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PO Box 117
221 00 Lund
+46 46-222 00 00

Occupational Perspectives on Health in People with Schizophrenia

*-Time Use, Occupational Engagement
and Instrument Development*

Ulrika Bejerholm



Department of Health Sciences
Division of Occupational Therapy
and Gerontology



OCCUPATIONAL PERSPECTIVES ON HEALTH IN PEOPLE WITH SCHIZOPHRENIA

*–Time Use, Occupational Engagement
and Instrument Development*

Ulrika Bejerholm

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Department of Health Sciences, Division of Occupational Therapy and Gerontology
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Abstract <p>The thesis has provided with systematic information about how people with schizophrenia live their everyday life, and the results have shown significant relationships between occupational perspectives and health. The thesis departed in two in-depth studies that concerned time use and occupational engagement in relation to what people with schizophrenia do in their everyday life, with whom they are with, where they are and how they perceive and experience what they do, as reflected by time-use diaries. The first study showed that most time was spent alone, at home, where few occupational situations worked as a routine, providing a structure in terms of familiarity of habits. The second study showed that the participants functioned at different levels of occupational engagement, which ranged from performing mostly quiet activities alone, at home, with few routines and a little sense of meaning, to having ongoing occupational engagement that were interpreted as having meaning, in a greater variety of social and geographical environments. In particular, the function of performing quiet activities, the different ways of being social and of interpreting on experiences, have provided with new aspects that concern the occupational behaviour in people with schizophrenia. Based on these findings elucidated so far, the third and fourth study concerned the development of a reliable and valid instrument, the Profiles of Occupational Engagement in people with Schizophrenia. In study four and five, the POES was used to assess occupational engagement in relation to health related variables. The results showed that a high level of occupational engagement was related to higher ratings of self-related variables, fewer psychiatric symptoms, and better ratings of quality of life, and vice versa. The results of this thesis add a new dimension to understanding mental health. Consequently, identifying the level of occupational engagement in clients with schizophrenia is imperative to, understanding occupational balance and disability, the forming of a supporting relationship, providing appropriate occupational challenges and environmental support with intention to facilitate self-definition.</p>		
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Ulrika Bejerholm, Division of Occupational Therapy and Gerontology, Department of Health Sciences, Lund University, Sweden.

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Date December 5, 2006

The whole of human organisation has its shape in a kind of rhythm...night and day, of sleep and waking hours, of hunger and its gratification...work and play and rest and sleep, which our organism must be able to balance even under difficulty. The only way to attain balance in all this is the actual doing...of wholesome living as the basis of wholesome feeling and thinking and fancy and interests (Meyer, 1922/1977).

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- III. Bejerholm, U., Hansson, L., & Eklund, M. (2006). Profiles of occupational engagement in people with schizophrenia, POES: Development of a new instrument based on time-use diaries. *British Journal of Occupational Therapy*, 69, 1–11.
- IV. Bejerholm, U., & Eklund, M. (2006a). Construct validity of a newly-developed instrument: Profiles of Occupational Engagement in people with Schizophrenia, POES. *Nordic Journal of Psychiatry*, 60, 200–206
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Occupational Perspectives on Health in People with Schizophrenia

*–Time Use, Occupational Engagement
and Instrument Development*

Ulrika Bejerholm

Introduction

This thesis has aimed at visualising an occupational perspective on health in people with schizophrenia, by illuminating everyday life and investigating its relationships to health-related variables. This perspective on health is not always evident and visible for professionals who work with clients' with schizophrenia, sometimes on a weekly basis but often at longer intervals. However, having schizophrenia affects the entire existence and all the hours of the week. It is important to understand what people with schizophrenia do with their time, what engages them, what they perceive as meaningful or not, how they interact with their environment, in order to understand their health. Such an understanding could help health-care planners and professionals find strategies for how to enable people with schizophrenia to engage in their everyday life in a way that supports their health.

In this thesis, occupation refers to everything that we do and occupy ourselves with in everyday life, and not only work. Occupation refers to performance or doing in time and place, and the experiences attached (Pierce, 2001a). Occupation involves the dynamic interplay between the person, the occupation and the environment (Law *et al.*, 1996). Doing things enables people to meet and obtain the requirements for living, survival, health and well-being and form the actual building stones that make people engaged and find meaning and well-being in everyday life (Wilcock, 1998). Among occupational therapists, the occupational perspective on mental health has been present since the turn of the last century. It was stated that the proper use of time in some helpful and meaningful occupation was a fundamental treatment of any psychiatric patient (Meyer, 1922/1977). Occupational therapists are concerned with treating the consequences of disease or injury as they

affect a person's ability to engage in occupations and it is assumed that people have the ability to influence their own health through engaging in occupations (Yerxa, 1998). Accordingly, this thesis aims to contribute to a complex, but also a realistic perspective on health, well-being and quality of life in people with schizophrenia.

Schizophrenia and Psychopathology

In Sweden, people with schizophrenia constitute about 0.8% (70,000) of the population (Socialstyrelsen, 2003c). Schizophrenia is a complex disorder. The aetiology involves interactions between both genetic, environmental and vulnerability factors. Schizophrenia is characterised by psychotic symptoms and cognitive dysfunction, leading to a certain way of thinking, feeling and relating to the outside world. Schizophrenia involves losing the sense of self and control over the cognitive, emotional and attentional resources (Austin, 2005). A cognitive decline is most often associated with the illness onset, but tends to remain over time (Muesser & McGurk, 2004). Consequently, schizophrenia can dramatically affect the functioning of a person in his or her everyday life, and to the extent to which that person can coordinate and engage in occupations (Austin, 2005; Davidson, Stayner & Haglund, 1998; Green, Kern, Braff & Mintz, 2000; Liberman, Neuchterlain & Wallace, 1982; McKibbin, Brekke, Sires, Jeste & Patterson, 2004; Tsang & Pearson, 2000). For example, the future perspective is usually dependent on the extent to which persons can perceptually organise life events and project themselves into the future (Neville, 1980). Furthermore, every occupational situation is often regarded as a new phenomenon by people with schizophrenia, whose experiences are often regarded as having little coherence or anchorage with either the past, the present, or the future (Neville, Kreisberg & Kielhof-

ner, 1985). Moreover, the goal setting is often proximal and immediate, and in everyday life there are few social roles to fulfill (Suto & Frank, 1994).

There have been different ways of classifying schizophrenia throughout the 20th century. The term schizophrenia was first introduced by Bleuler and the conceptualisation of the disorder was not as narrow and pessimistic as the one that was introduced earlier by Kraplin (Sadock & Sadock, 2003). In a meta-analysis regarding the outcome of schizophrenia, based on the literature from 1895 to 1992, the main predictive factors were if a narrow or a broad diagnostic system was used, and the use of anti-psychotic medication (Hegarty, Baldessarini, Tohen, Water-naux & Oepen, 1994). According to Austin (2005), there are currently no biological markers for schizophrenia. Consequently, the diagnosis relies on subjective assessment and of an individual clinical presentation. Internationally and in Sweden there is consensus about using two systems, the Diagnostic and Statistical Manual of Mental disorders, DSM-IV (American Psychiatric Association, APA, 1994, 2000) and the International Classification of Diseases, ICD-10 (Armenteros *et al.*, 1995; Austin, 2005; Jakobsen *et al.*, 2005; World Health Organization, 1997). All main categories used in the DSM are found in the ICD-10 and the systems are fully compatible (Sadock & Sadock, 2003).

Positive and negative symptoms are clinical characteristics that are further used for the classification of schizophrenia, and they have significantly influenced research. The positive symptoms refer to delusions and hallucinations that are added to an individual's behaviour and perceptions (Pogue-Geile & Zubin, 1988; Sadock & Sadock, 2003), and the negative symptoms refer to lacks in behaviour and perceptions, including affective flattening, poverty of speech, poor grooming, lack of motivation and social withdrawal (Austin, 2005; Pogue-Geile & Zubin, 1988; Sadock

& Sadock, 2003). However, individuals who suffer from characteristic symptoms at one point in time may still have varying outcomes and courses of symptoms as time passes (Ciompi, 1980; Liberman *et al.*, 1982).

Transitions in the Mental Health Care System

People with schizophrenia have been a disadvantaged group concerning both living conditions and access to adequate care, support and rehabilitation towards integration in society. During the last three decades the mental health care system in Sweden has moved its focus from treating patients with schizophrenia in institutions, towards a community-based health care system with geographically defined sectors (Markström, 2003). This process of deinstitutionalisation started in the 1970s and had its main peak from 1985 until 1994, when a large number of discharges were made of people with severe mental illness (Gahnström-Strandqvist, 2003; Markström, 2003). In order to overlap the gap between a hospital-based and a community-based mental health care system, the Swedish National Board of Health and Welfare in the 1980s presented guidelines for mental health, which forwarded the importance of providing care and rehabilitation in the patients' own living context (Socialstyrelsen, 1980). Mental health care was subsequently assembled into local geographical sectors.

These sectors had coherent responsibility for both hospital care and community care. However, the community care system was not built up at the same pace as the institution-based care system was closing down. Therefore, for people with schizophrenia, deinstitutionalisation often meant going from being cared for around the clock and externally controlled, with little time on their own and spending most of the time in a hospital, to getting too little care, support and rehabilitation, with too much time on their own. This

shift, which was implemented in most western countries, although at a different pace, led to feelings of loneliness among people with schizophrenia, often described in research (Davidson & Stayner, 1997; Gahnström-Strandqvist, Andersson & Josephson, 1995; Gerstein, Bates & Reindl, 1989). Another consequence of the reform was that the throughput in the acute wards increased (Markström, 2003). This was in accordance with the interventions, but in addition, there was an increased risk for homelessness, addiction, and mortality (Harvey *et al.*, 1996; Scott, 1993; Wasserman, 2003; Ösby, Correia, Brandt, Ekblom & Sparén, 2000). Increased violence in connection with people with mental illness has also worsened the socio-cultural climate for people with schizophrenia as a whole and a recent report showed that many people with schizophrenia have no structured occupations and gain little meaning from the occupations they do perform (Socialstyrelsen, 2005). According to Wasserman (2003), people with severe mental illness are a marginalised group today, and they seem to be as segregated from society now, if not more, as they were when they were living in institutions. Despite these circumstances, little has been done in society to help establish everyday life for people with schizophrenia, although they clearly have difficulties in engaging in occupations and in participating in modern society (Socialdepartementet, 1992; Socialstyrelsen, 2005).

Ever since the change in the mental health care system, due to the deinstitutionalisation, the pioneering work of multi-disciplinary teams that work in outpatient care centres has aimed at building up adequate care, adapted living environments and vocational rehabilitation centres. This outpatient mental health care has most often been successfully co-ordinated by different forms of case management, where case-management refers to co-ordinating and adapting care and rehabilitation according to individual needs

(Holloway, 1991). Besides antipsychotic medication, a number of evidence-based psychosocial interventions may assist everyday life for people with schizophrenia. In addition to case-management, such interventions might be social skills training, family interventions, cognitive behaviour therapy, and supported employment. The goal is to enable people to develop social and vocational skills for independent living, and the interventions are carried out in different environments, such as in the outpatient care centres, hospitals, day-care centres, and people's homes and social clubs (Sadock & Sadock, 2003).

The clients, the users, have become more alert to looking out for their own group and their rightful place in society. It is increasingly assumed that a mental health care that considers the users' experience of everyday life and autonomy provides requirements for effective care and rehabilitation with better results (Hansson, 2006). In this respect, it would be warranted to investigate the experience that people with schizophrenia have in their everyday life. Research has shown that meaningful occupations seem to be related to their perception of health, well-being and quality of life (Eklund, Hansson & Bejerholm, 2001; Goldberg, Brintnell & Goldberg, 2002; Strong, 1998). However, not much is known about how people with schizophrenia actually perceive their everyday life.

Disability

The individual's disability is part of the decision making of whether he or she has schizophrenia (Sandlund, 2005). This implies that having schizophrenia involves disabilities in everyday life. Moreover, the transitions in the mental health care system have led to changes in how to view health and people with schizophrenia are focused on not only as a group of severely mentally ill, but increasingly as a group of people with certain disabilities. Thus, it is rather the disability than

the psychiatric diagnosis that will form the basis for planning care and service. Presently, however, the development of psychosocial interventions in mental health care has been accomplished with little support from research and knowledge regarding disability and the constituents of everyday life. Such knowledge could assist the professionals in that part of their clinical reasoning that concerns disability in an ever-changing personal and environmental context. Moreover, as a consequence of this void of knowledge, it has been difficult for the professionals working in mental health care to fully understand and take on the responsibility stated in the National Guidelines given by the Swedish Board of Health and Welfare (Markström, 2003), including the provision of meaningful daily occupations. A Swedish report showed that, in general, the mental health care in the community does not have a clear picture of the way of life among people with disabilities caused by severe mental illness (Socialstyrelsen, 2003b). Sandlund (2005) stressed that the interpretation of the disability also seems to depend on who you ask, on the professional category and its main theoretical and ideological position in the matter. A reason may be that disability could be viewed as something that is dynamic and unstable over time. It would probably be easier to grasp mental health care when disability is viewed as something stable and static, as when a medical and an illness perspective are reflected in the outcome of care and rehabilitation.

Current views on disability

The International Classification of Functioning (ICF) (Socialstyrelsen, 2003a; WHO, 2001) can be used in order to grasp the functional limitations following a disease and how these limitations can lead to decreases in occupational engagement and participation in society. According to the ICF, functioning and disability are viewed at two interacting levels. These levels are the body structures and

function level, and the activities and participation level. In addition, contextual factors, such as personal and environmental factors, affect the levels of functioning and disability. Accordingly, the activities and participation level is influenced by the underlying health condition, the body structures and functions level, the environment, and personal factors (WHO, 2001). In a way, disability becomes the comprehensive link between the body functions and structures, and the activities and participation (Socialstyrelsen, 2003a). The National Swedish Board of Health and Welfare (Socialstyrelsen, 2003c) declared that both limitations in body functions, and limitations that concern activities and participation have to be attended to among people with schizophrenia.

The current view on disability among people with psychiatric disorders, that is taking form in Sweden, concerns the consequences in everyday life. According to National psychiatric services coordination (2006), a person has a disability if she/he has substantial difficulties in performing activities concerning important life domains, and if these limitations have existed or can be assumed to remain for a longer period of time. The difficulties shall be a consequence of having a psychiatric disorder. Moreover, the consequences can be a result of functional limitations and the activity limitations of a person, and/or a result of limitations in the environment.

Occupational therapists also find it important to assess the persons abilities and the environmental influences, outlined in a series of events throughout the day (Kielhofner, 2003; McLaughlin Gray, 2001; Wilcock, 2005). The reason for disability could exist on a personal level, but also on an environmental and an occupational level, thus the disability may appear in different ways according to what the person does (CAOT, 2002). This occupational therapy perspective on disability and health is in line with the concepts and underlying assumptions about disability and

health that the ICF system (Socialstyrelsen, 2003a; WHO, 2001) provides, and the current view that the National psychiatric services coordination (2006) has.

Occupational Therapy in Mental Health

Theory Development

Occupation has a therapeutic value and has been an integral part of treating people with schizophrenia ever since the moral treatment movement in the early 19th century (Scull, 1979). The American psychiatrist Adolf Meyer is often regarded as the founder of occupational therapy, along with other professionals that worked together as a team. The team consisted of two psychiatrists, a nurse, a social worker, a physician, and an architect, and they worked with severely mentally ill people by helping them retrain or adjust to a meaningful living by means of performing occupations (Creek, 2003). A Swedish physician, Dr Westlund, also promoted this trend in treatment, that people could be cured through engagement in suitable occupations (Palmborg, 1940). Since then, occupational therapists have taken over the baton. They have contributed to different methods of using occupations as therapeutic means and ends and they have enabled people to engage in meaningful occupations (Hasselkus, 2002; Trombly, 1995). In addition, related knowledge, that is knowledge developed outside the discipline of occupational therapy (Kielhofner, 2004), such as the psychoanalytic approach, has been used by occupational therapists in order to understand and explain the symbolic meaning of occupations (Bruce & Borg, 1993; Fidler & Fidler, 1963; Finlay, 1997). For instance, the object relation theory has been used, since relations to others and to objects are fundamental to occupational engagement. In treatment, engagement in creative and meaningful occupations may facilitate both verbal and

non verbal communication (Eklund, 2000; Fidler & Fidler, 1978; Winnicott, 1965). Also humanistic, cognitive/behavioural and sociological approaches have been necessary in order to understand therapeutic factors inherent in occupations (Creek, 2003; Finlay, 1997; Hagedorn, 1995). The interpretation of this related knowledge in relation to occupations has helped occupational therapists to assume therapeutic benefits of occupational engagement, and clinical experiences have added to such beliefs, but little empirical research supports this assumption. However, since the 1990s, the discipline of occupational science has enticed many researchers, also outside the field of occupational therapy, to study the occupational life in different populations. The main purpose of occupational science is to understand how people engage in and experience occupations and how different aspects of occupation may determine health and wellbeing (Clark *et al.*, 1991; Wilcock, 2005; Zemke & Clarke, 1996).

Change in Context

The process of deinstitutionalisation also brought about a radical change in the professional role of occupational therapists. The treatment context changed from treating people with schizophrenia in hospitals, towards treating and helping people to recover in their real life context outside psychiatric institutions, closer to where the patients lived (Gahnström-Strandqvist *et al.*, 1995). Moreover, ever since the 1970s, there has been a gradual shift in the category of clients. At that time, occupational therapists were treating a more varied group of patients. Now, people with more complex needs, such as people with schizophrenia, are the main concern. It could be said that occupational therapists implemented occupations as therapeutic means differently before and after the process of deinstitutionalisation. In the hospitals, the occupations aimed at increasing the

clients' mental functions. After the deinstitutionalisation action the occupational therapists faced a new arena that concerned the total occupational situation of their clients. Thus, occupational therapists moved from focusing on the person and more functional features of the schizophrenia illness, toward a more holistic perspective of schizophrenia in relation to occupation, health and quality of life. Hence, the use of occupation as an integral part of treatment has changed throughout the history along with social and political factors, and the fluctuating beliefs in the cause of mental illness (Creek, 2003). Furthermore, the changes in the mental health care system meant that occupational therapists that had previously worked together in separate organisations came to work together with professionals in multidisciplinary teams. According to Gahnström-Strandqvist *et al.* (1994), this new role of being a team member meant a fine balance between adjustments to the team and professional identity. As a consequence, the occupational therapists have become more visible to other professionals which has contributed to the recognition of their professional identity.

