# Experiences of Everyday Occupation among People with Psychiatric Disabilities - Relationships to social interaction, the worker role and day centre attendance

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# Experiences of Everyday Occupation among People with Psychiatric Disabilities

## – Relationships to social interaction, the worker role and day centre attendance

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EXPERIENCES OF EVERYDAY OCCUPATION AMONG PEOPLE WITH PSYCHIATRIC DISABILITIES
- Relationships to social interaction, the worker role and day centre attendance

Abstract

The thesis aims to explore subjective experiences of everyday occupation, social interaction and the view of the worker role among people with psychiatric disabilities (PD), while also addressing the importance of day centre attendance. The thesis consists of one qualitative study, exploring which characteristics in everyday occupation provide meaning to people with PD, and three quantitative studies based on questionnaires to both day centre attendees and non-attendees. Study I showed that feeling competent and having a balance between different meaningful occupations helped having control over mental illness. Being social, creating routines and being productive and creative were important to the experience of meaning, as was taking care of body and mind. Study II showed that having less depression and a high activity level were strong predictors of having highly valued everyday occupations. Having a high level of self-mastery seemed to predict both better occupational value and satisfaction with daily occupation. Better satisfaction with daily occupation was further related with being older and having less general psychopathology. The result from Study III showed that the person who was the most supportive and closest to the participants was a family member, but many of them reported to be without such a close and supportive person. Cohabitating and having a high level of positive subjective experiences of occupation were predictors of the quantity of social interaction. Having a high level of self-mastery, a low level of depression and fewer positive symptoms as well as being more satisfied with daily occupation were important for qualitative aspects of social interaction. Study IV showed that having a high activity level, a high level of self-mastery, being younger and having less severe depressive symptoms were indicators of a more positive view of the worker role. The importance of day centre attendance was also explored. The day centre group experienced a higher level of occupational value, was more active and met more people than the non-attendees. When examining aspects of the worker role significant differences were found on the item level, indicating a stronger worker role among participants attending day centres with a work focus. The results of this thesis add new knowledge regarding the everyday life among the target group and may be used in developing community-based mental health care services.

Key words: Meaning in occupations, activities of daily living, , social support, social environment, mastery, occupational therapy, work and community mental health

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CLIMATE
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*To my family*

# Contents

**Paper I-IV**

# List of Publications

This thesis is based on the following studies referred to by their Roman numerals:

**I.** Argentzell, E., Håkansson, C. & Eklund, M. (*in press*). The experience of meaning in everyday life for people with severe mental illness. *Scandinavian Journal of Occupational Therapy.*

**II.** Argentzell, E., Leufstadius, C. & Eklund, M. (*in press*). Factors influencing perceived satisfaction and value in everyday occupations among people with psychiatric disabilities. Comparing day centre attendees with non-attendees. *Scandinavian Journal of Occupational Therapy.*

**III.** Argentzell, E., Leufstadius, C., & Eklund, M. (2011). *Social interaction among people with psychiatric disabilities and the importance of occupational factors: Comparing day centre attendees with non-attendees.* Manuscript submitted for publication.

**IV.** Argentzell, E. & Eklund, M. (2011). *Perceptions of the worker role among people with psychiatric disabilities – Description and investigation of associated factors*. Manuscript submitted for publication.

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# Preface

My interest in rehabilitation for people with psychiatric disabilities was founded during my training as an occupational therapist. During a clinical fieldwork course as an exchange student at La Trobe University in Australia, I experienced my first meeting with a person with severe mental illness; a young boy with a diagnosis of schizophrenia. The devastating changes the illness had caused in his everyday life overwhelmed me and I experienced a strong admiration for his determination to recover. Later on, as a graduated clinician, I started working in various mental health settings in Sweden, first at an inpatient ward and later on at different outpatient settings within the mental health care. During my clinical work within this field I learned a lot from experienced colleagues but also from meeting people with psychiatric disabilities who would tell me their story and ways of recovering from mental illness. Regardless of work setting within the mental health care I, as an occupational therapist, continually had contact with the staff in community-based mental health care. The ambition was, together with the client, to form a rehabilitation plan, aimed at helping the person to create a "meaningful everyday life" in the community. This was, however, never an easy task, and I often wondered how these processes could have been done and organized differently. As I later on got the opportunity to work in a project that among other things aimed to evaluate the community-based psychiatric care, I did not hesitate to take that chance. The desire to carry out research in this area was awakened and has since then grown stronger with an aim to contribute to evidence-based knowledge within care and rehabilitation for people with psychiatric disabilities.

