 1998; Clark et al., 1997; Nelson, 1996; Persson et al., 2001; Wilcock, 1993) and also with empirical findings (Mee & Sumssion, 2001). Rebeiro and Cook (1999) found that individuals with severe mental disorders who were engaged in occupations of their choice increased
their self-competence, and subjective well-being. Meaningful occupation appears to interrupt the cycle of disempowerment (Deegan, 1992). In a study by Strong (1997), occupation was found to be meaningful when it fits with the individual’s values, interests, goals, sense of self, and in relation to the individual’s disorder. The participants described that the occupational therapist created interest and helped them to cope with the task at hand. The therapists also challenged the individuals to perform the occupation as planned, despite their limited ability. These findings agree with how occupational therapists perceive themselves as action-oriented helpers with a focus on motivating, strengthening of self and adapting to the individual and her/his reality (Norrby & Bellner, 1995). According to Eklund (1996), the patient/therapist relationship is important for the outcome of occupational therapy, as is the ward atmosphere, including the physical environment where occupational therapy is performed. In the present study, the occupational therapy environment was reported to be homelike or deliberately chosen.

The first EOPQ factor “Confidence in own ability”, is in line with the findings of Rebeiro and Cook (1999) who found that participants receive confirmation of their competence through direct involvement in and feedback from the occupation. The factor “Capability to perform” is in agreement with the results by Webster and Schwartsberg (1992) as well as those by Eklund (1997) who described development of new skills as a therapeutic factor. The factor “Challenge” reflects feelings that the occupation may take much energy and may be difficult to perform. This factor may also be seen as the challenge of performing the occupation despite its difficulty as discussed in the theory of flow (Carlson & Clark, 1991; Csikszentmihalyi, 1990). The factor “Ability to handle difficult situations” may be compared with findings of Rebeiro and Allen (1998) who found that occupations provided the individual with a tangible means of testing the limits of illness. The factor “Forgetting time and self” is similar to the notion of self-reward value as a dimension that “focuses on immediate rewards that are inherent in the experiences of performing a certain occupation” (Persson et al., 2001) p. 10. The joyment is the main characteristics of this dimension and in this enjoyment comes a experiences of forgetting oneself and time (Person et al., 2000). In addition, MacRae (1991) found that when individuals with severe
mental illness performed occupations, this took their mind off problems and gave them relief for a while. The last factor, “Identification with others” mirrors a social dimension such as identification with others, and identification with different social roles. This is in agreement with the model of Persson et al (2001) who stated that the performance of the chosen occupation links the individual to a certain social group or subgroup, and with other studies indicating that occupation facilitates a sense of belonging (Rebeiro & Cook, 1999) and enables the individual to became identified in a social role (Rebeiro & Allen, 1998). In a study by Topor (2001), it was demonstrated that individuals with several mental disorders described that in relationship with others they could test the viability of their recovery. To my knowledge no other tools have been developed from the individuals’ own experiences of participating in occupations. The EOPQ may be a basis for developing a tool to evaluate effects of occupation-based treatment.

**Perceived burden in daily life among caregivers**

Caregivers’ experienced burden was described by the three factors ”Activity limitation”, “Feelings of worry and guilt” and “Social strain”. It should be noted that the first factor reflects objective burden and the second and third factors subjective burden in accordance with Schene (1990). These results agree with the findings of Reinhard et al (1994). The factor structure was not identical to that of the Reinhard et al (1994) studies. These authors demonstrated five-factor solutions and distinct objective and subjective dimensions. The first factor “Activity limitation”, reflecting mostly consequences for daily activities with missed work and upset household routines. This factor is similar to the factor “Disrupted activities” that was found in the two samples of the Reinhard et al (1994). These results should be compared to those in a study by Gopinath and Chaturvede (1992) who found that self-care related activities, household, leisure and work related activities were perceived to be most distressful to the caregivers. Also, Jones et al (1995) found that caregivers reported more of burden related to day-to-day tasks than those related to caretakers’ behaviours. These findings indicate that treatments are needed to support caregivers to handle burdensome situations related to daily activities.
A majority of the caretakers were men. Men become ill three to four year earlier than women, and these few years may give women a better social start than men (SOU, 1998). It has also been found that more women are married or cohabitants and have children (SOU, 1998). In the present study, most caretakers lived alone and in own living, which agrees with the investigations by the Swedish National Board of Health and Welfare (SOU, 1998).

The results confirm that family caregiver burden is complex and includes several areas such as activities in daily life, worry and guilt and social strain. Given this knowledge about caregivers’ situation, it is critical that families be given opportunities to identify what treatment might help. Further research is needed to identify such treatments. The findings that caregivers’ burden was related to leisure time activities in daily life and to household routines indicate that such problems might be a treatment area for occupational therapy. No study has been found of treatments aimed to reduce family burden related to daily activities.