Occupational Perspectives on Health

The occupational perspective on health, that the human being is by nature active and needs to engage in occupations in order to develop, and to find meaning and well-being in life, has been guiding occupational therapists since the profession was established (Kielhofner, 2002). This occupational perspective on health has been supported by a number of occupational scientists (Wilcock, 2003, 2005; Yerxa, 1998; Zemke & Clarke, 1996). Health is viewed as the ability to engage in occupations that are related to the primary goals in everyday life (Yerxa, 1998). The dynamic perspective on health recognises the individual differences, in contrast to health based

on a medical paradigm (Kielhofner, 2003). In clinical practice, this perspective is reflected in how occupational therapists use occupations as therapeutic means and how they enable the clients to use their own capacity. Moreover, occupational therapists adjust the environment so that the client can engage in individually motivating and purposeful occupations, which in turn is supposed to lead to health and well-being (Wilcock, 1993). The growing research, that aims to investigate relationships between occupation and health in different populations, can help to form a knowledge base that supports occupational therapists and other professional in their clinical work.

Occupational Performance

Occupational therapy focuses on the complex and dynamic relationships between the personal, the environmental and the occupational domain of occupational performance (Law *et al.*, 1996). Occupational performance can be interpreted as the outcome of the transaction between these domains (Dunn, Brown & McGuigan, 1994; Kielhofner, 2002; Law *et al.*, 1996; McLaughlin Gray, 2001; WHO, 2001). By adjusting the person, the environment and the occupations in order to provide a good fit between the three domains of occupational performance, the person gains the ability to go on performing occupations that provide meaning and purpose (Strong *et al.*, 1999). However, if there would be a misfit between the three domains, perhaps as a consequence of an illness, a disability would become apparent in that person's life (Strong *et al.*, 1999; WHO, 2001). Thus, when it comes to understanding disabilities, the person cannot be viewed as being separate from the contextual influences.

The PEO model

The person-environment-occupation PEO-model is used as a general frame of refer-

ence throughout this thesis. Assessment and treatment of the disability of schizophrenia could potentially be focused on any of the constituents and links in such a model. The PEO model builds on concepts and ideas from Csikzentmihalyi and Csikzentmihalyi (1988) and Lawton and Nahemow (1973), and from the Canadian guidelines for occupational therapy practice and measurement (Canadian Association of Occupational Therapists, 1991; Law *et al.*, 1994). In the model, it is acknowledged that behaviour cannot be separated from contextual influences, temporal factors, and physical and psychological characteristics (Christiansen, Baum & Bass-Haugen, 2005; Law *et al.*, 1996). This is in line with the dynamic view on human behaviour in to the International Classification of Functioning (ICF) (Socialstyrelsen, 2003a; WHO, 2001), and according to the general systems theory, which states that there is a constant interplay between the human organism, as an open system and its environment (Kielhofner, 2002, 2004; Reed & Sanderson, 1992). A key strength with the PEO-model is that it considers daily occupations as they appear in everyday life. Furthermore, there is also a consideration of evaluations and interventions that target the person, the environment and the occupation, offering multiple avenues for facilitating engagement in occupations. However, little research exists that investigates factors from all three domains in a systematic way (Crist, Davis & Coffin, 2000; Robinson, 1997).

The personal domain of occupational performance involves the physical, social, cognitive and psychological capacities of a person (Law *et al.*, 1996). The personal domain includes the self-concept, personality, cultural background and competencies. Values and beliefs shape the perceptions of self in relation to occupations and environments, and through internal processes they influence the way in which the world is observed and explored. Personal characteristics can either

support capacities or limit occupational engagement.

The environmental domain provides a context in which persons engage in occupations (Dunn *et al.*, 1994). Environmental contexts occur outside the individual and elicit responses from him or her. The environment has physical, social, economical, political and cultural characteristics, and occupational therapists often consider enabling or disabling qualities of the environment (Law, 1991). According to Harvey (1999), the behaviour is regularised in different social and physical environmental settings. For example, the spatial dimensions alter the possibility to act, cultural or institutional factors provide orientation and reinforcement, and a sufficient social network provides motivation to make things happen.

The occupational domain concerns ‘what’ we do (Law *et al.*, 1996). The occupation is carried out by a person in an environmental context and provides the basis for feelings about ourselves. Engagement in meaningful occupations shapes our sense of self and identity. They make us engage ourselves in the surrounding world in order to survive and maintain who we are.

Occupational Engagement

The concern of occupational science and occupational therapy is people’s ability to engage in meaningful occupations throughout their life span (Law *et al.*, 1996). Occupational engagement provides means to mental and physical health and, most importantly, a sense of meaning and purpose to existence (Meyer, 1922/1977; Wilcock, 1993; Yerxa *et al.*, 1990). A person can be engaged in daily occupations to various extents. This is reflected in the richness and the variety of personal experiences and physical, social and temporal contexts. The dynamic interplay between the person, the environment and the occupation, the three domains involved in occupation-

al performance, could further be viewed as the basic units of occupational engagement. Furthermore, occupational engagement is a lifestyle characteristic, which if identified can help form the basis for occupational therapists in finding appropriate strategies for evaluation and intervention (Christiansen, 2005; Fidler, 1996).

Process of Occupational Engagement

To be engaged in daily occupations, in terms of interacting with the environment according to one’s capacities and experiences, involves a process of occupational engagement (Rebeiro & Cook, 1999). This process is about the connection between the occupational performance factors, the outcome of it, and how it is perceived. It is also about maintaining or altering the individual’s capacities and in that generating ongoing experiences that affirm and reshape motivation (Kielhofner, 2003). Thus, the process of occupational engagement serves as a means to confirmation and maintenance of self over time (Rebeiro & Cook, 1999). To have ongoing occupational engagement provides a way of learning about self, discovering meaning and organising everyday life (Csikszentmihalyi, 1993; Hasselkus, 2002; Mee & Sumsion, 2001). Through “doing”, people are confronted with the evidence of the ability to function competently and take control of their lives as far as they are able. There is nothing which sooner and more satisfactorily increases an individual’s sense of self than the ability to accomplish something. Thus, the ongoing process of occupational engagement is essential to self-organisation, and by “doing” over time we shape who we are (Kielhofner, 2002).

Meaning

The human being needs to engage in occupations to develop and to find meaning in life (Wilcock, 1993). Meaning refers to the individual’s interpretation of occupational performance, the sense that is made out of the ex-

perience (Nelson, 1988, 1996). According to Kegan (1982), the sense of self is that “place” between occupational performance and the reaction to it, where meaning is privately composed. According to Kegan (1982) and Bruner (1990), this narrative and reflective process enclosed in the occupational engagement process is called meaning-making. Kegan (1982) means that the very act of being a person and having self-identity is an act of meaning-making. Expressed differently, to be human is to compose meaning out of experiences. This process is done by linking single everyday life experiences or perceptions together (Kegan, 1982; Ricoeur, 1984), whereby experiences are imprinted with greater or lesser amount of facets of emotions or meaning (Csikszentmihalyi, 1997).

Occupational Balance

Occupational balance is mostly considered as a temporal concept (Townsend & Wilcock, 2004). This refers to a balance between the time spent in different areas of occupations, such as work, self-care and recreation, and thus the daily rhythm between active and restful occupations (Christiansen, 1996; Nurit & Michal, 2003). Occupational balance is also understood as the balance between personal capacities and environmental and occupational challenges while engaging in occupations (Christiansen, 1996; Csikszentmihalyi, 1997). Hence, engagement in a variety of balanced and meaningful occupations that provide just the right challenges, that are neither too stimulating nor too under-demanding, are important to health and well-being (Christiansen & Townsend, 2004; Wilcock, 1998). However, occupational balance is a relative state and varies over time, and the perception of balance is highly individual (Backman, 2004). Occupational imbalance may precipitate or aggregate problems with health and quality of life and may occur as a consequence of a disabil-

ity (Pentland & McColl, 1999).

According to Backman (2004) studies on occupational balance have so far concerned groups of adults, women from a not ill population, persons with post polio syndrome, middle aged women with quadriplegia, mothers of a child with disabilities, people with rheumatoid arthritis and working adults. However, no research seems to have investigated time use and occupational balance in people with schizophrenia. According to Meyer (1922/1977), knowledge of the way in which people with mental illnesses use their time can contribute to the understanding of the functional limitation of a person and its impact on health.

Research related to Occupational Perspectives in People with Schizophrenia

Having schizophrenia is likely to affect the ongoing process of occupational engagement. The individual’s interpretation of performance is often jumbled and fragmented and the quality and flow of emotions are easily disrupted as well. This often means that people affected by this illness have to reconfigure everyday life (Gould, DeSouza & Rebeiro-Gruhl, 2005). According to Liberman and colleagues (1982) a disruption between affect and reality produces inappropriate expressions of emotions and affect, inferring that emptiness and a lack of feelings become a part of the schizophrenic experience. As a consequence of this lack of pleasure and emotional responsiveness, the person become apathetic and withdrawn, loses interest in the outside world and shows little motivation to pursue purposeful and meaningful occupations. Consequently, a pervasive loss of affective expression and experience characterises having schizophrenia. This affective state often results in emptiness in performing daily occupations (Davidson & Stayner, 1997).

Course of Illness

Occupational engagement in people with schizophrenia could be interpreted in the light of the course of their illness. It has been emphasised that the personal abilities to engage in daily occupations depend on psychopathology and stage of illness (Brown, 1998; Emerson, Cook, Polatajko & Segal, 1998; Nagle, Cook & Polatajko, 2002). The acute stage of a psychotic disorder clearly limits the possibility to engage and interact with the outside world (Nagle *et al.*, 2002). However, there seems to be a reciprocal relationship between the stage of illness and the extent to which people with schizophrenia engage in everyday occupations (Emerson *et al.*, 1998). For instance, psychosocial treatments (Thorup *et al.*, 2005) and occupational engagement have shown to have impact on negative symptoms among people with schizophrenia (Halford, Harrison, Kalyansundaram, Moutrey & Simpson, 1995; Leff, Thornicroft, Coxhead & Crawford, 1994; Mairs & Bradshaw, 2004), and delusions have also shown to decrease when engaging in social occupations (Myin-Germeys, Nicolson & Delespaul, 2001). Furthermore, negative symptoms have shown to be better determinants than positive symptoms of how people with schizophrenia manage everyday life (APA, 1994; Green, 1996; Green *et al.*, 2000; Hoffman & Kupper, 1997; Palmer *et al.*, 2002). Still, much remains to be known about the relationship between occupational engagement and the severity of psychopathology.

Sense of self

The consequences of having schizophrenia seems to involve losing the sense of self and not being fully equipped to coordinate and engage in daily occupations (Davidson *et al.*, 1998; Green *et al.*, 2000; McKibbin *et al.*, 2004). Topor argued (2001) that the obliteration of self constitutes the very essence of psychosis. There is a breakdown regarding

the self's capacity to cope with reality as a consequence of personal conflicts, caused by occupational and environmental demands or by psychological tension (Strauss, 1989). A longitudinal study by Davidson and Strauss (1992) showed that the recovery process developed in congruence with the increase of a sense of self. The result described how the sense of self, over time, increased its capacity to relate to and make sense of the outside world.

Self-related constructs, such as sense of coherence (Antonovsky, 1987, 1993), and mastery (Pearlin, Menaghan, Lieberman & Mullan, 1981) might be regarded as being involved in the interpretative and reflective process involved in occupational engagement. Among adults and children, higher levels of occupational engagement have shown to be related to increased self-control (Freeman, Anderson, Kairey & Hunt, 1982; Nowicki & Barnes, 1973). Moreover, in schizophrenia research, occupational aspects that have shown to be associated with self-variables are, satisfaction with daily occupations (Aubin, Hachey & Mercier, 1999; Eklund *et al.*, 2001), the need to engage in daily occupations, living conditions (Bengtsson-Tops, 2004), access to social contacts (Bengtsson-Tops, 2004; Pearlin *et al.*, 1981), and structured daily occupations (Rosenfield, 1992). Among people with severe mental illness, the perception of being in control of one's life situation has been shown to mediate the relationship between psychopathology and perceived health (Eklund & Bäckström, in press).

Quality of Life

Quality of life measurement aims to reflect and capture the current life situation in people with schizophrenia (Chan, Krupa, Lawson & Eastabrook, 2005; Hansson, 2006; Hansson *et al.*, 1999) and has become an important indicator of community adjustments among people with severe mental illness. One rea-

son for an increasing focus on quality of life might be the contextual change in treatment that came about in the transition of mental health care from treatment in institutions, where the illness and the psychopathology were the focus of treatment, to treatment in the community, where the psychiatric disability is focused on. Another reason for using quality of life as an indicator of adjustment is that people with schizophrenia often have disabilities that last for longer periods of time, and quality of life is regarded an adequate outcome when progress of treatment is to be evaluated (Hansson, 2005). Quality of life is often operationalised as satisfaction with life in different life areas (Barry & Zissi, 1997; Lehman, 1988; Oliver, Huxley, Priebe & Kaiser, 1997).

Among occupational therapists, the increase of occupational engagement is viewed as a goal towards enhanced quality of life (Chan *et al.*, 2005; Christiansen *et al.*, 2005; Goldberg *et al.*, 2002; Laliberte-Rudman, Hoffman, Scott & Renwick, 2004). Moreover, the role of occupational therapists is often to offer and provide occupational opportunities and thus the necessary conditions for quality of life (Hachey & Mercier, 1993). However, whether there is a connection between the degree of engagement in everyday life and quality of life is not clear, despite the fact that disruption in everyday life is a major area of disability among people with schizophrenia (McKibbin *et al.*, 2004). However, some research findings indicate such relationships (Chan *et al.*, 2005; Eklund & Bäckström, 2005; Eklund *et al.*, 2001; Goldberg *et al.*, 2002; Laliberte-Rudman *et al.*, 2004; Mercier & King, 1994). For instance, subjective quality of life has shown to be related to qualitative and quantitative aspects of social life and psychopathology (Caron, Tempier, Mercier & Leouffre, 1998; Lam & Rosenheck, 2000; Ritsner, 2003), just as perceived meaning and satisfaction with daily occupations have (Eklund & Bäckström, 2005; Eklund

et al., 2001; Goldberg *et al.*, 2002). Objective conditions, like the range of daily occupation or to have a job, have also shown to be related to subjective quality of life (Aubin *et al.*, 1999; Borge, Martinsen, Ruud, Watne & Friis, 1999; Ruggeri, Gater, Bisoffi, Barbui & Tansella, 2002). However, other studies failed to identify such relations (Eklund, Hansson & Ahlqvist, 2004; Kelly, McKenna & Parahoo, 2001). Against this backdrop of results, it is difficult to pinpoint what aspects of daily occupations have a more or less favourable influence on quality of life. Probably, this research area should benefit and be supplemented with qualitative research on the constituents of daily occupations that support satisfaction. However, considering the findings presented above, occupational engagement would constitute a potential indicator of quality of life among people with schizophrenia.

Everyday Life

Society is faced with the challenge of planning and providing health and welfare services that meet the needs of persons with severe mental illness (Markström, 2003), schizophrenia being the most disabling condition (Walkup & Gallagher, 1999). People with schizophrenia have been found to experience less satisfaction with everyday life than people in the population generally (Röder-Wanner, Oliver & Priebe, 1997). It is widely recognised that the disorder's heavy impact on everyday life constitutes an important aspect (Girard, Fisher, Short & Duran, 1999; Laliberte-Rudman, Yu, Scott & Pajouhandeh, 2000; Shimitras, Fossey & Harvey, 2003; Weeder, 1986), and in everyday life the disability becomes actualised (McLaughlin Gray, 2001).

Time use studies give a realistic picture of everyday life. So far, time-use research has shown that performing occupations in a passive and quiet way tends to predominate everyday life (Hayes & Halford, 1996; Minato

& Zemke, 2004; Shimitras *et al.*, 2003). People with schizophrenia often have problems with organising their daily occupations, which results in a chaotic way of dealing with time (Melges, 1982; Neville, 1980; Neville *et al.*, 1985), and a disharmony between the future images, plans of action, and emotions (Melges, 1982). Time appears to stand still, often because of a decreased ability to integrate perceptual information. A volitional problem is common in people with schizophrenia, and a social regression occurs with few roles to fulfil (Creek, 2003).

In studies that regard occupational perspective on health and quality of life, work is the occupational area that is most often addressed (Meuser *et al.*, 1997; Priebe, Warner, Hubschmid & Eckle, 1998; Strong, 1998). This focus may be due to the fact that work enables people to integrate socially and provides them with opportunities to explore and master their environment and thereby become integrated in society (Hayes & Halford, 1996; Marwaha & Johnson, 2004; Nagle *et al.*, 2002). Another reason for this focus in research might be the development of new service models that target work and the fact that the economic cost for unemployment in this group of people is tremendous (Marwaha & Johnson, 2004). Having a job is also associated with a better quality of life and well-being among people with schizophrenia (Eklund *et al.*, 2001; Priebe *et al.*, 1998; Van Dongen, 1996). Yet, few persons with schizophrenia are engaged in work occupations (Boyer, Hachey & Mercier, 2000; Crowther, Marshall, Bond & Huxley, 2001; Marwaha & Johnson, 2004; Nagle *et al.*, 2002; Shimitras *et al.*, 2003). In a survey that made an inventory of the number of people with severe mental illness registered in Sweden, about 43 000 people, only 8% had gainful employment, and 60% had no structured occupations at all (Socialstyrelsen, 1998). In European countries, the estimation is that only between 10–15% of people with severe mental illness has employment. In

the UK the employment rate has been slowly dropping, and stigma, discrimination, fear of loss of benefits and lack of appropriate professional help have been identified as barriers to getting employment (Marwaha & Johnson, 2004). There are also indications that people that are severely mentally ill derive less enjoyment, competence, and sense of importance from work than persons without such problems do (Crist *et al.*, 2000). Furthermore, in a time-use study where unemployed and employed single male schizophrenia participants were compared, Hayes and Halford (1996) concluded that unemployment only made a modest contribution to the impoverished lifestyle among the participants. In fact, it has been shown that even more than work, satisfaction with occupations in a broad sense, including self-care, household work and leisure occupations, was strongly related to quality of life and other aspects of health and well-being (Eklund *et al.*, 2001). Consequently, all occupational areas need to be investigated in order to understand health and quality of life in people with schizophrenia (Christiansen & Baum, 1997; Wilcock, 1993; Zemke & Clarke, 1996).