# Introduction

A person's life and everyday activities are affected in a number of ways when interrupted by a severe mental illness. For example, many experience having problems with organizing time and tend to spend much of the day sleeping and resting (Nagle, Valiant Cook, & Polatajko, 2002; Bejerholm & Eklund, 2004). The term psychiatric disability (PD) is generally used to denote the main condition of the target group in this thesis. The definition of PD includes having difficulties (present and assumed to remain for a longer period of time) performing occupations in important life areas due to a mental illness (Official Reports of the Swedish Government, 2006). People with PD who are not employed but rely on community and mental health care to structure their day are the target group to be studied in this thesis. According to research people with PD generally have little social contact and often lack the experience of meaning and satisfaction in their everyday life (Bejerholm & Eklund, 2004; Krupa, Mc Lean, Eastbrook, Bonham, & Baksh, 2003; Leufstadius, Erlandsson, & Eklund, 2006; Minato & Zemke, 2004). Research has also shown that among the everyday occupations, work is one that has been shown to be linked with both greater satisfaction and meaning for people with PD (Eklund, Hansson, & Ahlqvist, 2004; Leufstadius, Eklund, & Erlandsson, 2009). Work has also been shown to promote recovery (Dunn, Wewiorski, & Rogers, 2008), indicating that access to work and work-like occupations should be considered in the psychiatric rehabilitation process. Reports show (Official Reports of the Swedish Government, 2006), however, that a majority of people with PD lack employment, which also can be seen as an obstacle for integration in society. Being engaged in work is a major part of people's lives, but research shows that when people lack work or work is experienced as too stressful, other everyday occupations, such as for example engaging in occupations at a day centre, become more important and meaningful (Kennedy-Jones, Cooper, & Fossey, 2005). There is today, however, limited research on the subjective experience of everyday occupations of people with PD and on the specific features that bring meaning in non-work occupations, which thus makes this area important for further studies.

Despite this scarcity of knowledge regarding what characteristics of everyday occupations bring meaning to people with PD the goals of a national strategy in Sweden state that by the year of 2015 all people with PD will be guarantied work or so called meaningful occupations and also be integrated in society (National Board of Health and Welfare, 2005). This is in line with the recent published guidelines stating that the municipalities are responsible for providing a person with PD with meaningful occupation (The National Board of Health and Welfare, 2011). There is also a general international movement towards community-based models of care within the mental health services for people with PD (Meehan, Robertson, Stedman, & Byrne, 2004). As part of the obligation to provide meaningful occupations, day centres within the community-based psychiatric care services offer opportunities for taking part in various everyday occupations, including the possibility to socialize with others (Tjörnstrand, Bejerholm, & Eklund, 2011). Attending a day centre and taking part in the occupations and social interactions there might influence people's everyday situation and how they perceive and value their everyday occupations. Research regarding how the attendees experience participation in day centres and the effect this type of rehabilitation may have on people with PD is, however, scarce (Catty, Burns, Comas, & Poole, 2007). One of the few studies that does exist could not identify any differences regarding satisfying and valued everyday occupations between a day centre group and an outpatient group without regular everyday occupation (Eklund, *et al.*, 2004), which raises questions regarding the influence day centre attendance has on people with PD. Thus, whether day centre participation adds to positive subjective experiences of occupation is far from being clearly understood.