Methodological considerations
In Study I, the participants were asked to use as a basis for their replies their experiences of performing daily activities and in Studies III and IV of performing occupations organized by the health care system. These results have an unknown limited generalizability since diagnosis, onset of illness, and hospital admissions among the participants were not known in Studies I and IV. These psychiatric variables are commonly used to identify cases in mental health research (Dworkin, 1992). These studies focused on individuals’ ability to perform daily activities and their experiences of performing occupations rather than on their illness. Throughout the history of psychiatry, the definitions of mental illness have shifted and symptoms may be viewed from several theoretical perspectives and in relation to the developmental course of the illnesses (Ottosson, 1995). For these reasons, was judged to be more important to describe the ability to perform occupations rather than adopt a diagnostic perspective.

About 75 % of the individuals participating in the activity settings in Study I did not want to participate in the study. It is unclear why so many refused to participate,
and if those who participated had the most positive attitude to communication or to participating in occupations. However, the individuals who participated in Study I were a heterogeneous group concerning age, educational level, civil status and living situation. In spite of this, the results should be interpreted with caution. In all the studies of individuals with severe mental disorders, the main difficulty was to get in touch with the participants. When the contact was taken, most participants were positive to sharing their experiences.

The occupational therapy records varied concerning the number of pages (1-30), structure and content, from highly structured to narrative (Study II). These variations agree with Lundgren Pierre and Sonn’s (1999) findings. These authors found from highly structured to communicative descriptions in occupational therapy records. The records provided by occupational therapists in the present study represented a geographical distribution from all parts of Sweden, and were from diverse settings such as large institutions, adult care and rehabilitation units. The 64 charts were found to be sufficiently detailed for identifying the goal, treatment and outcome of occupational therapy. This suggests that the records mirror the occupational therapy process for individuals with psychosis.

The response rate among the occupational therapists who were asked to send in records was very poor. It can be suspected that this was due to unclear documentation of occupational therapy in patients’ records or that the occupational therapists felt themselves questioned by the request. The main reason for non-participation was “no answer from physician in charge”. The poor response rate (23%) and the large proportion of non-responders calls for caution when interpreting the results. An alternative data collection method would have been to randomly select institutions providing occupational therapy to individuals with severe mental disorder.

To identify and sample cases is a well-known problem in mental health research (Dworkin, 1992). In spite of this, as many as 106 individuals were recruited for Study IV. Tabachnick and Fidell (2001) and Combrey and Lee (1992) recommend a sample size of 200 to 300 for factor analyses. Thus, it may be questioned if the factors identified in the EOPQ in Study IV are valid. Replication in a larger sample is needed.
In Study IV, the two daily CPDO activities, “Home maintenance / repair work” and “Use the dishwasher” were not applicable for most of the participants. This suggests that these activities should be deleted when using the CPDO for individuals with severe mental disorders. The six questions in the CPDO were found to give valuable information about self-perceived capability to perform daily activities, although it was developed for individuals with chronic pain. In spite of the fact that only three items in the CPDO concerned leisure time, the results showed that the participants experienced leisure activities as most problematic.

No published study has been found in which the Swedish version of the ACLS has been used. Further research should explore the psychometric properties of the Swedish version, although the results from Study I correspond with earlier findings (Allen, Erhart & Blue, 1992, APA, 1994).

The findings in Study II may have been influenced by the fact that only one person performed the analyses of the patient records. However, the Template of Occupational Therapy (TOT) questions were structured and were asked in relation to all records. Also, explicit sentences, terms and words were used as answers. No attempts were made to interpret the documentation.

The phenomenological research design of Study III was found suitable for capturing the individuals’ experiences of occupational therapy. At first sight, some parts of the narratives seemed rather poor for such an analysis since the women described their experiences in short utterances rather than in narrative form. However, almost every meaning unit could be analyzed in the light of occupational therapy terminology, maybe due to the fact that the interviews were conducted immediately after a session in which the women had been involved.

It can not be excluded that the analyst’s own opinions influenced the analysis of the interviews. A few unclear transformations found by the second and third authors were checked against the original text and discussed with the first author until consensus was reached. Some parts of the methodology should have served to counteract influences from the analyst. The analysis focused on the experience of occupational therapy, not on the experience of mental illness. No attempt was made to interpret obscure parts of the text as signs of psychosis. When meaning units were
difficult to analyze, the whole original text was read repeatedly to see how this specific part could be understood in the focus of occupational therapy.

Half of the sample in Study IV completed the EOPQ as an interview and half as a mailed questionnaire. A comparison between the answers of participants included by the staff and by the relatives showed a significant difference in the factor “Challenge” (t = -4.31; df = 104; p = 0.000). The participants included by their relatives reported less experiences of “Challenge” than did the participants included by the staff. There were no differences between the two groups regarding the remaining six EOPQ factors. In the sample that received the EOPQ by mail, eight questionnaires could not be included because of missing values. This indicates that the EOPQ might be more suited for an interview. It also suggests that the questions need to be developed further. For the sample that performed the EOPQ as an interview, the individuals had opportunities to ask if they did not understand the questions.
SUMMARY OF FINDINGS AND CONCLUDING REMARKS

The results showed that the participants interrupted and avoided Activities of Daily Living occasionally and perceived some exertion and inconveniences when performing such activities. The Play and Leisure Activities seemed more problematic to the participants. Men, participants who reported a diagnosis and those who lived alone perceived Work and Productive Activities as more problematic than the comparison groups. The participants reported that they were satisfied after performing the daily activities.