In relation to everyday life, it is worth questioning what it means to have a poor temporal framework and to have few time-bound occupations. People with schizophrenia often fail to accomplish age-related occupational areas of work, self-maintenance and play (APA, 2000). Few people with schizophrenia engage in work or other productive occupations, in the household at home or elsewhere in society, few engage in meaningful leisure, and to perform predominantly solitary and passive occupations is common (Hayes & Halford, 1996; Minato & Zemke, 2004; Shimitras *et al.*, 2003). These results contrast with findings regarding people that have other psychotic disorders (Brown, 1998; Haglund, Thorell & Wålinder, 1998) and results based on the general population (Crist *et al.*, 2000; Delespaul, 1995; Weeder, 1986).

Meaningful occupations

Engagement in occupations leads to unfolding layers of meaning (Hasselkus, 2002).

Meaning refers to an individual's interpretation and experience of the occupation (Nelson, 1988). The greater the breadth and depth of the experience in occupations, the greater the contribution of unique personal contexts and history to the meanings in that person's life (Reker & Wong, 1988).

Research regarding meaningful occupations in people with schizophrenia is underdeveloped, although the experience of meaning has shown to be related to increased quality of life in this group (Aubin *et al.*, 1999; Goldberg *et al.*, 2002). To work or study, to have structure in the day, and to sleep has shown to be meaningful occupations (Aubin *et al.*, 1999; Goldberg *et al.*, 2002; Mee & Sumsion, 2001). However, rest and free time has been found to be less meaningful compared to people without schizophrenia (Crist *et al.*, 2000). It has been found that occupational opportunities that could promote the experience of meaning seem to be lacking or inadequate for most people with schizophrenia (Goldberg *et al.*, 2002).

Environment

O'Brien *et al.* (2002) asserted that the environment can create disability as much, if not more, than personal and occupational limitations. Regarding environmental factors, a study showed that an occupational therapy day-care unit provided beneficial psychosocial environmental conditions, and a good balance of supportive and explorative factors, also in comparison with other care units (Eklund & Hansson, 1995). This kind of psychosocial environment has also been shown to be related to engagement in daily occupations and quality of life (Eklund & Hansson, 1997). In another study that focused on the living environments, engagement in daily occupations was limited to that specific social

environment (Leisse & Kallert, 2000). Furthermore, the localisation of the living environment, both in regard to living alone and in supported housing, has shown to be of importance to participation in society (Aubry & Myner, 1996). In addition, occupations performed outside the home and the living environment where related to increased engagement and meaning in occupations (Mee & Sumsion, 2001; Shimitras *et al.*, 2003).

Gender

Gender may also have an impact on occupational engagement in everyday life. For example, the fact that there is a tendency of a later onset of illness for women than for men infers that women have had more time to develop capacities and skills. Thus, women may have better opportunities for social and occupational achievements after the onset of their illness. (APA, 2000; Castle, 2000; Hafner & an der Heiden, 1997; Röder-Wanner *et al.*, 1997). In an overview, Angermeyer, Kuhn and Goldstein (1990) found that women more often had regular employment and showed superior family and occupational role functioning compared to men. Shimitras *et al.* (2003) showed that women were significantly more engaged than men in terms of time spent on household or domestic occupations. However, there appears to be no major gender differences with regard to satisfaction with life generally (Röder-Wanner *et al.*, 1997).

Age

Age has also been found to have an impact on how people with schizophrenia engage in daily occupations. In a time-use study, the youngest participants spent significantly more time socialising compared to older participants, and the older participants spent more time in passive occupations (Shimitras *et al.*, 2003). In addition, the psychiatric disabilities among younger participants were likely to vary to a greater extent (Green *et al.*,

2000). Another study showed that disabilities increased with age in people with schizophrenia (Palmer *et al.*, 2002).

Assessment

Assessment in Occupational Therapy

Assessment is the basis for clinical decision making in occupational therapy practice (McCull & Pollock, 2001). It is also crucial for occupational therapy research. In Sweden, occupational therapists are required to document the treatment process of their clients. This documentation is most often based on the occupational therapy problem solving and treatment process (CAOT, 2002; Finlay, 1997). The process involves identifying a suitable frame of reference for the occupational problem at hand and collecting data, by procedures such as interviews, standardised tests and self-rating scales, structured observation of occupational performance, and visiting different geographical and social environments, e.g by performing home and work-place visits (Creek, 2003; Finlay, 1997). Sometimes, also creative and projective occupations used in the assessment in order to evaluate the client's relation to his or her own feelings and to persons and objects in the environment (Creek, 2003; Finlay, 1997; Gunnarsson, Jansson & Eklund, in press). Against the backdrop of collected information, the client and the occupational therapists go on to encircle resources and disabilities regarding how the client manages to engage in daily occupations. Goals are set and suitable occupational opportunities are provided, and/or adjustments in the environment are implemented in different ways. Hence, occupational therapy assessment takes into consideration both the client's and the occupational therapist's view on abilities and disabilities (McCull & Pollock, 2001). However, in clinical practice, the use of standardised instruments and methods

is not always appreciated, mostly since they may seem too artificial, cold, and mechanical and not always suitable for people with severe mental illness (Finlay, 1997). Still, specific and standardised assessments promote a clearer understanding of particular issues and the assessor bias can be reduced by adopting a standard routine. Furthermore, a focused assessment allows a more focused treatment (Law, Baum & Dunn, 2001). Most importantly, the clients deserve the professionalism encountered in standardised assessment. Finally, the stronger the research behind the assessment, the more credibility can be given to assessment and outcome instrument in use (Finlay, 1997).

Traditionally, occupational therapists focus on assessing and helping clients towards independence. However, this might be a double-edged objective for occupational therapists working with people with severe mental illness, since people with schizophrenia often associate independence with being lonely and isolated (Gahnström-Strandqvist *et al.*, 1995). Instead, a main concern for occupational therapists is to help clients strengthen their identity and relate to others (Eklund, 2000). Another concern is to help people with schizophrenia establish an everyday life with ongoing meaningful occupational engagement, preferably in a variety of societal contexts where they can collaborate with others (Creek, 2003). Hence, rather than assessing ADL-functioning and independence, it seems vital to assess to what extent the client is able to engage in occupations and whether or not their pattern of occupations supports health sufficiently. Moreover, Fisher (1992) and Law (1993) argued that it is more vital to focus on the level of engagement than on isolated factors of occupational performance. McLaughlin Gray (2001) asserted that a person's occupational engagement reflects aspects of recovery as well. Thus, to assess the level of occupational engagement can serve as a realistic point of departure when designing and fol-

lowing up an occupational therapy intervention (Law, 1993).

Assessment of Occupational Perspectives in People with Schizophrenia

One of the available measures when assessing aspects of occupation is the Canadian Occupational Performance Measure, COPM (Law, Steinwender & Leclair, 1998). It is based on self-perception and reflection regarding performance and satisfaction in the occupational areas of self-care, productivity and leisure. It has been used with people with mental illness COPM (Chesworth, Duffy, Hodnett & Knight, 2002), but not specifically with persons with psychotic disorders. Therefore, there is no evidence that the COPM can reliably be used with people with schizophrenia, given that they often have cognitive and emotional limitations (Green *et al.*, 2000). It might be difficult for them to reflect on and interpret given occupational areas that have already been defined by theorists of occupational therapy. Moreover, according to Hammel (2004), important dimensions for understanding well-being and health are overlooked when an assessment is based on predefined occupational categories, such as self-care, household work and leisure. It is therefore better to assess how real life appears in relation to its context and meaning.

However, another instrument, The Occupational Case Analysis Interview and Rating Scale, OCAIRS (Kaplan & Kielhofner, 1989), was found to be a useful instrument in the screening process of occupational performance in people with long-term mental illness (Haglund, 2000). The focus of OCAIRS concerns occupational functioning and is based on a theoretical model, the Model of Human Occupation (Kielhofner, 2002). Thus, it is not based on knowledge that emanates from a real life context, reported by people with schizophrenia themselves.

Moreover, generic measures like the COPM and the OCAIRS might not be appropriate or relevant for all groups of people with disabilities, since a given disease or disability affects people's life differently (Dunn, 2001). Dunn further pointed out that validity might also be threatened by the fact that many people with disabilities cannot meet the rigours of standardised test protocols. In people with cognitive impairment such instruments may be contributing to nothing but noisy information with limited validity (Lawton, 1999).

The instrument, Satisfaction with Daily Occupations (SDO), that measures activity level and satisfaction with daily occupations, was recently developed and found to have satisfactory psychometric properties for people with severe mental illness (Eklund, 2004). However, the instrument is more of a screening tool and regards already defined fixed occupational categories, such as work, leisure activities, domestic tasks and self-care, and the client is asked only whether or not he or she performs this kind of occupations and to what extent they are satisfied. Thus, SDO assessment does not emanate from how real life appears in relation to its context and meaning, and the clients do not express themselves in their own words.

Assessment of Time Use

Time use research shows how people use their time. During the second decade of the past century, time use research emerged in Europe in conjunction with early studies on the changing living conditions of people caused by the rise of industrialisation. Ever since, time use research has been applied on different populations in different countries, among women, workers, students and so forth (Pentland, Harvey, Lawton & McColl, 1999; Robinson, 1997). Furthermore, Harvey and Pentland (1999) indicated that time use research is widely spread among different kinds of disciplines, such as economics, gerontology, oc-

cupational therapy, recreation, physical and health education, sociology, anthropology, psychology and political science, in order to enrich their understanding of human behaviour.

Time use methodologies have been proposed to be the most established research techniques when exploring important aspects of human occupations and lifestyles (Wilcock, 2003). Time use measures provide a glimpse of the actual lifestyle (Robinson, 1999) and serve as estimates of both participation and of impact of disability on quality of life in different populations (Backman, 2001; Harvey, 1999). Accordingly, time use studies investigate a variety of aspects of health empirically (Harvey & Pentland, 1999). Moreover, in order to understand why people engage in occupations to various extents and in certain ways, equal attention should be given to the person, the environment and the occupations (Kielhofner, 2002). Thus, when research is aimed at providing information about what people do and simultaneously consider contextual information, the time use methodology can generate invaluable information for understanding the quality of everyday life in people with disabilities (Harvey & Pentland, 1999).

Concerning people with schizophrenia, the most important flaws concerning time-use research are that the fixed categorisation of occupations is not sensitive enough for the type of daily occupations that they have (Hayes & Halford, 1996). The data becomes limited and does not often address meaningfulness, different kind of environments, and other variables necessary to understand experience and meaning of occupations (Delepaul, 1995; Lawton, 1999; Michelson, 1999). Minato and Zemke (2004) asserted that understanding experiences associated with the occupations is necessary in order to understand how time use relates to health and well-being for people with schizophrenia. Thus, this type of research is in its infancy (Wil-

cock, 1999), and the relationship between the severity of disabilities and time use is not clear (Pentland & McColl, 1999).

Time-use diaries

There are a few time-use methods, one of which is the time-use diary. Time-use diaries are often used to collect data that can help understand a person's daily occupations in a comprehensive way. All occupations within a specified time period are recorded, including the start and completion of each occupation (Harvey & Pentland, 1999). Thus, the time-use diary places the occupations in their natural temporal context. As stated earlier in this thesis, the personal and environmental factors of occupational performance should be addressed as well (Hasselkus, 2002; Law, 2002; Michelson, 1999). Up to date, this comprehensive perspective has typically not been employed in time-use research in occupational therapy (Christiansen, 2005). Studies among people with schizophrenia (Hayes & Halford, 1996; Minato & Zemke, 2004; Shimitras *et al.*, 2003), and among people with severe mental illness (Leufstadius, Erlandsson & Eklund, 2006) did not include all the dimensions of occupational performance. However, gathering a rich array of contextual information when trying to investigate occupational engagement among people with schizophrenia could contribute to a deeper understanding of their occupational life. Shimitras (2003) *et al.* suggested that time-use diaries could be used in both research and practice to further explore the patterns of occupational engagement and participation in society in people with schizophrenia. A problem related to this is that there are no specific guidelines for how to interpret the information yielded by the time-use diary, and the information obtained is rich and unstructured and is not easy to conclude or communicate (Ujimoto, 1999). Moreover, the conclusion drawn from the time-use diary is also likely to be biased by the assessor. Thus, according to the ex-

isting methodology, the diary is not possible to use as an outcome measure of treatment. Therefore, the development of new analytical approaches is crucial if the full richness of time-use data is to be utilised.

Time-budget. Time use studies that concern data on frequency and duration help to develop an understanding of the allocation of time to various occupations. This is often referred to as time-budget research (Robinson, 1999). The measure is quantitative, and the reported time, spent on different occupations and other related variables, is summed up and analysed on a group level (Szalai, 1972). However, the amount of time spent in a particular occupation can hardly be said to reveal its degree of meaningfulness and importance (Hammell, 2004; Pentland *et al.*, 1999). In the general population, time use in different occupations is likely to vary depending on gender, location, culture, stage in life cycle, marital status, child-care, work-status and income (Erlandsson & Eklund, 2006; Law, 2002; Robinson, 1997; Zuzanek, 1998; Zuzanek & Manell, 1993).

Experience sampling method

The Experience Sampling Method, ESM, is another method for data-collection. ESM reveals information about personal factors like experiences and perceived meaning (Csikszentmihalyi & Larson, 1987). When employing the ESM, a programmed beeper goes off at random time points during the day, and the person writes down in a protocol what he or she is doing and how the event is experienced. This method was, for example, used to investigate the context of delusional experiences among 48 patients with schizophrenia (Myin-Germeys *et al.*, 2001). However, what is not in the data is episodic and typically taken out of its context and does not provide an understanding of how and where the investigated small time segment fits with what is done during the rest of the day (Pentland *et al.*, 1999).

Implications for Research

Since the 1990s, the discipline of occupational science has enticed many researchers, also those outside the field of occupational therapy, to study the occupational life in different populations. The main purpose is to understand how people engage and experience occupations in relation to health and wellbeing (Clark *et al.*, 1991; Wilcock, 2005; Zemke & Clarke, 1996). In this sense, this thesis aims at contributing to the discipline of occupational science, but also to the knowledge base of occupational therapy regarding people with schizophrenia.

This thesis has had the ambition to visualise an occupational perspective on health among people with schizophrenia. It is vital to know more about health in relation to real-life occupational engagement in this group, involving the dynamic interplay between the person, the environment, and the occupation. Knowing in what types of occupations people with schizophrenia engage and how these occupations are experienced, and in what environment, would be important information for the planning of care for people with schizophrenia and for assisting them in setting adequate life goals, congruent with their abilities, interests and their environmental context (Goldberg *et al.*, 2002). That type of knowledge could also support and back up the occupational therapists in communicating more clearly the relevance of using occupations as means and ends with people with schizophrenia. Furthermore, elicited information may contribute to an increased understanding of how to enlarge the occupational arenas in society for people with schizophrenia. However, research findings that support occupational therapists and other professionals in applying an occupational perspective on health are still scarce. As of today, there is no clear picture on what this group of people do in real life and what kind of occupational life serves as more favourable in relation to health and well-being (Markström, 2003; McKib-

bin *et al.*, 2004; Minato & Zemke, 2004; Priebe, Kaiser, Huxley, Röder-Wanner & Rudolf, 1998; Shimitras *et al.*, 2003). Moreover, there is a scarcity of empirical research addressing the broad range of occupations in everyday life in which persons with schizophrenia are engaged (Eklund *et al.*, 2001; Minato & Zemke, 2004; Shimitras *et al.*, 2003).

There is a lack of rightful measures that cover the nuances of real life occupational engagement, of how people with schizophrenia use their time on a day-to-day basis (Hayes & Halford, 1996; McKibbin *et al.*, 2004; Minato & Zemke, 2004). Moreover, research regarding how people engage and experience occupations in relation to health and wellbeing, that could help form the basis for this type of evaluation, is scarce (Gould *et al.*, 2005; Minato & Zemke, 2004; Shimitras *et al.*, 2003), although this kind of evaluation based on everyday life has been stressed as vital for enabling healthier lifestyles in the target group (Minato & Zemke, 2004; Shimitras *et al.*, 2003). Thus, it seems important to develop a methodology that relies on typical and relevant features of daily occupations in people with schizophrenia.

Aims

The overall aim of the present thesis was to employ an occupational perspective on health in people with schizophrenia, by investigating daily occupations, environments and personal experiences in a time use perspective, and to study the interconnectedness between aspects of occupations, health-related factors and quality of life.

The specific aims were:

Study I: To investigate occupational performance in a time-use perspective in a group of people with schizophrenia. The aim was also to reflect as original a picture as possible of what they did, in what social

and geographical environments they performed their daily occupations and how these occupations were experienced.

Study II: To investigate occupational engagement in a group of men and women with schizophrenia, including how they interacted with their environment and endeavoured to make sense of their experiences. The aim was also to provide occupational therapists with relevant knowledge that could help them in their clinical reasoning and reflective practice regarding this group of persons' different ways of engaging in daily occupations.

Study III: To develop an instrument that will help interpret and evaluate data gathered by means of time-use diaries, and help estimate to what extent people with schizophrenia engage in daily occupations. The aim was also to estimate the instrument's psychometric properties in terms of content validity, inter-rater reliability and internal consistency.

Study IV: To examine the construct validity of the instrument, assessing occupational engagement, developed in Study III. It was hypothesised that occupational engagement would be related to global functioning, activity level and satisfaction with daily occupations, on a general level as well as on an item level.

Study V: To explore possible relationships between occupational engagement and self-related variables, psychopathology and quality of life in people with schizophrenia. It was hypothesised that a high level of occupational engagement would be associated with higher ratings of self-related variables, less severe psychiatric symptoms and better quality of life.