The studies cited above imply that there is need for research regarding the experience of meaning and satisfaction related to everyday occupations for people with PD and also research that further investigates how day centre attendees perceive everyday occupations, including social and work related aspects.

## Living with a psychiatric disability

As stated above, the term PD is used in this thesis to denote the target group. However, the term severe mental illness (SMI) will also be used when relevant. The term SMI is based on the 'two dimensional definition' by Ruggeri, Leese, Thornicroft, Bisoffi and Tansella (2000), stating that a person is regarded as having SMI if he or she has a duration of psychiatric illness of at least two years and has a psychosocial dysfunction. Thus, whereas PD refers to functional status and the ability to manage everyday life, SMI also includes consideration of duration of illness. None of the definitions is based on diagnosis, but some diagnoses are more common. Some examples of diagnoses that are associated with PD are schizophrenia and affective disorders. PD appears as a long-term consequence of a severe mental illness and becomes a disability when the disability limits the person's ability to fulfil goals in life. A PD is thereby a multifaceted concept that includes limitations regarding both activity and participation in everyday life (Hydén, 2005; Lundin & Olsson, 2002; World Health Organization, 2001). Lundin and Ohlsson (2002) state that there is a great risk that a person with an SMI may develop cognitive disorders, mainly of the so-called executive functions, such as the ability to take initiative, to manage time, to plan and organize, to self-motivate, to form structure in everyday life and to hold on to and focus attention. Mueser and Tarrier (1998) maintain there are different levels of disabilities and mean that there are different dimensions of PD that range from the lack of performing basic cognitive abilities (such as memory) to everyday life (such as personal hygiene or cooking) to more complex social behaviours (such as social relationships with family and friends). A combined effect of both positive symptoms, for example hallucinations, negative symptoms (such as withdrawal), different types of cognitive disabilities and varied side-effects of psychotropic medicine may also result in engagement in fewer and more quiet occupations such as sleeping, resting or watching TV (Bejerholm & Eklund, 2004; Nagle, *et al.,* 2002) and having a poorer social life (Mezzina, et al., 2006). Living with disabilities thus often means a diminished ability to perform many of those regular everyday actions that are important for living a well-functioning and social life (Lundin & Olsson, 2002). Morover people with PD may lack a worker role or engagement in other roles for shorter or longer periods in their life (Nagle, *et al.*, 2002). As earlier mentioned, people with PD also often seem to lack the experience of meaning in their everyday life (Bejerholm & Eklund, 2004; Krupa, *et al.*, 2003; Leufstadius, et al., 2006; Minato & Zemke, 2004). Consequently, persons in the target group, with its different types and levels of disabilities, needs varied amounts of support and help from professionals, relatives and friends in structuring everyday life and finding occupations that are experienced as meaningful.

## The view and treatment of people with PD past and present

A short historical description of the view and treatment of people with PD is helpful in order to be able to understand the mental health care services of today.

Sadly, the living conditions for people with psychiatric disabilities have historically consisted of discrimination, economical, social and political marginalization, and powerlessness (Scheff, 1998). History shows that during the 15th century, “the insane” were chased out of cities, put in prison or were separated from the community by being placed on boats that were put to sea. It was seen as sinful to be unoccupied, and therefore work was endorsed, not in order to help the person to recover from mental illness, but rather because it was believed that a person would be ”freed” in the sense that he or she through work would “join the human existence moral pact” (Foucault, 1983). Some centuries later, during the beginning of the 19th century, the so called moral treatment movement grew strong, which paved the way for a more humane and therapeutic view and treatment of people with mental illness (Sjöström, 1992). During this era work was again emphasized and this time seen as an actual treatment for curing mental illness (Foucault, 1983). The profession of occupational therapy, with its foundations in the moral treatment movement, was formed during the first decade of the 20th century. The early ideas in the field of occupational therapy emphasized the use of occupations to help the person with mental illness regain confidence, to find interests and be able to organize his/her everyday life (Barris, Kielhofner, & Hawkins Watts, 1988; Creek & Lougher, 2008).