The findings also indicated that more than half of the participants were in need of assistance in performing occupations and the reminder were in need of supervisory assistance in specific situations that require planning and organisation. Participants’ cognitive level seems to correlate with their performance of WPA.

The content of the occupational therapy records concerning “occupational therapy goal” ranged from goals referring to the patient’s inner life to goals relating to the patient’s practical ability to structure daily life. “Treatment outcome” was related to patient experiences and how they were able to manage their activities of daily life. The documentation of “occupational therapy interventions” concerned mainly the occupations that were used as a means in therapy.

Women with psychosis reported that participation in occupational therapy had affected them by giving relief, self-knowledge, belief in the future, capability, resistance and satisfaction. The form of occupational therapy was expressed in terms of time, environment, guidance, voluntaries and collaboration and describes how the women experienced the arrangement of occupational therapy.

The EOPQ was developed on the basis of experiences of women participating in occupational therapy. A principal component analysis yielded the seven factors, “Satisfaction with own ability”, “Confidence in own ability”, “Challenge”, “Ability to handle difficult situations”, “Forgetting time and self” and “Identification with others”. These factors were found to have acceptable homogeneity. There were no significant gender differences for any of the factors. The EOPQ represents an attempt to develop an assessment tool for evaluation of occupational therapy outcome.
The BAS was found to have an underlying structure with three factors, “Activity limitation”, “Feelings of worry and guilt” and “Social influence”. The findings indicated that caregivers experienced more “Activity limitation” and “Social strain” in relation to the youngest caretakers and to those who had an elementary educational level than they did for comparison groups.

The ability to perform daily activities among individuals with severe mental disorders has been studied from three perspectives, the individuals’, the occupational therapists’, and the experienced burden of the family caregivers. These perspectives are complementary and thus necessary for planning and implementation of individually adapted occupational therapy as well as for evaluating outcomes. The participation in occupational therapy was experienced to strengthen the individuals confidence in their own ability, which supports assumptions in occupational therapy. The relationship between occupation used as a therapeutic mean and health has to be further investigated.
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REFERENCES


Appendix

The Template of Occupational Therapy (TOT) used for analysing the concepts goal, treatment and effect/outcome of occupational therapy in mental health services. Each question starts with the phrase: What is documented about…?

<table>
<thead>
<tr>
<th>Occupational therapy goal</th>
<th>Occupational therapy treatment</th>
<th>Effect or outcome of occupational therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Planning goals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The patient’s and the therapist’s cooperation and the patient’s involvement in the planning process?</td>
<td>Concept from a theoretical base?</td>
<td>Patient’s experiences of health effect or outcome and or occupational effect of outcome?</td>
</tr>
<tr>
<td>The patient’s restriction in occupational performance?</td>
<td>Expected results based on theoretical explanations?</td>
<td>Observable occupational effect or outcome?</td>
</tr>
<tr>
<td>The patient’s ability in occupational performance?</td>
<td>What assessment types are used by occupational therapists in order to identity the patient’s need?</td>
<td>Measuring effect or outcome</td>
</tr>
<tr>
<td>The way of measuring the goal</td>
<td>Planned measures?</td>
<td>Methods/instruments, according to whether assessment was done by patient or therapist or both?</td>
</tr>
<tr>
<td>In terms of time?</td>
<td>Occupational therapy recourses available</td>
<td></td>
</tr>
<tr>
<td>In behavioural terms?</td>
<td></td>
<td></td>
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<tr>
<td>In objective terms?</td>
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<tr>
<td><strong>The step-by-step goals</strong></td>
<td></td>
<td></td>
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<tr>
<td>Health goals such as the patient’s expected, optimal occupational health?</td>
<td>The occupational therapists use of self?</td>
<td></td>
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<tr>
<td>The expected final long-term goal of occupational therapy?</td>
<td>Use of the group as a resource?</td>
<td></td>
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<tr>
<td>The expected intermediate goal of occupational therapy?</td>
<td>Use of the non-human environment?</td>
<td></td>
</tr>
<tr>
<td>The short-term goals of occupational therapy, according to Their hierarchical order?</td>
<td>Measures used to meet the patient’s health needs?</td>
<td></td>
</tr>
<tr>
<td>Which is first?</td>
<td>Measures used to facilitate prevention?</td>
<td></td>
</tr>
<tr>
<td><strong>The group goal</strong></td>
<td>Measures that have been used to facilitate the change process?</td>
<td></td>
</tr>
<tr>
<td>The goal of the group?</td>
<td>Measures that have been used to facilitate maintenance?</td>
<td></td>
</tr>
<tr>
<td>The goal of the individual members?</td>
<td>Measures that have been used to facilitate management?</td>
<td></td>
</tr>
</tbody>
</table>