Methods

An overview of the methods used in Studies I–V is summarised in Table 1.

Table 1. Method overview of the thesis.

Study	Study approach	Participants ($n=74$)	Data collection	Data analysis
Study I	Descriptive and qualitative study	10 clients Consecutive sample	24-hour time-use diary with a supplementary interview	Content analysis Time-use calculations
Study II	Descriptive and qualitative study	10 female and 10 male clients Purposive sample	24-hour time-use diary with a supplementary interview	Content analysis
Study III	Instrument development	41 clients, Purposive sample, however randomly selected in different steps from the total sample 10 occupational therapists	24-hour time-use diary with a supplementary interview Questionnaire designed for content validation Pilot version of Profile of Occupational Engagement in people with Schizophrenia. POES	Content analysis Weighted kappa Cronbach's alpha
Study IV	Construct validity testing/ correlational	72 persons Consecutive sample	Profile of Occupational Engagement in people with Schizophrenia. POES Global Assessment of Functioning, GAF Pilot version of Satisfaction with Daily Occupations, SDO	Spearman's rank correlation test
Study V	Correlational/ comparative	72 persons Consecutive sample	POES Lancashire Quality of Life Profile, LQOLP Sense of Coherence scale, SOC Locus of Control scale, LOC Mastery scale Brief Psychiatric and Rating Scale, BPRS	Frequency distribution Kruskal-Wallis test Jonkheere-Terpstra test Chi-squared test Spearman's rank correlation test Multiple regression analysis t-test

Participants, Selection Criteria and Procedure

The studies of this thesis were based on a single sample, or on subgroups derived from it. The participants were registered clients at an outpatient unit in a geographically defined catchment area around Malmö, Sweden. The selection criteria were an age of 20–55 years, a diagnosis of schizophrenia based on DSM-IV (APA, 1994), and having visited the unit within the past 12 months. Initially, 124 individuals were identified. Five of them were considered dangerous or unable to communicate, and the physicians responsible for their treatment advised against contacting them. Thus, 119 individuals were eligible.

The primary contact person for each individual was asked to make an initial contact and ask for the client's consent. Forty individuals declined participation at this stage. The interviewer, the author of the present thesis, contacted and maintained subsequent contact with the individuals that had agreed to participate and appointments were arranged. If a person did not show up for the first appointment, two additional appointments were made, if necessary. In this part of the procedure another five individuals were lost. The total of 45 non-participants resulted in a participation rate of 62%. In all 74 individuals participated. Demographic characteristics are given in Table 2.

Analysis of Non-Participants

There were no differences regarding age ($p=0.48$) or sex ($p=0.55$) between the non-participants and the participants. The analysis revealed no statistically significant differences with respect to subgroups of participants ($p=.192$); hebephrenic, catatonic, residual, and undifferentiated schizophrenia being classified into one subgroup, participants with paranoid schizophrenia into a second subgroup, and those with schizophreniform

disorder or schizoaffective disorder forming a third subgroup.

Ethical Considerations

The principles of informed consent and voluntary participation were carefully considered, and in this process the addressed participants were met with great respect and empathic consideration. For confidentiality reasons, the primary contact person was asked to make the initial contact with the participant, provide them with an information sheet about the studies and ask for consent. The participants were also informed that participation was voluntary and that their identity would be protected. Furthermore, they were informed that they could decline participation at any time. By these procedures, the participant had the freedom and opportunity to go through the information given about the study, and navigate through the fantasies and expectations raised by taking part in a study. If a person decided to take part in the study the consent was written down.

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Medicine, Lund University.

Selection Criteria and Participants in Study I

A consecutive sampling method was employed among the 74 participants, and the first 10 participants who entered the study context were selected. Eight participants were men and two were women. Five participants were diagnosed with paranoid schizophrenia. Other subgroups of schizophrenia represented among the patients were the disorganised type, the catatonic type and schizoaffective disorder. Three of the participants had a relationship with a person of the opposite sex, but only one of them lived with that person. Nine participants lived alone in their own flats. Three of them had satellite accommo-

Table 2. Demographic characteristics of the participants (n=74).

Characteristic	Number of subjects (%)	Characteristic	Number of subjects (%)
Diagnosis (n=74):		Children (n=73)*:	
Paranoid schizophrenia	36 (49)	yes	8 (11)
Hebephrenic schizophrenia	10 (14)	no	65 (89)
Catatonic schizophrenia	1 (1)	Housing situation (n=74):	
Undifferentiated schizophrenia	9 (12)	apartment	55 (74)
Residual schizophrenia	2 (3)	sheltered living	7 (9)
Schizophrenia, not specified	4 (5)	institution	2 (3)
Schizophreniform disorder	4 (5)	no permanent address	2 (3)
Schizoaffective disorder	8 (11)	other	8 (11)
Sex (n=74)*		Education (n=73)*:	
men	49 (66)	no high school	29 (40)
women	25 (34)	high school	25 (34)
Civil status (n=72)*:		college	19 (26)
never married	57 (79)	Work situation (n=73)*:	
married	5 (7)	open market employment	7 (10)
divorced	7 (10)	sheltered work	5 (7)
widowed	3 (4)	unemployed	6 (8)
Living single/with partner (n=72)*:		student	2 (3)
single	52 (72)	disability or sick pension	53 (72)
partner	8 (11)		
parents	1 (1)		
sheltered living	7 (10)		
other	4 (6)		

* Missing data on 1-2 persons

dation, which meant living near a group home and having the opportunity to contact the staff there. All participants took medication for their mental disorders and none of them worked or had any children.

Selection Criteria and Participants in Study II

Ten male and ten female persons were selected from the larger study context where 74 participants were included, but those 10 participants who had taken part in Study I were excluded.

A purposive sampling (DePoy & Gitlin, 1998) was employed in selecting the 20 participants from this group of participants as to ensure a reasonably even age and gender distribution. It was assumed that considerable variation regarding occupational life, which was desired, would also be achieved in this way. Firstly, the larger group was divided into gender groups. Secondly, each gender group was divided into three separate age groups, 20–32, 33–44, and 45–55 years of age, and three participants were randomly selected from each age group. Finally, a tenth female and a tenth male partici-

pant were randomly selected from the respective age group to which the greatest number of persons belonged.

Selection Criteria and Participants in Study III

The present study involved an expert panel consisting of ten occupational therapists who viewed and criticised the content of the developed instrument in two different steps.

The *first step*, which concerned content validity, involved eight experts. A purposive sampling method (DePoy & Gitlin, 1998) was used in order to identify experts that had different ways of practising occupational therapy, had a conceptual understanding of occupational therapy that was based on current international literature and were familiar with the English language. Two occupational therapists were doctoral students, one within the field of psychiatry and one outside. Two occupational therapists had a Ph.D., one within the field of psychiatry and one within the field of occupational science. The remaining four occupational therapists were working with clients within the field of psychiatry, two of them in Manchester, Great Britain, and two in Malmö, Sweden. The *second step* of the content validity procedure involved another two occupational therapists, working within the field of psychiatry in Malmö, Sweden.

In study III, time-use diaries of 41 participants from the group of 74 participants were included. The participants were selected on the basis that they had not been included in the previous Studies I and II. This was to accomplish a strict test of the content validity, and it was considered important to develop the instrument on the basis of as many different aspects as possible of the daily occupations.

In the testing of inter-rater reliability and of calculations of internal consistency, another two occupational therapists were employed.

Selection Criteria and Participants in Studies IV and V

All the 74 participants were included in Studies IV and V. However, because of missing responses the statistical calculations were only based on a sample of 72 participants.

Data Collection

The data collection was carried out by the author of the present thesis. The data collection took between 2 and 3.5 hours, depending on the capacity of the participant and contextual circumstances, such as whether or not having a shorter coffee break.

Instruments and Questionnaires

The time-use diary (Studies I–III)

The time-use diary used in Studies I–III covered what the participants had been doing during the previous 24-hour period. The instrument developed for these studies was inspired by a diary that was used in an investigation concerning time use and living conditions among men and women in Sweden (StatisticsSweden, 1992). However, additional questions that concerned the social and geographical environment and personal reflections and experiences were added to the original diary, which was restricted to asking about the performed activities. Hence, the time-use diary developed was composed of four columns, each with rows representing one-hour intervals (Figure 1). Each column had a question on top, the first asking what the participant performed, the second about geographic environment, the third about social environment, and finally personal comments or reflections about the performance.

The participants were asked to provide a description of their actual time use in the past 24 hours. Twenty-four hours is considered to be an appropriate time limit, suggested by Sz-

The time-use diary

The client is asked to fill in the diary and provide an account of the use of time during the previous 24 hours. The assessor goes on to perform a supplementary interview which works as a cognitive aid and helps the client to recall the chronological orders of the events and the experiences associated. The interview data are added to the time-use diary.

What did you do?	Was there anyone else around at the time?	Where were you at the time?	How did you experience the activity?
Record everything that you did, and for how long the activities were performed.	Record who you were with, if other people were present, or if you were on your own.	Name the place and location.	Record your personal reflections and comments
one-hour intervals ↓			

Figure 1. The time-use diary.

alai (1972) to render good validity when used on a group belonging to the same population as studied in this thesis. The appointments for the recording of the time-use diary were set on a weekday, except Mondays, implying that all reports concerned information about time use during weekdays. The time-use diary was open-coded, which meant that the participants responded in their own words. The time-use diary was administered as a self-report questionnaire in a first step. The time-use diary was then completed with a supplementary interview, and the elicited information was added to the time-use diary. The interview questions emanated from what had been written in the 24-hour diary and worked as a cognitive aid and helped the participant to recall what she or he did, for how long, and so on. Thus, the interview functioned as a check for consistency and completeness and to ensure that there were no gaps in time use and in contextual information. This served to increased the validity (Robinson, 1997), since different types of data sources minimise distortion from a single data source or from a

biased researcher (Knafl & Breitmayer, 1989; Krefting, 1991).

Robinson (1977) found that estimates from time-use diaries produced reliable and replicable results, as indicated by a correlation coefficient of .95 when comparing national diaries with diaries from a single site location. Moreover, when comparing different diary approaches, a correlation coefficient of .85 was found. When observational studies and ESM-studies were performed side by side, to validate time-use diaries in different studies, the agreement between measures were between 80 and 90% (Juster & Stafford, 1991; Robinson, 1977; Robinson, 1985; Robinson, 1999). Moreover, several studies have shown that the open-response diary is more valid since it comes close to the full range of occupations performed, rather than when what is being reported is already categorised.

Profile of Occupational Engagement in People with Schizophrenia (Studies IV–V)

The POES was developed on the basis of the qualitative research concerning time use

and occupational engagement of people with schizophrenia that constitutes the first studies of this thesis (Bejerholm & Eklund, 2004; Bejerholm & Eklund, 2006b). Its first part involves data-collection, in terms of completion of one or more 24-hour time-use diaries. The second part, the assessment, consists of nine items that are rated on a four-point scale. The estimation of each item may be plotted on a graph, resulting in a profile of occupational engagement, and a sum score indicates the level of engagement. POES has been shown to have satisfactory construct and content validity, good inter-rater agreement and internal consistency. This was shown in the Study III and IV of this thesis (Bejerholm & Eklund, 2006a; Bejerholm, Hansson & Eklund, 2006). In order to obtain an unbiased rating regarding the assessment part of the POES, an independent rater who was not influenced by previous information about the participants' functioning or information elicited via data collection was consulted for the present study.

Questionnaire used in the content validation process of POES

A questionnaire was designed to obtain detailed information about the pilot version of POES and was filled in by the experts. The questions concerned administration and introduction, content, distinction and differentiation of items and rating-categories, terminology, reflections of the target group, and general comments. All the questions had three response options, "yes", "in between", or "no". A written rationale for each answer was required at all times.

The Global Assessment of Functioning scale, GAF (Study IV)

The GAF included in DSM-IV axis five (APA, 1994), was employed to assess the overall level of psychosocial functioning. Ratings range from 0 to 100 and the assessment is based on a hypothetical continuum of mental health.

The scale is divided into 10 operationalised intervals and the exact rating is made relative to the two adjacent intervals. It is based on behavioural criteria and descriptions of symptoms and forms a global rating of psychological, social and occupational functioning. GAF is equivalent to the Global Assessment Scale, which has acceptable validity and reliability (Endicott, Spitzer & Fleiss, 1976; Startup, Jackson & Bendix, 2002; Tungström, Söderberg & Armelius, 2005).

The pilot version of Satisfaction with Daily Occupations, SDO (Study IV)

Activity level and satisfaction with daily occupations in a broad sense were assessed by means of the pilot version of SDO, which is an interview-based questionnaire (Eklund *et al.*, 2001). The pilot SDO comprised 7 items covering the occupational areas of work, leisure activities, and domestic tasks. Each item consists of a two-part question. The first part is about the activity level. It asks whether or not the participant presently performs the targeted kind of occupation and a rating of 1 (yes) or 0 (no) is obtained. Thus, activity level can range from 0–7. The second part asks the participant to rate his/her satisfaction with daily occupations on a seven-point scale, i.e., a person with employment rates his or her satisfaction with having a job, and a subject without work rates that condition. The pilot SDO had an internal consistency of $\alpha=.79$. This is equivalent to the value obtained for the revised version, for which also construct validity and discriminating power has been satisfactory. The revised version of SDO also includes the occupational area self-care (Eklund, 2004), which was consequently not assessed in Study IV.

The Lancashire Quality of Life Profile, LQOLP (Study V)

A Swedish version (Hansson, Svensson & Björkman, 1998) of the Lancashire Quality of Life Profile (LQOLP) (Oliver, Hux-

ley, Bridges & Mohamad, 1996; Oliver *et al.*, 1997) was used. It is administered as a structured interview and includes the individual's subjective ratings concerning nine quality-of-life domains: work, leisure, religion, finances, living situation, safety, family relations, social relations and health. The subjective ratings are made on a seven-point scale. The ratings of the quality of life domains were summed up to give an overall self-rated quality of life score. The global well-being scale and the global assessment of quality of life according to Cantril's ladder, also included in the LQOLP, were used as well. The LQOLP has demonstrated good internal consistency and test-retest reliability (Hansson *et al.*, 1998; Niewenhuizen, Schene, Boevink & Wolf, 1998; Oliver *et al.*, 1997).

The Brief Psychiatric Rating Scale (Study V)

Psychopathology was assessed by means of the Brief Psychiatric Rating Scale, BPRS, (Kolakowska, 1976; Overall & Gorham, 1962). It consists of 18 items, which are rated on a seven-point scale on the basis of an interview and observed behaviour. The items include, e.g., disorganisation, disorientation, depressive symptoms, and hostility, and allow for analysis into positive, negative and depressive symptoms and general psychopathology. Good inter-observer and intra-observer reliability has been demonstrated, but the fact that worse psychometric properties were obtained when the scale was used by less experienced BPRS raters (Andersen *et al.*, 1989) implies that proper use of the scale requires specialised training. A test of interrater reliability, comparing the interviewer trained for the present investigation with another researcher, resulted in a coefficient of 0.87.

Scales assessing self-related variables (Study V)

Self-control, mastery and a sense of coherence are concepts that actualise the interpretative

function of the self, involved in the occupational engagement process. In this process the self recognises and realises itself in relation to the environment and the occupational event (Rotter, 1966; Topor, Svensson, Bjerke, Borg & Kufås, 1998).

The Locus of Control (LOC) scale was constructed by Rotter (1966) and the scale refers to whether an individual perceives reinforcements to be a function of his own actions (internal control) or externally determined (external control). Having an internal locus of control is generally seen as desirable. A Swedish version was used (Eisemann, Perris, Palm, Palm & Perris, 1988). Ratings are made on a four-point scale, and a higher rating indicates more external locus of control. The LOC scale has fair internal consistency and test-retest reliability (Rotter, 1966).

The Mastery scale is intended to measure the individual's perceived control over circumstances that significantly affect his or her life (Pearlin *et al.*, 1981). Mastery is measured using a seven-item scale with four rating alternatives, where four indicates the highest level of perceived mastery. The scale has shown satisfactory psychometric properties (Marshall & Lang, 1990; Rosenfield, 1992).

The Sense of Coherence scale (SOC) indicates how well a person manages stress and stays healthy in various circumstances (Antonovsky, 1987, 1993). Comprehensibility, manageability and meaningfulness are the constructs that constitute the SOC scale. Items are rated by the participants on a seven-point scale with two anchoring responses (e.g., never and very often). The instrument has proven to be valid and reliable (Antonovsky, 1993; Bengtsson-Tops, Brunt & Rask, 2005; Langius, Björvell & Antonovsky, 1992; Marshall & Lang, 1990; Rosenfield, 1992). A short version with 13 items, shown to have the same properties as the original 29-item scale, was used (Langius & Björvell, 1993; Langius *et al.*, 1992).

Data Analysis and Statistics

Content Analysis

Content analysis was used to categorise the reported material in time-use diaries in Studies I–III. Content analysis is a technique for systematically describing the content of written or spoken material (Berg, 2001; Fox, 1992; Kerlinger, 1969; Sommer & Sommer, 1991). The content refers to specific themes or categories. In this thesis, more than one person was involved in this process of identifying themes or categories, since duplication of effort is essential in order to ensure methodological rigour in content analysis (Millward, 2000; Neuendorf, 2002). The material was skimmed over to identify major themes or categories, listed as they were found. When these themes or categories were beginning to repeat themselves the analysis was stopped and the themes or categories that overlapped and duplicated one another were combined (Millward, 2000; Sommer & Sommer, 1991). A template to guide the placement of responses in themes or categories was established. The content analysis comprised both a mechanical and an interpretative component (Krippendorff, 1980; Millward, 2000). For example, in Studies I–III the mechanical aspect involved physically organising and subdividing the data into themes or categories whilst the interpretative component involved determining what categories were meaningful in terms of the themes developed. Thus, the mechanical and interpretative aspects are inextricably linked in a cycling back and forth between the transcripts and the more continuous process of developing a meaningful and refining themes or categories (Millward, 2000).