In the middle of 20th century it was recognized that people with PD, who lived in mental hospitals, led passive and institutionalized lives and in large became hindered from forming a life outside the mental health settings (Goffman, 1961; Meeuwisse, 1997; Wing & Brown, 1970). To counteract that, Sweden, and many other countries went through a process of so called deinstitutionalization during the 1970s and the 1980s when large psychiatric hospitals were closed down. The aim of this action was to bring people with PD out of hospitals and provide the opportunity to live active lives in the community. At this time the psychiatric care services moved from hospital institutions to community settings, although support strategies and community-based rehabilitation were not sufficient to enable community interaction for the target group (Markström, 2003; Palmblad, 1992). The provision of support and rehabilitation for people with PD thus changed and the many attempts seen throughout history to treat people with mental illness in isolation from the society resulted in a stronger focus and a general international trend towards more community-based models of care and services. The aim of these services was to assist people with PD in order for them to be able to live their lives as ordinary citizents participating in community life (Leff & Warner, 2006; Meehan, *et al.*, 2004).

## Community-based day centres

In 1995 the Mental Health Reform was introduced in Sweden with the aim of filling certain gaps in the care and support for people vid PD in the community, which had emerged as unintended consequences of the deinstitutionalization. The reform urged the local authorities to take responsibility for the needs for support of people with PD and their well-being and recovery, for example, by providing meaningful everyday occupation (Markström, 2003). The promotion of satisfying and meaningful occupations has also generally been shown to be of great importance in the rehabilitation of people with PD as such occupations facilitate the recovery process (Haertl & Minato, 2006). Such meaningful occupations may include paid work and work was also recently emphasized as important in the Swedish national guidelines of support for the target group, in order to enhance well-being and social integration (The National Board of Health and Welfare, 2011). Many individuals with PD, however, still lack paid work or other meaningful occupations. For that purpose, day centres have been developed in many Western countries to meet the needs for meaningful everyday occupation and social interaction among people with PD who are unemployed. In Sweden the national guidelines state that the day centres should provide social contacts and help towards a functional daily structure. A further aim in some units is to provide rehabilitation and to contribute to personal growth, community integration and help towards future employment. The day centres range from meeting place-oriented settings, with the possibility for visitors to drink coffee or have a meal with others, to more work-like settings where each attendee has a structured schedule with certain activities planned at certain times a week. Examples of occupations offered at day centres are maintaining the premises, catering, working in second-hand stores, and performing different types of work such as installations and packeting. Sometimes this is combined with a selection of study circles or recreation programmes (National Board of Health and Welfare, 2011). Empirical studies confirm this picture (Andersson, 2009; Erdner, 2006; Tjörnstrand, *et al.*, 2011). Internationally, community-based services seem to put more emphasis on, for example, consumer-run services (Ekholm & Bergrot, 2006). This type of service, together with higher education among staff in psychiatric care services, are reported as areas that need to be developed in Sweden (National Board of Health and Welfare, 2011). Although studies show that people with PD report to be largely relying on community mental health programmes for engagement in occupations (Merryman & Riegel, 2007), research regarding how attendance at community-based day centres is perceived is limited. Those few studies that have been performed show some positive perspectives, such as that day centres provide daily structure and a secure environment (Bryant, Craik, & McKay, 2004; Mannerfelt, 2000), a feeling of purpose and belonging (Catty & Burns, 2001), possibilities for social engagement (Andersson, 2009; Gahnström-Strandqvist, Liukko & Tham, 2003; Tjörnstrand, *et al.*, 2011) and social support (Catty, Goddard, & Burns, 2005). Mannerfelt (2000) describes day centre attendees as forming groups of *being, doing* and *heading*, based on the attendees' own view of what they wanted to accomplish when being at the day centre. Mannerfelt stated that the attendees that belonged to groups aiming at being and doing seemed to be more often located at different types of meeting place-oriented day centres while the groups focused at heading were more often at work-oriented day centres.