The content was classified qualitatively according to the values or attitudes expressed (Berg, 2001; Sommer & Sommer, 1991). The expressions can be further illustrated by using quotations, which was the case in Studies I and II. The occurrences of themes or cat-

egories were then counted (Fox, 1992; Kerlinger, 1969). In Studies I and II, numbers related to time use or duration, and frequencies of occurrence were presented in relation to the themes and categories identified. According to Millward (2000), once frequency and distributions are developed the relative frequency of the different categories can be treated as ordinal data. This way the content analysis can become a procedure of producing data that could be analysed statistically further ahead. This principle was employed in the process of developing the POES instrument in Study III.

In Studies I and III, the time-use diaries were analysed as they were. However, in study II, the diary material was converted into a narrative. The reason for this procedure was to be able to retain the features of a time-use diary, such as chronological order, time use, accuracy, and closeness to the real life events, and still illuminate the narrative features of time-use reports.

Statistics

The *Weighted kappa* coefficient was used to analyse inter-rater reliability of the POES. Weighted kappa is the sum of the weighted frequencies corrected for chance agreement (Cohen, 1968). The strength of agreement is considered moderate if κ .41–.60, good if κ .61–.80 and very good if κ .81–1.00 (Altman, 1991) (Study III).

Cronbach's alpha (Cronbach, 1951) was used to calculate internal consistency of the POES. Cronbach's alpha is considered acceptable if $\alpha > .70$ (Nunally & Bernstein, 1994) (Study III).

The *Spearman's rank correlation test* was used to investigate variables on the ordinal level (Studies IV, V).

The *Kruskal-Wallis test* was used for testing differences between subgroups of level of engagement, and self-related variables, psychopathology and age (Study V).

The *Jonkheere-Terpstra test* was used to determine whether there were any positive or negative linear trends in scores in relation to the subgroups of level of engagement (Study V).

Multiple regression analysis was used, where self-related variables and variables of psychopathology were treated as independent variables influencing occupational engagement. An enter model was employed with successive removal of the independent variables (Study V).

The *Chi-square test* was used to compare gender in relation to the subgroups of level of engagement (Study V). The chi-squared test was also used in the initial analysis of non-participation in order to detect differences between participants and non-participants regarding diagnosis and gender.

A *t-test*, was used to calculate differences between participants and non-participants regarding age.

Results

An Occupational Perspective on Health in People with Schizophrenia

Time Use and Occupational Performance

In Study I, the time use in relation to the domains of the person, the occupation, and the environment, involved in the dynamic interplay of occupational performance, was presented separately. The categorisation is shown in Table 3.

The personal domain

The personal domain was divided into factors. The first factor concerned the emotional reaction or feeling that was connected to the experience. The most common categories within this factor, in descending order with respect to time use, were escapism/emptiness, anxiety/worry, pleasure, and being paranoid/afraid.

The other factor that regarded the personal domain was reflection on the outcome, which was discerned as being neutral, negative or positive in nature. A neutral statement, like “it was okay”, “a habit”, “as usual”, was the most common reflection.

The environmental domain

The environmental domain referred to the geographical and social environment. Concerning the geographical environment, for all the participants, most of their time was spent at home. Being outdoors mostly meant being in the neighbourhood, for instance going to small shops to buy cigarettes and snacks. Other places that were visited were day-care centres, outpatient units, shops, restaurants/café and public places indoors, such as the central station or the public library. Concerning the social environment, most of the participants’ time was spent alone. Still, it was rather common that they spent time in social environments. However, they did not interact socially in a reciprocal manner. The participants spent least time socialising with other persons.

The occupational domain

The complexity of the occupational domain was angled from three different perspectives.

The first perspective covered time use in relation to activities performed, for each participant as well as for the whole group. Within that set of results, the time spent performing different activities was presented individually. In descending order the performed activities for the group as a whole were: sleeping, smoking, consuming mass media, performing quiet activities (which meant sitting or lying, looking at other people or objects), eating/drinking, talking, transportation activities, indoor walking, personal care, playful activity, household work, thinking/brooding, and seeing professionals. All the participants slept, performed quiet activities, consumed mass media, ate and drank and took care of

Table 3. Domains, factors, and categories related to occupational performance, as analyzed in Study I.

Domain	environmental			personal
	occupational	geographic	social	
Factor	performed activity			reflection on the outcome
Category	personal care household work eating/drinking transportation mass media playful activity quiet activity professionals smoking indoor walking thinking/brooding sleeping talking	at home outdoors open-care centre shop restaurant/café day-care centre public places indoor	alone other people social interaction	neutral negative positive escapism/ emptiness anxiety/worry pleasure paranoid/afraid

themselves, however to various extents. Least time was spent in personal care, which mostly meant getting dressed or undressed and going to the toilet. The participants who did not spend much time performing household work often said that they bought microwave dinners and fast food. Most of the participants smoked, and as to transportation the participants mostly walked. Half of the group spent more than two hours walking around indoors. Also thinking and brooding was an important constituent in their day. Playful activities could mean playing musical instruments, writing philosophical notes, browsing in or reading books, and painting in an occupational therapy session. Talking was reported as an activity and most often referred to small talking with staff or visitors at a day-care centre. Two participants reported having a whole conversation.

The second perspective referred whether the reported activities were performed on their own or in combination with other activities. Personal care, household work, transportation, seeing a professional, and sleeping were activities that were mostly reported as being performed as single activities. However, all the other activities were mostly registered as being performed simultaneously with another activity.

The third perspective concerned the most usual combinations, modules, of the performed activities. Quiet activities and smoking, was the most frequent activity module. Furthermore, quiet activities were included in the 49 most frequently occurring activity modules.

Occupational performance modules

Finally, the result in Study I reflected the most common interplay between the occupational, the environmental and the personal domain, denoted occupational performance modules. The most common occupational performance module was the combination of performing personal care, being alone, at

home, and feeling neutral as to how the activity was performed. The second most common module involved consuming mass media and smoking, combined with being alone, at home, with negative reflections on the performance, and they all felt worried and anxious. Further modules showed that being at home and alone was usual, while the personal experience varied.

Another common combination was when the participants were drinking coffee, and sitting and watching other people when they were in day-care centres, however seldom implying interaction with others. Moreover, most modules that involved transportation involved feelings of paranoia and fear.

Occupational Engagement

The results from Study II showed a variation regarding the extent to which the ten female and the ten male participants were engaged in occupations throughout the day (Figure 3). This observation resulted in one overarching core theme, engagement in occupations, and two sub-themes. The sub-theme *daily rhythm* reflected the balance between different types of occupations and between activity of rest, and the sub-theme *a sense of meaning* reflected the interpretative process of making sense of experiences. Thus, in this study, engagement in occupation included both objective and subjective aspects of performance.

The daily rhythm

The activity peaks among the female participants who functioned at the first and second level of engagement according to Figure 2 were concentrated in the earlier parts of the day, meaning from early in the morning until lunchtime (Study II). These women often started with some kind of household activity based on routine. For the males who functioned at these levels the activity peaks took place after lunch or later on in the afternoon. Five out of the six male participants spent the

First level of engagement	Second level of engagement	Third level of engagement
<p>Daily rhythm</p> <ul style="list-style-type: none"> • an uneven mix of longer periods of quiet activities and shorter activity peaks • the quiet activities most often meant not interacting with the environment or engaging with occupations • the activity peaks consisted of activities around food intake and other immediate needs, and there was a small variety of different areas of occupations 	<p>Daily rhythm</p> <ul style="list-style-type: none"> • an even mix of periods of quiet activities and activity peaks • the quiet activities were often a result to few occupational opportunities • the activity peaks consisted of a larger variety of different areas of occupations 	<p>Daily rhythm</p> <ul style="list-style-type: none"> • no specific activity peak or longer periods of quiet activities. Instead there was an ongoing engagement in occupations throughout they day, and a variety of different areas of occupations could be discerned
<p>A sense of meaning</p> <ul style="list-style-type: none"> • little sense of meaning was experienced while performing quiet activities; occupations performed during the activity peaks were mostly attached with little or no sense of meaning 	<p>A sense of meaning</p> <ul style="list-style-type: none"> • little sense of meaning was experienced while performing quiet activities; occupations performed during the activity peaks were mostly attached with a sense of meaning 	<p>A sense of meaning</p> <ul style="list-style-type: none"> • occupations performed were generally attached with a sense of meaning

Figure 2. Three levels of occupational engagement ($n=20$), Study II.

first hour or two after waking up performing quiet activities, which meant sitting or lying down watching different objects in the home environment, sometimes in combination with smoking. This resulted in a slow start to the day.

For those participants who functioned at the third level of engagement, no specific activity peak could be distinguished. The day had continuity, and their occupations were se-

quential, interwoven and performed in a continuous flow. What was specific for these participants was that most of them left home after the early morning waking-up routines, to engage in varies types of recreational and productive occupations. All female participants in the study started the day with some kind of routine-based household occupation. No corresponding typical start of the day could be discerned among the male participants.

All participants reported about quiet activities although the function of spending time in quiet activities appeared to vary among the participants. The participants functioning at the first and second level of engagement reported situations in which a pause could easily be extended to last for hours. These quiet activities functioned as a coping strategy for everyday situations, a way of dealing with having nothing else to do or to keep a safe distance from reality. Whatever the reason, during these periods the participants became disengaged and their energy was directed inwards. It was the participants' immediate needs, such as being hungry and thirsty or tired, or their wish to be part of a social environment, that interrupted their extended periods of quiet activities and put an end to their often distressing and passive state.

The quiet activities could also function as breaks between ongoing occupations and have a recreational purpose. The persons who had these breaks belonged to the third level of engagement and had ongoing occupations throughout the day. In addition, the participants who functioned at the second level also had quiet activities within the activity peaks that functioned as breaks. There were an equal number of male and female participants who had these episodes of quiet activities in the shape of breaks in their day. The only observable difference between the female and the male participants here was that five out of six women took breaks from their household chores and self-care, but none of the men did. In contrast, the men took their breaks in conjunction with out-of-home occupations (Study II).

A sense of meaning

All participants tried to interpret and make sense of their experience by interpreting and commenting on their occupational performance (Study II). The majority experienced a sense of meaning in at least some respects

and to some extent. However, the participants who functioned at the first level of engagement did not (Figure 2). Hence, to engage in few occupations, and to spend time in few types of social and geographic environments, were connected to a little sense of meaning, and vice versa.

The occupations performed in a social environment were most often experienced as being valuable and filled with meaning. It was clearly meaningful to belong, to be wanted, and to be affirmed in a social environment. It helped the participants to experience a sense of self, which in turn often facilitated further occupational engagement. This was also found in the previous study, Study I, which illuminated different ways of relating to others in a social environment. One way involved social interplay, which meant that the social interaction was reciprocal. This often meant having a closer relationship with a person of the opposite sex as a partner or as a friend. The other more typical way of being social did not involve reciprocal relatedness. Instead, the social environment was something that was quietly observed. However, such a non-demanding social environment often led to the development of social interaction and further on to social relationships that extended beyond that social environment. Thus, social interaction could develop in accordance with the participants' own capabilities. Also having contact with pets was meaningful for those who did.

Another component of a sense of meaning involved relaxation, recreation, enjoyment and getting feedback when performing productive occupations. However, the types of occupations that were interpreted as having a sense of meaning were individual. To note is that four participants explicitly mentioned interpretative and mindful activities as valuable, such as thinking, reflecting, and solving problems in a creative manner (Study II).

Assessment of Occupational Engagement

The POES

The instrument that was developed in this thesis was named Profiles of Occupational Engagement in people with Schizophrenia, POES (Study III). It consists of an introductory section and a part I and a part II. The introduction section sets the scene, provides definitions of the concept and items in use, and gives instructions regarding how to use POES. Part I in the POES involves the data-collection by means of the 24-hour yesterday time-use diary with a supplementary interview, as also used in Studies I and II. Part II involves the assessment of the information gathered in Part I. Part I includes nine items, which can be rated according to ranked categories from 1 to 4. In clinical practice, the POES estimation can be plotted in a graph, giving a visual summary that preferably may be interpreted by the client and the assessor jointly.

1. The item *Daily rhythm of activity and rest* concerns an overall picture of engagement, including how rest/quiet activities are distributed in relation to more active participation in occupations throughout the day. The ranking categories range from a daily rhythm characterised by withdrawal and disengagement to ongoing engagement in occupations throughout the day.
2. The item *Variety and range of occupations* sets the scene regarding the type of occupations performed. The ranking categories range from little variation between and little range within the occupations performed, to variation between and a wide range within the occupations performed.
3. The item *Place* is viewed as the setting or location in which occupational performance occurs and refers to the extent

to which places are visited and used, and roughly what kind of places they are. The ranking categories range from spending time in mainly one place to spending time in a variety of places and moving without hindrance in society.

4. The item *Social environment* concerns the occurrence and type of social environments. The ranking categories range from spending most time alone to spending time in a variety of social environments without hindrance.
5. The item *Social interplay* refers to the extent of social interplay or interaction that occurs. The ranking categories range from not being very socially responsive, where others often initiate interplay, to being socially responsive and collaborating with others in a reciprocal relatedness.
6. The item *Interpretation* refers to the extent to which the client interprets and reflects on occupational experience. It concerns the client's identification with action and comprehends the experience it evokes. The ranking categories range from a low degree of interpretation and making sense of experience to interpretation that is ongoing and where the occupational experience is reflected on in a nuanced way.
7. The item *Extent of meaningful occupations* indicates what type of occupations that are likely to be associated with an increase of meaning or purpose at each ranking category. The ranking categories range from being barely engaged in occupations which can be recognised as being meaningful, to being engaged in a variety of occupations with that quality.
8. The item *Routines* refers to the extent of routines and organisation of the occupations. The ranking categories range from few organised routines, apart from fulfilling immediate needs, such as hunger, to a flexible routine dealing with environmental and occupational contingencies.

9. The item *Initiating performance* refers to what initiates and triggers performance. The ranking categories range from initiative that is triggered mostly by others or by immediate needs with a proximal goal, to engagement that is mostly self-initiated, but also with initiative embedded in the occupational roles.

Reliability and validity of the POES

In Study III, the process of content validation of the pilot version of POES resulted in a revision into two steps. The revision led to enrichment of the introduction, integrating the time-use diary into the POES instrument, and changing the wordings on the item level and the ranking level.

Two raters and 24 hour time-use diaries were included in the testing of inter-rater variability. The testing was based on the content validated version of POES. The mean weighted kappa for all items in POES was .70. Internal consistency, the homogeneity of the items in POES, was calculated for both raters separately. The alpha coefficients were in both cases satisfactory, .97 and .95.

Regarding construct validity of the POES (Study IV), the hypothesis that there would be a moderate relationship between the POES and the GAF, satisfaction with daily occupations and activity level was confirmed. The GAF had the strongest association with the POES. The association indicated a shared variance of more than 50%. The correlations between the items of the POES and Activity level were all highly significant, ranging between .52 and .70. The items Daily rhythm of activity and rest and Variety and range of occupations were found to have the strongest relation to Activity level, which was in line with the hypothesis. Furthermore, the correlations between the POES items and Satisfaction with daily occupations ranged from .33 to .58, suggesting that they constituted mainly separate phenomena.

The Continuum of Occupational Engagement

Low, medium, or high level of occupational engagement

In Study V, the subgroups of low, medium, or high level of engagement, as measured by the POES, scored significantly differently regarding psychopathology and self-related variables. In addition, a significant linear trend was confirmed. It showed that the scores of psychopathology and the self-related variables increased from low, to medium, to high level of engagement. There were no differences between the subgroups regarding age ($p = .58$) or sex ($p = .87$).

Occupational engagement, self-related variables, psychopathology, and quality of life

Occupational engagement, was significantly related to self-related variables and psychopathology (Study V). Furthermore, regression analysis resulted in a model in which negative symptoms and locus of control together explained 47% and negative symptoms alone explained 35% of the variation.

The associations between occupational engagement and different estimates of quality were also found to be statistically significant.

Discussion

This thesis has provided information about how people with schizophrenia spend their time and how their engagement in daily occupations is related to health. Since all studies involved data generated from time-use diaries, the time-use perspective has had a major influence on the thesis as a whole. According to Harvey (1993), time-use research captures the science of living, as it is lived in terms of what is being done, with whom, where, and in what frame of mind. Furthermore, as stat-

ed in the introduction part of this thesis, the connection between time and occupation is fundamental to occupational therapy. Within the field of occupational science, time-use methodology is one of the most prominent research methods there is in order to understand humans as occupational beings (Wilcock, 2003). Christiansen (2005) stated that occupations mark the passage of time and asserted that time and occupations are two sides of the same coin.

The Occupational Perspective on Health

The foremost concern of this thesis was to increase the knowledge base regarding an occupational perspective on health in people with schizophrenia. This knowledge was aimed at supporting occupational therapists and oth-

er professionals in their clinical reasoning, when they try to grasp the issue of disability and problems with occupational engagement that their clients with schizophrenia may have to various extents. Furthermore, systematic knowledge about occupational health might help form the basis for occupational therapists when devising psychosocial treatments for people with schizophrenia. On the basis of the results from Studies IV and V, such interventions could in theory lead to satisfaction and a higher level of occupational engagement in conjunction with an increased sense of self and decreased psychopathology (Figure 3). Accordingly, the way in which the self-processed experiences, under the influence of the prevailing symptoms, seems to have had an impact on the extent to which the participants become engaged in occupations. In this respect, investigating time use and occupation

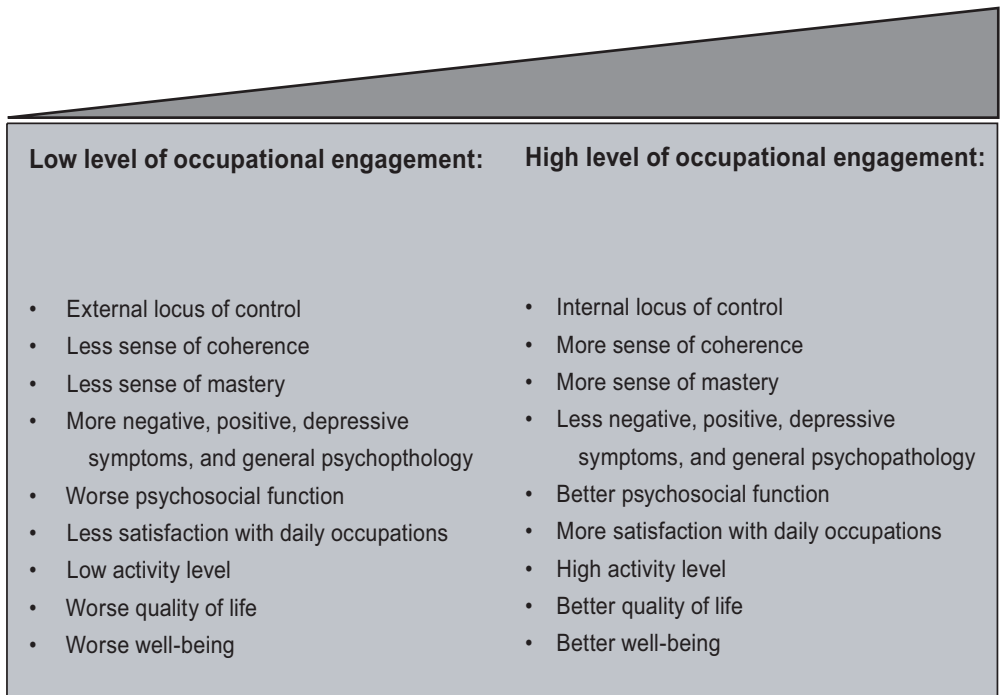


Figure 3. A tentative structure of the occupational engagement continuum, based on the results in Studies IV and V.

seemed to have caught the very essence of the disability and its consequences in everyday life among people with schizophrenia.

The Continuum of Occupational Engagement

Being diagnosed with schizophrenia did not automatically mean having a certain way of engaging in daily occupations (Studies II–V). Instead, occupational engagement can be expected to range, vary, increase and decrease along a continuum. Especially, the results in Studies IV and V showed that the participants' scores regarding self-related variables and composite score of quality of life increased with increasing level of occupational engagement, while the level of psychopathology decreased, as illustrated in Figure 3. Consequently, occupational engagement may depend on the stage of illness of the person. It is likely that acute illness leads to disengagement, and also that disengagement may worsen the course of illness. Hence, the client's level of occupational engagement could serve as one point of departure in general psychiatric treatment.

Occupational Engagement

The PEO model (Law *et al.*, 1996) has guided this research when collecting and interpreting qualitative data, developing an assessment method, and when forming and testing hypotheses. Hence, this theoretical model of a complex interactive open system has simplified the understanding of occupations and its connections to health variables greatly. Therefore, it seems relevant to discuss the results based on this somewhat simplistic pre-understanding.

The personal domain

Psychopathology. The results from Studies IV and V showed that positive, negative, and depressive symptoms and general psychopa-

thology, were significantly correlated to occupational engagement, and thus increase and decrease along the occupational engagement continuum (Figure 3), according to a linear trend (Study V). Furthermore, Study V showed, in line with previous research (Green, 1996; Green *et al.*, 2000; Palmer *et al.*, 2002), that especially the negative symptoms were an important determinant for occupational engagement. In a cross-sectional study, negative symptoms constituted an indicator of the severity of schizophrenia (Rocca *et al.*, 2005), and increased engagement in real life has been shown to decrease the degree of psychopathology and negative symptoms (Halford *et al.*, 1995; Mairs & Bradshaw, 2004; Thorup *et al.*, 2005).

On the basis of the results from Studies IV and V, it could be assumed that the relation between a high score of negative symptoms and a low level of occupational engagement could be explained by some of the constructs' common characteristics, such as a lack of motivation (Kiang, Christiansen, Remington & Kapur, 2003) and social withdrawal (Blanchard, Meuser & Bellack, 1998). Moreover, the significant correlations between a low level of occupational engagement and positive and depressive symptoms could be explained by the fact that these symptoms might instantly have an impact on the perception and interpretation involved in the occupational engagement process, in which the outside world is perceived and reflected upon. Nevertheless, it is still unclear whether a low level of occupational engagement follows negative symptoms, if it is vice versa, or if they are largely overlapping phenomena (Hayes & Halford, 1996). However, a situation with a low level of engagement, time spent in predominantly quiet activities with little sense of meaning, alone, in a home environment, probably has multiple causes, such as too few occupational opportunities, a deprived environment, and/or deficient processing of stimuli.

In all, psychopathology and occupational engagement are presumably related in a dynamic way. This is also reflected in the PEO-model, psychopathology forms part of the personal domain involved in the interplay with the occupational and the environmental domain. Consequently, the lack of energy and loss of ability to engage in occupations should not be understood in relation to personal factors alone, affected to various extents by personality (Eklund & Bejerholm, in press), medication (McKibbin *et al.*, 2004), stage of illness and psychopathology (Emerson *et al.*, 1998; Nagle *et al.*, 2002), but also in relation to occupational and environmental circumstances (Studies, II, IV and V). In line with this understanding, it could be suggested that occupational therapy could be about helping the clients to attend to, become occupied and experience events that are real, instead of them being occupied with the chaos of thoughts and symptoms that sometimes takes over their perceived world. That occupational therapy may contribute to reality orientation is supported by the results in Studies IV and V, showing that there is an obvious link between occupational engagement and psychopathology.

Gender and age did not differ among the participants that belonged to the sub-groups of low, medium and high level of occupational engagement (Study V). Thus, no general conclusion can be drawn about gender in this sense. However, in Study II, the result showed gender differences that regarded some qualitative aspects of the performance of daily occupations. For instance, the home environment did not seem to have as disabling an impact on the female participants as on the male participants. In contrast, for the male participants, the activity peaks mainly occurred outside the home environment. Thus, in clinical practice it would be important for the professionals to attend to possible differences between genders concerning what occupations and what socio-cultural contexts that may bring meaning.

Interpretation of experience. Another perspective on the personal domain concerns the emotional processes and the cognitive functions involved in interpretation and meaning making, which have been claimed to be central to developing self-identity (Hasselkus, 2002; Kegan, 1982; Mee, Sumsion & Craik, 2004). Thus, having schizophrenia seems to detach a person from his or her active, creative and reflective potential involved in the occupational engagement process. Thereby, the possibility of meaning-making becomes hindered. According to Marwaha and Johnson (2004) and Green (1996), cognitive problems may to some extent underlie the disability following schizophrenia. Consequently, the impact that cognitive problems may have on meaning-making is important to consider when trying to understand occupational engagement. In the POES (Studies III, IV, and V), the items *Interpretation* and *Extent of meaningful occupations* contributed with information about to what extent the clients interpreted and reflected on the occupational experience. These items can be said to have reflected the client's identification with action. According to Mee, Sumsion and Craik (2004), to engage in occupations brings forth the ability to perceive and make view of self, a process that is likely to contribute to a sense of meaning or purpose. The results from Study V support this reasoning, since self-related variables, such as mastery, locus of control and sense of coherence, were significantly correlated to occupational engagement.

According to Hans (2000) the experience involved in occupational engagement can change previous patterns of success and failure, and as a consequence people can regulate their own behaviour. Trombly asserted (1995) that when a person finds meaning, he or she may have the desire to do something further and act upon the situation. This is what Rebeiro and Cook (1999) referred to as the spin-off effect of occupational engagement, which provides an ongoing means of

actualisation of self and capacity. This way of reasoning may help explain the results in Studies II, showing that the ongoing process of occupational engagement was intimately linked with the experience of meaning. Thus, it could be indicated that, the more the participants occupied themselves and engaged in reality, and the more they experienced and came to reflect on and make sense of reality, the less room was left for delusions and other symptoms. This assumption resembles what Reker and Wong (1988) proposed, that the greater the breadth and depth of a personal experience, the greater the contribution of unique personal contexts and history to the meanings in that person's life.

Study V showed that locus of control was an important determinant that could help explain occupational engagement. Internal control was related to a higher level of occupational engagement. Thus, feeling in control of the occupations performed and the environment interacted with was linked with having adequate strategies for dealing with everyday life. Conversely, external locus of control, where meaning probably derived more strongly from societal expectations, seemed to be related to that the participants had few strategies for managing everyday life on their own. Breier and Strauss (1983) identified different ways for feeling in control and handling symptoms in everyday life among people with schizophrenia. The most concrete strategy found meant identifying the undesired experience or behaviour or a threatening situation. This way, the individuals could admonish themselves and have internal control in the occupational situation. Another strategy was to depart or avoid the threatening situation or disrupt the stressful behaviour by doing something else, like going for a walk. Similarly, some of the participants in Studies I and II took control of their symptoms at times. Often, it was about disrupting a longer period of distressing quiet activities at home by consuming mass media or seeking up a non-demanding social environ-

ment, such as the day-care centre. In all, this thesis showed that when people with schizophrenia felt in control and perceived a sense of mastery they also occupied themselves and engaged in occupations to a larger extent.

Enriched life experiences can enhance quality of life among people with schizophrenia (Awad, Voruganti & Heslegrave, 1997), and increased occupational engagement may be regarded as an example of this. Therefore, it would be important for occupational therapists to continue to enable people with schizophrenia to engage in meaningful occupations where they experience, employ problem solving or otherwise creative methods to deal with the environment around and the occupation at hand. Thus, occupational therapy could promote health by attempting to create situations in which people with schizophrenia get different reinforcements. Consequently, when the disability concerns the personal domain, the importance of enabling a meaning-making process seems urgent. In order to accomplish this, occupational therapists use creative arts as means for starting occupational story making and occupational story telling, which will get the reflective and meaning-making process going (Gunnarsson *et al.*, in press).

The environmental domain

The geographical and social environment seemed to have a profound impact on the extent to which the participants engaged in occupations. Studies I and II showed that the social and geographic environments could be restricted and under demanding. In such cases, most time was spent at home, and being alone was the most usual social situation. According to O'Brien and colleagues (2002) this kind of restricted home environment can create disability just as much, if not more, than disability caused by personal factors per se. Little engagement (Lieberman *et al.*, 1982) and the presence of delusional moments have shown to increase within such an environment (Myin-Germeys *et al.*, 2001). Furthermore, quiet ac-

tivities have been shown to be least beneficial to health in a home environment (Mee & Sumsion, 2001; Shimitras *et al.*, 2003). In line with this, Studies I and II showed that the home environment could at times be viewed as a place where the participants felt isolated and withdrew from occupation. At the same time, however, the home can be viewed as a place of safety where one is able to rest and conserve one's energy, not needing to worry about stigma and discrimination (O'Brien *et al.*, 2002; Rebeiro & Cook, 1999). Home can also be viewed as a place from where social dimensions of occupational engagement depart from. Studies I and II showed that consuming mass media, in terms of watching television, listening to the radio, reading the newspaper and using the internet, and to have pets, were stated to transform the home environment into a more social one. These were occupations considered to be meaningful and they made many of the participants feel as if they were being part of something and in a sense the participants felt as if they had company. Understanding the implications of the home environment and the impact it may have has on occupational engagement would be of great value and should put home assessment in its rightful place when evaluating occupational engagement in people with schizophrenia. For example, some of the items in the POES (Study III), *Place, Social Environment and Social Interplay*, could help to encircle the status of interaction with the environment. In addition, it would be necessary to make a home assessment, including whether the equipment needed for engaging in daily occupations is at hand. Hence, occupational therapists and other professionals need to acknowledge that the home is where everyday life starts off, and that is an environment that seems to have a great impact on occupational engagement, and thus health, as a whole.

It would be important to assess the geographic environment in the neighbourhood in order to make this environment accessible

for people with schizophrenia, as suggested by Creek (2003). Shops, cafes, restaurants, day-care centres and so forth would be important facilities to have close to home, mostly since the most usual way of transportation for the participants was walking (Studies I and II). In addition, the social dimension of the living environment needs to be understood and assessed as well. Do people with schizophrenia feel accepted by neighbours, or by people they meet in the local shop, etc? Do they leave home at all, and do they have a home to begin with? Perhaps there is a lot of crime in their neighbourhood that makes it frightening to leave the home. A study showed that people with schizophrenia in Malmö Sweden lived predominantly in neighbourhoods that were characterised by a high incidence of public order disturbances, fear of crime and weak social integration among the residents (Lögberg, Nilsson, Levander & Levander, 2004). In any of these circumstances it would be important to assess the home environment and the neighbourhood that people with schizophrenia may have in order to truly understand their disability, which may partly be caused by the constituents of the geographical and social environment.

The local day-care centre was another type of environment where many participants spent quite some time. In such a non-demanding social environment, professionals usually have a supportive role (Björkman, Hansson, Svensson & Berglund, 1995; Erdner, Nyström, Severinsson & Lutzén, 2002), and other types of social interaction are likely to take place with peer visitors. Most importantly, the social interplay seems to develop in accordance with a person's sensitivity to stimuli in the environment; the mere presence of others is often sufficient at an initial stage. This way, the social environment does not become too intrusive. In Study II, some participant reported that this type of stimulating and supportive environment led to the development of social relationships that went beyond the environmental setting. This

seems natural, and desirable, because in the long run a supportive environment, like the day-care centre, may lack sufficient challenge to stimulate the person into having meaningful reciprocal relationships, and if life does not extend beyond institutional environmental settings the person's way of life will remain static. Furthermore, environmental influences restricted to institutional contexts might reinforce the general picture of people with schizophrenia as having an impoverished lifestyle. There are too few occupational opportunities and stimulating environments in society that are adapted to and accessible for people with schizophrenia. Consequently, an important role for occupational therapists and other professionals is to take a stand for the occupational perspective on health. It would be urgent to implement challenging occupational opportunities and environments for people with schizophrenia and thereby maximise their participation in society.

The occupational domain

The participants went through periods of higher or lower arousal during the day, as indicated by the extent to which the participants engaged in occupations (Studies I–V). The increase or decrease of occupational engagement is reflected in the four-point scale of the nine items in the POES instrument (Study III). In particular, the first two items in the POES, *Daily rhythm of activity and rest*, and *Variety and range of occupations*, reflected the occupational domain. The quiet activities clearly differed in relation to the extent to which the participants were engaged in occupations, and the function of the quiet activities set out the pace of the day. However, people with mental health problems derive less enjoyment from quiet activities compared to persons with no mental health problems (Crist *et al.*, 2000). Thus, if quiet activities dominate, such as when a low level of occupational engagement is at hand, these activities are likely to be less appreciated.

In Study II, it was first anticipated that the extent to which people with schizophrenia engaged in daily occupations varied along a continuum. In that study, the participants functioned at three levels of occupational engagement. The participants that functioned mainly at the first level of engagement reported that they ended up in quiet activities for longer periods of time as a result of having nothing else to do. These quiet activities were mostly a result of few occupational opportunities, of having nothing to do, and a deprived environment. The participants were lacking experiences, and they often reflected on their occupational performance as being empty, with no sense of meaning. In these circumstances, the quiet activities were not a result from disabling thoughts or hallucinations. Instead, the participants seemed to have no other strategy to take them out of tedious situations. However, for those participants who functioned at a higher level of occupational engagement, who had ongoing engagement (Study II), the quiet activities were not associated with emptiness and they did not take over the entire day. They had a recreational purpose, with time for reflection and a link to the other occupations performed. They rather functioned as short breaks and contributed to a balance between rest and activity. Therefore, quiet activities should be studied with respect to quantity as well as quality and be understood in relation to the overall pace of the day (Christiansen, 2005; Hagedorn, 1995) the specific context, and groups of people (Hagedorn, 1995; Nurit & Michal, 2003). Furthermore, Sharp and Wessley (1998) pointed out that the distinction between gainful or harmful quiet activities should be clarified. This discussion will be followed up in the discussion regarding further clinical implications.

Quality of Life

The results in Study V showed associations between occupational engagement and qual-

ity of life. Thus, quality of life could be assumed to increase and decrease along the continuum of occupational engagement (Figure 3). The results support the assumptions by Chan *et al.* (2005), that there seems to be a connection between the quality of daily occupations and the quality of life.

Within occupational therapy practice, increased occupational engagement is already viewed as a goal towards enhanced quality of life (Chan *et al.*, 2005; Christiansen *et al.*, 2005; Goldberg *et al.*, 2002; Laliberte-Rudman *et al.*, 2004). And the role of occupational therapists is often to provide occupational opportunities for promoting quality of daily life. The results from Study V strengthen this previously identified link between the daily occupations and quality of life. The results highlighted the relevance of an occupational perspective on health and quality of life, which should give occupational therapy a central place within the field of mental health treatment of people with schizophrenia.

Further Clinical Implications

This thesis has provided knowledge concerning an occupational perspective on health in people with schizophrenia. Still, it is worth further questioning how this kind of knowledge can be implemented in clinical practice, how professionals that work together with these clients can reason in a way that treasures the understanding of how occupational engagement in everyday life seems to be intimately linked with having symptoms, little social interplay, and experiencing little sense of meaning.

Occupational Engagement and Occupational Balance

This thesis implied that it is important to understand the clients' level of occupational engagement when planning occupational therapy interventions and when estimating wheth-

er the current living situation is beneficial to health and well-being. In the results of Studies IV and V, a higher level of engagement was related to increased satisfaction and sense of self, and a decrease in psychopathology. However, a certain level of occupational engagement might not be related to a healthy occupational balance in a systematic way.

According to Backman (2001), achieving balance and rhythm between activity and rest is a goal with moving goalposts. It is an ongoing process which is defined individually (Backman, 2004). Thus, the level of occupational engagement that supports health for a certain person before the onset of schizophrenia might differ from the level that supports health after the onset, and the optimal level might fluctuate along the illness and recovery process. The point here is that having a higher level of occupational engagement may not always be associated with a good occupational balance. Similarly, a pattern with little engagement does not automatically mean having an imbalance between abilities and occupational opportunities. In fact, it may currently be the best occupational situation for that person (Study V).

The extraordinary vulnerability to the risk of being under-occupied with few occupational opportunities and a non-stimulating social environment, and the risk of being over-occupied with too much stimulation from an intrusive environment may be viewed as one aspect of disability in people with schizophrenia (Hirsch, 1976; Liberman *et al.*, 1982). Since rehabilitation seems to involve constantly walking the line between being over- or under-occupied, it would be vital to estimate whether the client seems over- or under-occupied or in occupational balance regarding activity and rest, and regarding the interaction of personal, environmental, and occupational factors (Backman, 2004; CAOT, 2002; Christiansen & Townsend, 2004; Csikszentmihalyi, 1997).