Although the community-based day centres do seem to provide different types of occupations and support, some authors are critical of these types of settings. Rosenberg (2009) argues that actors within the mental health systems still operate in what he terms "the institutional environment of the deinstitutionalization era" (p. 238). By this Rosenberg implies that the focus of the psychiatric care of today is still on the geography between the hospitals and the new structures for care in the community, while the demands of people with PD are in the new geography that exists in the space between the community mental health care and the natural community of today. According to Rosenberg, a greater focus within rehabilitation must thus be put on participation and inclusion. Bryant and colleagues (2004) similarly argue that although day centre settings help to, for example, structure the day for the attendees, these settings might hinder integration into society when forming mental health services with little connection to the outside community. Andersson (2009) reports, when studying the everyday life of people with PD, that many feel restricted and bound to the day centres, since they do not have any other social contacts. Andersson also means that, although there is a mutual understanding at the day centre which can create a feeling of belonging, the attendees may at times find it difficult when having to socialize with others with mental health problems since these meetings risk to increase their own mental distress. Pinfold (2000) mean that day centres may act as forms of "safe havens" but that people with PD face challenges towards integration in a wider community that might be hard to overcome until mental illness is de-stigmatized and "society celebrate difference" (p. 210). Ineland and Sjöström (2007) discuss the paradox in care that tries to resemble some sort of "normality" (such as day centres that are "work-like") when it is obvious that those in need of care usually do not have all the capacities to handle what is "normal" (for example a paid job). The authors further argue that the thinking of "normality" holds certain power aspects; someone has the power to determine what is normal and desired behaviour and these strategies are then offered or sometimes even more or less forced on those in need of normalizing efforts (Ineland & Sjöström, 2007). This aspect is also reflected on in Mannerfelt's study where the day centre attendees seem to struggle with ambivalence towards the day centre settings; they both enjoy being at the day centres, which gives structure to their everyday life, but they also feel restricted and as an outsider in the community by being a day centre attendee. According to Mannerfelt this ambivalence could be viewed as a mild protest to the normalizing strategies that lack guarantees of an active life in the actual community (Mannerfelt, 2000). In these various discussions one might also find a possible explanation as to why a recent report showed that the target group tends not to experience meaning in their everyday life and that the occupations offered in the municipalities do not always meet the person's needs (National Board of Health and Welfare, 2005), despite the municipalities being responsible for providing meaningful occupations to people with PD. Further explanations may be found on an organizational level, in terms of difficulties with co-operation between the organisations involved, due to different views of methods of rehabilitating strategies and varying knowledge bases among the professional groups (The National Board of Health and Welfare, 2005). In relation to this latter aspect, research has also highlighted that co-operation between mental health services and organizations in the community, is vital in order to enhance community integration for the target group (Pinfold, 2000). Another aspect of importance in order to make occupations within the day centres meaningful is the previously addressed aspect of user involvement in community rehabilitation (Rebeiro, 2000).

Scholars argue that more research is needed regarding how attendance at community-based day centres is experienced by the target group (Catty, Burns, Comas, & Poole, 2007). Government reports also conclude that day centre attendance does not give the intended experience of meaningful everyday occupation (The National Board of Health and Welfare, 2005; Official Reports of the Swedish Government, 2006). This was also shown in an empirical study, which could not detect any differences between people who attended a day centre and non-attendees regarding how satisfying and valued they found their everyday occupations (Eklund, *et al.*, 2004). This raises questions regarding what kind of influence day centre attendance has on the everyday life of people with PD and what it takes to promote their recovery.