On the one hand, people with schizophre-

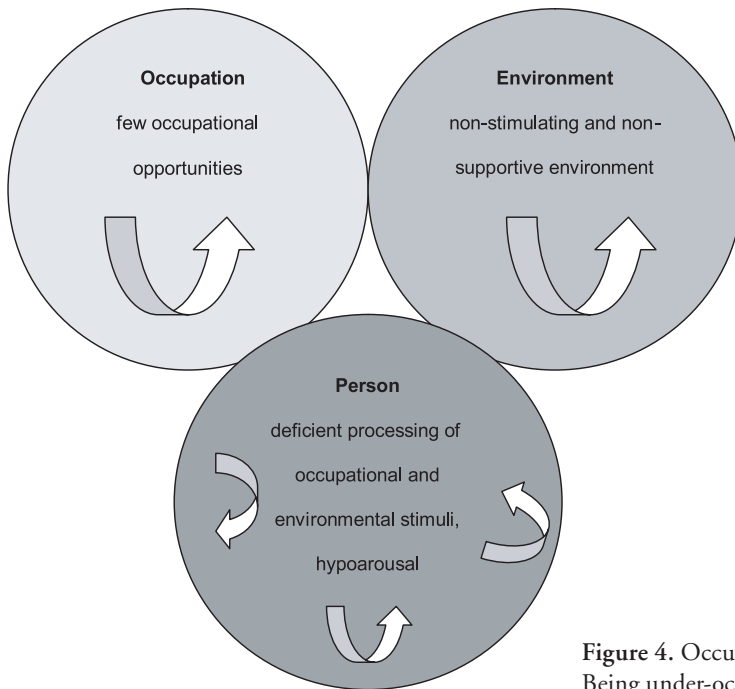


Figure 4. Occupational disengagement. Being under-occupied.

nia seem to be under-occupied in impoverished environments. They seem prone to develop negative symptoms, disabilities and in-adaptive behaviour, as reflected among the participants that were engaged to only a little extent (Studies II, IV, and V). This idea is reflected in Figure 4, where the arrows symbolise the directions of the, in this case, non-transactions between the three occupational performance domains. On the other hand, over-occupation and too stimulating environments, such as intrusive social relations or too intense treatment, may in turn produce psychotic relapses (Lieberman *et al.*, 1982; Sells, Stayner & Davidson, 2004), which is reflected in Figure 5, where the arrows symbolise an imbalance in transactions between the three domains. Thus, an increase or reappearance of symptoms could be an outcome of the imbalance between a person's problem-solving skills and life stressors found in the environment and in the type of occupations

performed (Zubin & Spring, 1977).

Since occupational balance refers to the fit between personal, environmental and occupational factors (Backman, 2004), occupational therapists should help to optimise a good fit between the three (Figure 6). The client's everyday life should be planned in such a way that it fits the personal needs like a well-tailored garment, because helping people to a balanced use of time and an optimal blend of meaningful occupations could support the rebuilding and maintenance of health and well-being in people with schizophrenia.

Positive and negative withdrawal

The function of withdrawn activities, such as the quiet activities in this thesis, differed in relation to the level of occupational engagement. It would therefore be vital to distinguish whether the quiet and withdrawn activities should be interpreted as being positive or negative in nature.

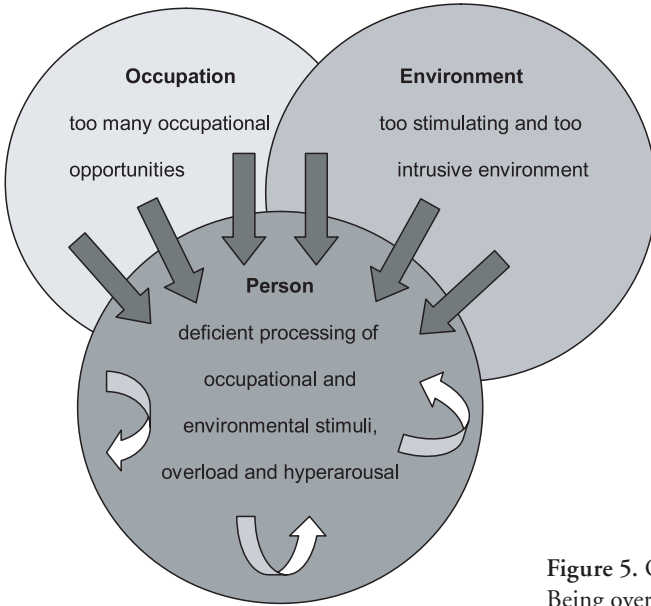


Figure 5. Occupational disengagement. Being over-occupied.

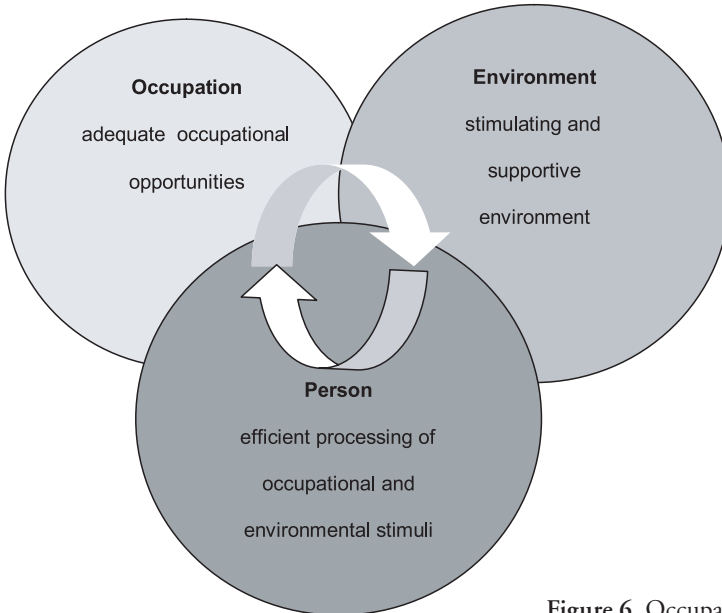


Figure 6. Occupational engagement.

In a review article by Sells Stayner and Davidson (2004), it was found that positive withdrawal can help a person balance the distance to a reality that might be difficult to confront. Thus, the quiet activities that were registered by the participants in Studies I and II, and that were estimated by POES in Studies IV and V could mean adopting a perceptual style that reduced the intensity of stimuli. The function could be to escape the current demanding situation, a way of dealing or coping with a chaotic inner life and keeping a safe distance to a loud and complex world. Not engaging in occupations could be a strategy for avoiding something that is worse. A state of not feeling or doing anything may serve to reduce excessive levels of arousal (Davidson & Stayner, 1997; Schooler & Spohn, 1982). It could be anticipated that such a strategy could enhance the possibilities for the person to achieve occupational balance, that these quiet and withdrawn activities would match his or her abilities and interests. According to Pierce (2001b), the least well understood occupational area is that of rest and restoration, which is important in order to understand occupational balance in relation to health. This notion seems especially applicable to people with schizophrenia.

Negative withdrawal could be identified in Studies I and II. Some of the participants reported that they ended up in quiet activities for longer periods of time as a result of having nothing else to do. They functioned at a lower level of occupational engagement, which was related to lower ratings regarding health factors (Studies IV and V). The quiet activities were mostly a result of few occupational opportunities and a deprived environment, of under-occupation. As a consequence, the participants often experienced emptiness and lack of meaning, and they simply did not seem to have a strategy to get out of this tedious situation.

To sum up, positive withdrawal could play an important part in recovery, while nega-

tive withdrawal would not. In recent qualitative research (Gould *et al.*, 2005; Sells *et al.*, 2004), and as indicated in Study II, it was emphasised that the resumption of self takes time and that withdrawal and quiet activities could play an important role and be viewed as a necessary stage in recovery, in people with schizophrenia. Thus, when planning interventions, the occupational therapist should consider that quiet activities may constitute meaningful occupational engagement that facilitates self-definition and corresponds to the internal needs of being. That being is intimately linked with doing has been suggested in previous literature (Eklund, 2000; Watson, 2006; Wilcock, 1998). Accordingly, within the occupational therapy profession, it is assumed that it is not through dramatic experiences that a sense of self can be resumed after a psychosis, but rather through nourishment that the repeated experience and interpretation of engagement in a variety of daily occupations provides.

Occupational Engagement and the Social Environment

The participants reported that, to be, to belong, and to do in a social environment was meaningful, regardless of the way in which they interacted socially and the level of occupational engagement at which they functioned (Studies I, II, IV, V). Furthermore, previous research has shown that the presence of others seems to decrease the incidence of experiencing delusions (Myin-Germeys *et al.*, 2001). Research has also indicated that if people with schizophrenia were unable to withdraw in a positive sense, some of them showed abnormality in the form of positive symptoms like hallucinations, delusions and odd behaviour (Lieberman *et al.*, 1982). According to Sells *et al.* (2004) this could mean that it is essential to keep a certain distance to the surrounding social environment when reaching for a higher level of occupational

engagement and recovery. Thus, as discussed earlier on, it is important for occupational therapists and other professionals to recognise positive withdrawal and acknowledge that quiet activities can be beneficial to the occupational balance and, thus, occupational engagement at the right level. For example, in Studies I and II, the quiet activities that meant sitting and observing other people, in combination with a non-demanding environment, made the participants feel in control, since this type of social interplay was not externally initiated. Perhaps, at some stage of recovery, people with schizophrenia prefer a less active social role, where they can study and observe their environment at their own pace, interacting socially according to their own ability and having internal control.

Initiating contact

In a qualitative study, the establishment and quality of the helping relationship, where the client felt understood, was found to be the most important factor for experiencing satisfaction with general psychiatric care (Johansson & Eklund, 2003). The present thesis has shown that the social environment was an important factor for experiencing meaning and initiating and enhancing occupational engagement (Study II). Thus, it seems important to start a helping relationship. Moreover, since it was shown (Study II) that the participants' abilities to interact socially varied in relation to occupational engagement, it seems important to provide appropriate levels of social support with the intention to facilitate self-definition and a helping relationship at any level of the occupational engagement continuum. However, future research needs to investigate how the helping relationship and the social environment should be monitored in relation to a person's ability to interact socially.

Lieberman (1982) asserted that the strategy in skills training has firstly to be about establishing a solid therapeutic alliance before eas-

ing clients into treatment and rehabilitation. Consequently, a gradual relationship building and induction of occupational therapy seems to be more relevant than offering brief courses or programmes that are carried out in formats that fit with the restrictive economic and political climate of today.

Participation in society

The results from Studies I and II clearly showed that although people with schizophrenia were engaged to a certain extent and often had ongoing occupations, they did not seem to participate in society to the same degree as one would expect from the general population. Also, people with schizophrenia are prone to live in neighbourhoods that are segregated (Lögberg *et al.*, 2004). In this sense, people with schizophrenia can be regarded as being a marginalised group in society. Homeless people, many of which have a severe mental illness, have explained how their kind of life meant living outside society (Griner, 2006; Robinson, 1997). Hence, further occupational opportunities, similar to those of the population in society in general, should be provided, since it is important that this group of people do not continue to form a subculture and remain in a chronically impoverishing situation. Consequently, it is not only the professionals working within the mental health care system that need to attend to new strategies of how to include people with schizophrenia into society. Rather, the society in large needs to take a stand and face the challenge of assuring supportive and not too socially demanding environmental settings. Just as the physical environment is adjusted for people with physical disabilities, the social environment needs to be analysed and adjusted for people with schizophrenia. Perhaps one way to go about this unmet need is to provide information about the occupational perspective on health with a focus on people with schizophrenia, such as the information that the studies in this thesis

have generated. Such information could enable people in a workplace where people with schizophrenia may work, for example, to be sensitive enough to recognise the tightrope of being under- or over- occupied. Another action to take would be to address society in large, by fighting stigma. Stigma denotes negative attitudes and prejudice about mentally ill people. Most likely, stigma contributes strongly to the disability shaped by social barriers and the accessibility of society. Marwaha and Johnson (2004), found that fear, loss of benefits and a lack of appropriate help were barriers to getting employment and thus take part in society. Consequently, the rules and regulations for the labour market and the social insurance system need to be assessed for their influence on participation in society. The importance of work for integration into society can not be overrated. A 10 year follow-up study in Norway showed that the ability to interact socially was related to having employment and being part of society (Melle, Friis, Hauff & Vaglum, 2000). Therefore, in order to understand how to make society more accessible, it seems important to expand the research arena and include different societal setting, such as different workplaces and other public places that few people with schizophrenia might visit today.

Methodological Considerations

Design Issues

This thesis is an example of the cyclical nature of research (Creek, 2003; Hagedorn, 1995; Kazdin, 2003). It started with inductive qualitative research and ended up with formal quantitative testing of hypotheses generated from the initial studies.

In generic terms, the thesis had a naturalistic, cross-sectional design. The phenomena and variables studied have been naturally oc-

curing among the participants. From an ethical point of view, such a design is in favour when studying people with schizophrenia, since it is regarded positive not to manipulate or intrude into these people's lives more than necessary (Medicinska forskningsrådet, 2000). In a more detailed perspective, the study design can be said to have varied according to the aims of the five studies. Both a qualitative, inductive approach (Studies I–III), and a quantitative more deductive methodology approach (Studies III–V) has been used. Moreover, in Study V, partly a comparative design was employed (cf. (Brink & Wood, 1998)). The results confirmed what had been indicated in Studies II–IV, that there would be differences regarding the extent to which the participants engaged in daily occupations. Thus, the comparative design revealed more about the theory on occupational engagement compared to what a correlational design would have done on its own (Brink & Wood, 1998; Kazdin, 2003). In addition, the testing of a linear trend (Study V) confirmed that occupational engagement seems to be increasing or decreasing along a continuum. Although causal relationships can not be directly demonstrated using a comparative design, Kazdin (2003) emphasised that a dose-response relation can provide a strong basis for a hypothesis about these relations, suggesting that the variables are related in a way that is consistent with a causal hypothesis. However, no time line is evident, which makes it difficult to establish whether one characteristic preceded the other, or emerged together. Therefore, the studies in this thesis do not reveal whether it is occupational engagement that promotes mental health or vice versa. However, the results in this thesis suggest that the personal domain of occupational performance is in constant dialogue with the environment through the act of doing. In this sense, the cause and effect relationship could be interpreted as an ongoing and dynamic process.

Validity Issues

A threat to validity might be selection bias. Since the primary contact persons took the initial contact with the patient, informed them about the study, and asked for their consent, one could expect that when a client had continuity in the contact and was pleased with the care received, he or she was more likely to participate in the studies, compared to a patient that did not have such a well-established contact. From this point of view, perhaps it would have been more accurate if the researcher had asked for consent. However, it was considered important not to violate ethical principles, such as informed consent and voluntary participation, which were carefully considered in this study.

In the whole group of eligible participants, there was a non-participant rate of 38%, which can be viewed as being a threat to internal validity. However, this rate is characteristic for a group of people with schizophrenia (Meuser *et al.*, 1997; Wallace, Tauber & Wilde, 1999), or somewhat better than previous studies on similar samples (Bengtsson-Tops *et al.*, 2005; Eklund *et al.*, 2004). The dropout analysis revealed no differences between the participants and the non-participants according to known background characteristics. However, it could be speculated that the non-participants were too ill to participate, and/or were homeless, or that they could have been people who felt well and did not need psychiatric services the past 12 months. Moreover, the participation rate was probably related to the selection procedure. The researchers were not part of the clinical staff, which probably made it easier for the patients to decline participation compared to if the research project had been synchronised with the units' normal activities (Eklund *et al.*, 2001). Moreover, for confidentiality reasons the researchers depended on the staff in establishing contacts with the patients, and a second link in communication is known to lead to loss of information. Furthermore, two

primary contact persons were on sick leave for periods of time, which may also have influenced the communication with some of the clients. Thus, the fact that the research project ran independently of the clients' general care resulted in a fairly large attrition rate but minimised bias concerning the participant – experimenter effect.

It seemed like the variables in this study were inter-related to a large extent, which might indicate, as Priebe *et al.* argued (Priebe *et al.*, 1998), that self-ratings are closely related because they reflect an underlying common construct. Another possible influence on connections between variables is the interviewer effect (Kazdin, 2003), which is a risk if all data are collected by the same person. However, this limitation was mitigated in that independent raters assessed the level of engagement according to the POES.

The psychometric properties of the instruments used in this cross-sectional study has been established. However, the 24-hour time-use diary with a supplementary interview was not such a well-tested method for collecting data. Therefore, the fact that the methodology has had a great influence in this thesis warrants some reflection. One validity concern regards the recording of the diary in terms of the accuracy with which the diaries were filled out. It has been stated that cognitive functions (Spaulding *et al.*, 1999) and flattening of affect (Gerhardsson & Jonsson, 1996) may influence the ability to identify recent events in people with schizophrenia. However, there are indications that a time-use diary together with a supplementary interview, as used in this thesis, reflects real-life events among people with schizophrenia in a rather accurate way (Pentland *et al.*, 1999). The temporal order implied in a time-use diary fits well with the natural logic of daily occupations, which facilitates the recall of experiences. Furthermore, at the time of the recording the event is still fresh in mind and the person is likely to stay closer to reality. Lawton (1999) pointed to the prominence of

using a 24-hour yesterday diary and interview, instead of a self-generated diary, when a person has sensory and cognitive impairments. Moreover, previous research has successfully used data collection based on the recall of performed daily occupations in a time-use perspective among persons with schizophrenia (Hayes & Halford, 1996; Minato & Zemke, 2004; Shimitras *et al.*, 2003) and among persons with persistent mental illness (Leufstadius *et al.*, 2006). Robinson (1999) asserted that there is a close relation between time-use diary data and observed time-use.

Although the time-use diary seemed to have served the purpose of the studies, further research that uses other time-use methods could be carried out in this group of people. The experience sampling method, ESM, and in depth-interviews could further reveal aspects of meaning that are likely to mobilise or initiate the ongoing process of occupational engagement, especially since meaning is likely to vary substantially with behaviours, locations and social contexts (Csikszentmihalyi & Larson, 1987). Furthermore, observational time-use methods, carried out in different geographic places and social environments, could further strengthen the understanding of how people with schizophrenia seize their world around them. However, observation would probably be a better alternative in institutions or other places where most occupational behaviour is open to public view, and less suitable in the private sphere, where observation would mean too much of an intrusion in the participants' daily life and thereby effect data collection (Lawton, 1999).