## To recover – what does it take?

The importance of recovery from mental illness is highlighted in the recently published Swedish national guidelines for support for people with PD (National Board of Health and Welfare, 2011). To recover from mental illness is about building a satisfying and meaningful life, as defined by the persons themselves, regardless of whether or not they have ongoing or recurring psychiatric symptoms or problems (Anthony, 1993; Slade, 2010). The focus on personal recovery (unlike clinical recovery) has emerged from the expertise of people with lived experience of mental illness. The most commonly used definition of personal recovery is given by Anthony (1993) who means that recovery is*:*

> *…a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (p. 527)***.**

According to Anthony, Cohen, Farkas & Cagne (2002) there is no universal definition of recovery but the concept often describes a process where people with severe mental illness regain control over their life and experience a new positive self image and meaning in life by the help of positive coping (Anthony, *et al.*, 2002). Deegan (1988) was one of the first mental health consumers to write about her own experience, and she described the process of recovery as moving from dependency towards empowerment and hope about a positive future life. Topor (2004) further describes recovery as a process that must emerge from the individual and focus on what is important to him or her and he argues that recovery is about conquering different malfunctions in order to live a fulfilling and meaningful life, having power over one's own life, and making one's own choices in life. Schön (2009) similarly highlights the individual process that takes place during recovery, with an emphasis on the importance of this process as created in relation to society. The author further argues that social support that promotes cooperation, involvement and hope is vital for recovery. Furthermore a practice is needed that strengthens the individual's power to define his or her own mental illness and that also recognizes the knowledge people with PD have of their illness and how to cope with it, as a complement to the knowledge of professionals. As a clinician it is also of great importance, to turn to the person and his or her next of kin in order to get a picture of what they view as being essential help for recovery (Schön, 2009). In line with both Schön (2009) and Deegan (1988), the network Rethink, which is a leading mental health membership charity in England, highlights that in order to support personal recovery, clinicians must move away from focusing on treating illness and move towards promoting general well-being. The network provides a view of what professionals should emphasize and highlights four domains of recovery: experiencing hope, viewing a current and future self-identity, experiencing meaning in life and taking personal responsibility (Slade, 2010). Further, Alphonce (2004) argues that it is easy to lose self confidence after having been treated for mental illness. Keys to recovery are, according to Alphonce, besides taking back the power and control in one's own everyday life, is to set small and realistic goals for each day. These small goals should be about engaging in occupations that make you feel good. Alphonce thus highlights the importance of meaningful doing in the recovery process. This is in agreement with the views of Sutton (2008), who denotes doing as a medium by which people with PD recover their sense of "being-in-the-world"(p. 213). Sutton thus indicates the significance of doing as a form of transactional process in recovery. The author also states that occupational performance is a desirable and meaningful outcome of recovery for people with PD. Furthermore Rebeiro (2005) highlights that there are striking similarities between the core beliefs of occupational therapy, with its focus on engagement in everyday occupations, and the ideas of recovery. For example, the individual's right to autonomy, that human beings are social and have abilities and competencies and, not least, that engagement in meaningful occupations are emphasized in both recovery and occupational therapy literature.

## Occupation

A number of different authors have for almost a century argued that engagement in occupation promotes wellness (Meyer, 1922; Wilcock, 2006). Strong relationships between occupation and health have also been shown in empirical studies of occupation for people with PD (Aubin, Hachey, & Mercier, 1999; Eklund, *et al.*, 2004; Goldberg, Brintnell, & Goldberg, 2002), lending support to this argument. A core belief in occupational therapy is the dynamic relationship between person, environment and occupation. The person-environment-occupation (PEO) model, developed by Law *et al.* (1996), illustrates the interaction of these three components that together form occupational performance. The three components are illustrated as dynamic and continue to interact throughout the person's life span. They are defined as follows; the *person* is a unique being who assumes multiple roles that can not be separated from the environment. The person's roles differ and vary in degree of importance depending on the developmental stage of the person but also on the present context. The person has physical, social, cognitive and psychological assets, as well as a certain cultural background. The *environment* is defined as the context in which the occupation takes place and is categorized into physical, social, economical, political and cultural aspects (Dunn, Brown, & McGuigan, 1994; Law, *et al.*, 1996). Finally, *occupation* is defined as self-directed meaningful tasks in which the person engages throughout life. Examples of areas of occupations are self-care, productivity and leisure. Occupational performance is the dynamic experience of a person's engagement in purposeful occupations within an environment (Law *et al.* 1996). The PEO model further proposes that, during the lifetime of a person, the interactions between the three components infer that the overlap between them may differ in size (Law *et al.*, 1996). In more recent litterature (Townsend & Polatjako, 2007) the concept of occupational engagement is viewed as capturing the broadest perspective on occupation and as encompassing all things people do in order to occupy themselves or others and to participate in society. Bejerholm and Eklund (2007) define occupational engagement as the extent to which a person has a balance between different occupations and routines, including the temporal aspect. Edgelow and Krupa (2011) further describe engagement as the connection felt when performing an occupation. Although the early PEO model puts an emphasis on performance, presently seen as a narrower concept compared to occupational engagement (Townsend & Polatjako, 2007), the model does include engagement and also highlights a temporal aspect when defining and describing occupational performance. The PEO model will because of this as well as due to its ability to simplify complex phenomena, be used as a general frame of reference for everyday occupation in this thesis.