Concerning external validity of the studies in this thesis, it is important to ask from what population the sample is taken and to what extent the findings can be generalised to other people with schizophrenia. The limited size of the final sample limits the external validity. However, the results are in accordance with the present literature in the research area. According to Ahlbom (1991), if criteria such as

this is met, not much threat to validity should be ascribed. Still, generalisations from the studies should be made with caution.

The time period studied is also important to consider in relation to validity. People's behaviour may vary in relation to time, season, and week, and it is important that the studied time period is appropriate with respect to the particular interest of the study (Harvey, 1999). All time-use data was collected over a 24-hour period in a weekday. Thus, the sampling of this sort may not have been fully representative of the participants' daily occupations as a whole and the exclusion of weekends may have limited the representativity. However, 24 hours has been suggested to be an appropriate interval for obtaining a satisfactory level of validity when used on a group level (Szalai, 1972), and one diary, when cumulated across a fairly large sample, provides a rather impressive and solid base for measurement (Robinson, 1999). However, it is doubtful that the 10 participants in Study I, and 20 participants in Study II, can be considered to be a fairly large sample. Still, the compatible results from Study II and Study V strengthen the validity. Furthermore, the findings from Studies I and II have features in common with other studies (Chugg & Craik, 2002; Crist *et al.*, 2000; Emerson *et al.*, 1998; Gould *et al.*, 2005; Laliberte-Rudman *et al.*, 2004; Mee & Sumsion, 2001; Minato & Zemke, 2004; Nagle *et al.*, 2002; Röder-Wanner *et al.*, 1997; Sells *et al.*, 2004; Shimitras *et al.*, 2003). Moreover, the sample size in the three different subgroups of occupational engagement that were compared (Study V) seemed to have been large enough, since, according to Brink and Wood (1998), 20 participants are enough when clinically important differences between groups are expected.

In addition, since people with schizophrenia are likely to be sensitive to new situations and contexts, such as the data-collection procedure, it would probably be important to acknowledge what Kazdin (2003) calls stimulus

characteristics and settings, and reactivity of the data-collection arrangement. However, validity in this respect was strengthened by the fact that the data-collection procedure, setting and interview person were the same throughout the data-collection.

Apart from the studies that concerned gender (Studies II and V) and age (Studies III, V) in relation to the results, sociodemographic factors were not explicitly investigated in this thesis. Such factors could be assumed to have a key role in relation to how a person with schizophrenia engages in occupations. Therefore, although this was not part of the aim of this thesis, it is therefore warranted to further analyse the data collected for this thesis against such factors.

Conclusion

- This thesis has provided an occupational perspective on health and thereby a new dimension for understanding mental health and quality of life for people with schizophrenia.
- The time-use study showed that many of the daily occupations are performed alone, in the home environment. Few occupations worked as routines and many occupations were triggered by immediate needs.
- It varied to what extent people with schizophrenia engaged in occupations. The levels of occupational engagement ranged from performing mostly quiet activities alone, with little sense of meaning, to having ongoing occupational engagement in a greater variety of social and geographical environments.
- Spending time in a social environment was meaningful to the participants, functioning at any level of occupational engagement. It could be about adding a social dimension to the home environment by consuming mass media, could be about spending time in and observing the social environment, and about having reciprocal social interactions.
- A higher level of occupational engagement was associated with higher ratings of self-related variables, fewer psychiatric symptoms, and better ratings of quality of life.
- In the development process of the POES, good psychometric properties were found. The POES may serve as a valuable measure and could reveal different perspectives of disability. It could be used as an initial step in the evaluation process of a client and help to identify the level of occupational engagement and possible lack of meaningful occupations, imbalance between rest and activity, and few occupational and environmental opportunities.
- The ability to interpret, reflect on and bring meaning to occupations seemed to play a key role regarding the level of occupational engagement, and also the severity of the schizophrenic disorder.
- Not only personal factors, such as having thought disorders or having emotional distress, were indicated as factors behind the disability, but also circumstances in the social and geographical environment, and the occupations performed, could become hindering factors to engagement in meaningful daily occupations.
- In addition to estimations that regard occupational engagement, occupational therapists and other professionals need to consider whether the client seems over- or under-occupied or in occupational balance. It would also be important to distinguish whether the longer periods of quiet activities is caused by withdrawal in a positive or negative sense.
- Regarding the therapeutic alliance with the client, it seems important to provide appropriate levels of social support with the intention to facilitate self-definition and a helping relationship, at any level of the occupational engagement continuum.

Svensk Sammanfattning/ Swedish Summary

Arbetsterapi och aktivitetsvetenskap fokuserar på vardagen varvid ett viktigt antagande är att det som människor gör varje dag har betydelse för välbefinnande. Den verklighet som personer har står i fokus. Människan behöver engagera sig i aktiviteter för att utvecklas och hitta mening i tillvaron. Det är inte främst genom dramatiska positiva händelser som en tillfredsställande tillvaro kan växa fram. Istället är det förståelsen av vardagliga händelser och reaktioner på de aktiviteter som personer dagligen engageras i som kan generera upplevelser av mening och tillfredsställelse med tillvaron. Hälsa och välbefinnande kan därför inte endast betraktas ur ett biologiskt perspektiv, utan måste ses utifrån hur personer med schizofreni lever sitt liv. Att se på hur personer använder sin tid, vad de gör, vem de är tillsammans med, var de är och hur de upplever sina dagliga aktiviteter och sysslor är alltså ett kunskapsområde som behöver belysas ytterligare.

Schizofreni påverkar individens vardag på ett genomgripande sätt. De kognitiva och känslomässiga begränsningar som sjukdomen medför leder till att personer med schizofreni ofta tänker, känner, upplever, och relaterar till världen runtomkring på ett särskilt sätt. Dessa begränsningar medför svårigheter med att lösa problem, planera tid, och utföra aktiviteter i vardagen. Även de förändringar i vårdapparaten som har gjorts de senaste 20–25 åren, i form av avinstitutionalisering, har haft betydelse för hur personer med schizofreni lever i sin vardag. Personer med schizofreni har blivit en eftersatt grupp både vad gäller livsvillkor och tillgång till adekvat samhälleligt vård och stöd, inte minst beträffande rehabiliteringsinsatser. Det föreligger risk för ökad hemlöshet, ett ökat missbruk, en förhöjd suicidfrekvens, men framförallt svårigheter med den dagliga sysselsättningen

och att vara delaktig i det moderna samhället. De stöd och vårdinsatser som erbjuds utgör oftast endast en bråkdel av den tid som en person med schizofreni har till förfogande under en vecka. Det personer med schizofreni gör resten av tiden, hur de upplever vad de gör, och med vem och var de befinner sig under dagarna, är ännu dåligt kartlagt. Det finns heller inga lämpliga datainsamlingsmetoder som är baserade på det liv som personer med schizofreni har, och som bedömer i vilken grad de engagerar sig i dagliga aktiviteter i olika sociala och geografiska miljöer. Slutligen, så är det inte empiriskt belagt om engagemang i det dagliga livet har betydelse för upplevd hälsa och livskvalitet för dessa personer. För att överhuvudtaget kunna sätta sig in i eller förstå vilka förutsättningar personer med schizofreni har i sitt dagliga liv, är det viktigt av att veta mer om hur deras vardag ser ut och hur deras aktiviteter, miljöer och personliga faktorer kan påverka hälsa och livskvalitet på olika sätt.

Det övergripande syftet för denna avhandling har varit att synliggöra vardagen för personer som har schizofreni, och hur denna vardag kan ha samband med hälsorelaterade faktorer och livskvalitet. Nyttan med avhandlingen ligger i att den kunskap den genererar skulle kunna bidra till en ökad förståelse, en begreppsapparat och en referensram som arbetsterapeuten och andra berörda kan använda i sitt kliniska resonemang kring den aktivitetsproblematik och de funktionshinder som personer med schizofreni kan ha i sin vardag. Systematiserad kunskap kan även ligga till grund för utformning av olika rehabiliteringsstrategier. Tanken med avhandlingen har varit att skapa en ökad förståelse för den vardag som annars kan vara både ogreppbar och osynlig för dem som kommer i kontakt med personer med schizofreni, där sjukdomsbilden oftare står i fokus. Det har varit viktigt att ge vardagen ett fokus och därmed bidra till ett mer komplext, men även ett mer realistiskt, perspektiv på hälsa, välbefinnande och

livskvalitet, så som personer med schizofreni själva upplever det.

I avhandlingsarbetet deltog 74 personer med schizofreni från öppenvården i Malmö. De har alla fyllt i en 24-timmars tidsdagbok och medverkat i en kompletterande intervju. De har även fyllt i självskattningsinstrument som avsåg att mäta känsla av sammanhang och upplevelsen av kontroll. Även skattning av symtom, livskvalitet och psykosocial funktion har använts. Vidare har tolv arbetsterapeuter varit med i studien för att bedöma aspekter av validitet och reliabilitet i samband med att ett instrument utvecklades, Profiler av aktivitetsengagemang bland personer med schizofreni. Ytterligare en arbetsterapeut har varit med för att bedöma aktivitetsengagemangs med hjälp av det utvecklade instrumentet.

De olika delstudierna

Studie ett syftade till att utöka förståelsen för den grundläggande byggstenen i vardagen, själva aktivitetsutförandet. Detta gjordes genom att aktivitetsutförandet bland tio personer med schizofreni studerades i förhållande till tid. Tidsdagboken täckte de senaste genomlevda 24 timmarna. En kartläggning av 10 personers tidsanvändning i förhållande till aktivitet, miljö och personliga reflektioner gav en glimt av den verkliga livsstilen och återgav handlingssekvenserna i kronologisk ordning. En innehållsanalys användes som metod, som i en komprimerad form återgav det som urvalspersonerna sagt och uttryckt i tidsdagboken. Resultatet visade att ensamhet och passivitet i hemmiljö, med lite upplevd mening, dominerade deras livsstil. Få personer arbetade eller deltog i en aktiv fritid eller studier. Det mest tillbakadragna tillståndet i hemmet, vilket gällde för flera av urvalspersonerna, var att sitta eller ligga och titta. Ibland utökades det stillsamma tillståndet med att röka och dricka kaffe, och att äta en bit mat som ofta någon annan tillrett eller som köpts

färdigt. Dessa aktiviteter igångsattes främst av omedelbara behov.

Att ta del av massmedia var ofta det första steget till att "ta in" omvärlden. Ofta var det just tidningsläsandet, radiolyssnandet eller tv-tittandet som ökade deras känsla av delaktighet i hemmiljön och tillförde en social dimension till deras isolerade hemmiljö. På så sätt kunde ett tillbakadraget förhållningssätt till den omedelbara omvärlden till viss del brytas. Därmed kunde även känslan av tomhet och viljan att fly bort mildras, en upplevelse som annars var en vanligt förekommande när dessa personer inte var engagerade i sin omvärld.

Det förekom även lustfyllda aktiviteter, såsom att spela gitarr eller att skriva, men ofta utfördes dessa i ensamhet och inte mycket tid gick åt till dem. Allra minst tid gick åt till personlig vård och hushållsaktiviteter. Utanför hemmet var det ofta olika former av sociala aktiviteter som dominerade. Vanligtvis gick personerna på kommunala träffpunkter eller hem till vänner som de lärt känna i den typen av miljöer, vilket understryker betydelsen av sociala mötesplatser för denna målgrupp. De deltog inte alltid aktivt i det sociala samspel som förekom, utan de hade ofta en mer stillsam och betraktande roll. Denna bild kan i vis mån återspegla att de var sociala i den utsträckning som de själva klarade av.

Studie två fortsatte med att undersöka vad personer med schizofreni gör. Tio män och tio kvinnor deltog i studien, men här lades tidsbudgetperspektivet åt sidan för att istället se på variationer och nyanser i tidsanvändningen, och för att se på mening och innebörd. I studie två togs det hänsyn till vilka aktiviteter som kom före eller efter varandra, när på dagen urvalspersonerna var mer eller mindre engagerade, relationen mellan aktivitet och vila, och i vilka sammanhang en känsla av mening växer fram. Studien hade ett uttalat könsperspektiv. För att frångå den struktur som tidsdagboken utgjorde, med sitt rutsystem av tid och aktivitetskomponenter, togs rutsystemet

bort och dagboksberättelses skrevs ut. Återigen användes en innehållsanalys för att återge en så genuin bild som möjligt av det som rapporterats. I huvudsak återger resultatet tre olika nivåer av engagemang. *Den första nivån* kännetecknades av lite engagemang och en daglig rytm där större delen av tiden gick åt till stillsamma aktiviteter. De utfördes i stort sett i en och samma miljö, med lite upplevd mening och där omedelbara behov satte igång de få aktiva perioderna under dagen, som oftast handlade om att äta, dricka eller att röka. *Den andra nivån* av engagemang kännetecknades av en jämn fördelning av stillsamma perioder och aktiva perioder i vardagen. För männen var det vanligast att de passiva perioderna kom först på dagen, i hemmet, och de mer aktiva perioderna senare på dagen, utanför hemmiljön. Kvinnorna däremot var mer aktiva under den tidigare delen av dagen, i samband med hushållssysslor i hemmet. De aktiva perioderna förknippades med engagemang och en känsla av mening. *Den tredje nivån* av engagemang innebar att ingen specifik aktiv eller passiv period kunde urskiljas, utan olika aktiviteter hakade på varandra och utfördes i jämn takt. Här utgjordes de stillsamma perioder av en rekreativ paus och de utfördes i samklang med de övriga aktiviteterna. Aktivitetsmönstret var mer varierat och det var vanligt att de rörde sig friare i olika typer av geografiska och sociala miljöer. Vad som framförallt var meningsfullt för dessa personer var att vistas och tillhöra olika sociala miljöer, både i och utanför en arbetsliknande situation. Sammanfattningsvis så visar denna studie att det inte automatiskt innebär att man har en passiv livsstil bara för att man har diagnosen schizofreni. Arbetsterapeuten och andra berörda kan här dra nytta av att identifiera olika nivåer av engagemang och därefter anpassa strategier och metoder för rehabilitering, som motsvarar de olikartade aktivitetsmönster som personer med schizofreni kan ha.

Den tredje studien handlade om att ut-

veckla en metod som utgick från den kunskap som framkommit i studie ett och två. Först inventerades resultatet i de tidigare studierna. Därtill gjordes en innehållsanalys av ytterligare tidsdagböcker, samt en genomgång av internationell litteratur. Sammanlagt medverkade 12 arbetsterapeuter, och 41 tidsdagböcker av de ursprungliga 74 inkluderades i utvecklingsarbetet av instrumentet. Syftet var att utveckla en metod för att identifiera den enskilda patientens/klientens aktuella aktivitetsmönster och engagemang. Instrumentet fick namnet Profiler av aktivitetsengagemang bland personer med schizofreni/Profiles of Occupational Engagement in people with Schizophrenia, POES. Syftet med POES är att strukturera, analysera och sammanfatta den värdefulla, men alltför omfattande, informationen som tidsdagboken ger. Instrumentet kom att bestå av två delar. Den första delen utgörs av en datainsamling via en tidsdagbok och den andra delen består av bedömningsdel. Bedömningsdelen resulterar i en engagemangsprofil, som utgörs av en nivåbestämning av daglig rytm, variation och omfattning av aktiviteter, vistelse i geografisk och social miljö, socialt samspel, förståelse och reflektion, förekomst av meningsfulla aktiviteter, rutiner, och initiering av aktivitetsutförandet. God innehållsvaliditet, intern konsistens och interbedömarereliabilitet kunde konstateras. Instrumentet kan användas i en inledande utredning och även kontinuerligt för att få ett grepp om förändrat status vad gäller aktivitetsmönster, personliga resurser eller olika vistelsemiljöer.

Studie fyra syftade till att undersöka begreppsvaliditeten av POES. Inga instrument som fokuserade just på aktivitetsengagemang fanns vid detta tillfälle. Därför jämfördes POES med andra mätskalor som ändå hade beröringspunkter vad gällde begreppet aktivitetsengagemang. Global Assessment of Functioning, GAF, var ett av instrumenten. Aktivitetsnivå och Tillfredsställelse med dagliga aktiviteter, var andra skalor som i nutid ingår

i ett instrument, Satisfaction with Daily Occupations, SDO, och som på en övergripande nivå mäter olika aspekter av aktivitetsengagemang. Resultatet visade att POES hade ett tydligt samband med GAF, vilket stärkte det faktum att POES speglar varierar i såväl psykosocial funktion som psykiatriska symtom. Ett samband framkom även mellan POES och SDO, speciellt vad gällde de skalor som mäter aktivitetsnivå. Utöver det att en engagemangprofil kan illustreras, eller att en engagemangsnivå kan mätas, ligger POES styrka ligger i att instrumentet ger information om hur vardagen ser ut vad gäller vad personen gör, med vem och i vilka miljöer etc, vilket gör att planering av insatser underlättas.

Studie fem visar på urvalspersonernas engagemangsnivå hade ett samband med självrelaterade variabler, psykopatologi- och livskvalitetsvariabler. En linjär trend identifierades mellan tre grupper som representerade

låg, medelhög eller hög engagemangsnivå, i form av att grad av symtom minskade och känslan av sammanhang och upplevelsen av kontroll i vardagen ökade. I en regressionsanalys framkom att negativa symtom och upplevelsen av kontroll tillsammans kunde förklara 47% av variansen vad gäller aktivitetsengagemang.

Avslutningsvis kan sägas att avhandlingsarbetet har visat, att meningsfulla aktiviteter och ett fortlöpande engagemang i dagliga aktiviteter är viktiga aspekter av hälsan och tillfredsställelse för personer som har schizofreni. Resultaten i avhandlingen understryker betydelsen av att identifiera och känna igen i vilken grad personer med schizofreni engagerar sig i vardagen. Det är viktigt att nå ut med detta aktivitetsperspektiv på hälsa, inte bara till arbetsterapeuter eller andra som arbetar inom psykiatrin eller social tjänsten utan även till samhället i övrigt.

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