The core of occupation is what people do (Wilcock, 1998) and most definitions of occupation therefore originate in the concept of activity (Pierce, 2001). The concept of occupation is, however, generally preferred to activity in this thesis. This is due to the definition of occupation, as proposed by Pierce (2001), including the subjective experience from performing a daily task, in contrast to the concept of activity, which has been described as a general and categorical definition of doing, attached with a general understanding in a specific socio-cultural context. The term occupation is thus used in this thesis to denote everyday chores in general.

## Activity level

Activity level is in this thesis seen as occupational participation or 'doing' in the broadest sense (Kielhofner, 2008). Research has shown that individuals with PD´s activity level, and especially individuals with a diagnosis of schizophrenia, mainly consists of quiet occupations such as sleeping, resting and watching TV (Bejerholm & Eklund, 2004; Hayes & Halford, 1996; Leufstadius, *et al.*, 2006; Minato & Zemke, 2004; Shimitras, Fossey, & Harvey, 2003). Moreover, Eklund and Gunnarsson (2008) found that people with mental illness had a lower activity level than people who were mentally well. Activity level is also likely to influence self-related variables and quality of life (Bejerholm & Eklund, 2007). Further, doing is one of the dimensions of the concept of meaning making according to Hammell (2004), as well as a means to recovery (Sutton, 2008). Research regarding how activity level and subjective perceptions of occupation relate to each other is still limited in scope. There are needs for further research in order to gain adequate knowledge for the organization and development of activity-based psychiatric rehabilitation for people with PD.

## Subjective experience of everyday occupations

Subjective experiences of occupation have been shown to be the most important factors in relation to well-being, as compared to, for example, activity level and time-use (Eklund & Leufstadius, 2007). There are many different types of subjective experiences related to occupation but in this thesis the concepts of *meaning*, *occupational value* and *satisfaction with everyday occupation* will be highlighted and discussed. How people experience their everyday life when struck by illness has been a subject for occupational therapy researchers for some time (Christiansen & Baum, 2005; Hasselkus, 2002; Kielhofner, 2008; Leufstadius, *et al.*, 2008; Townsend & Polatajko, 2007; Wilcock, 1998). This type of research is important not least in the field of psychiatric care.

### *Meaning in occupation*

Within psychiatric rehabilitation the importance of meaning and meaningful occupations for people with PD is underlined (The National Board of Health and Welfare, 2011). The concept of meaning in occupation is complex and can be understood from many different theoretical and cultural angles. Hasselkus (2002) means that occupational therapists' main goal is the fulfillment of meaning through occupation, and states; "With occupation as the core concept of our profession, we are, by default, custodians of meaning and meaning givers" (p. 22). The experience of meaning can be explained using a socio-cultural perspective but also from an existential and spiritual perspective (Jonsson & Josephsson, 2005), and different authors take different perspectives. Hasselkus (2002) mean that meaning can be derived from social and cultural perspectives and also highlights that the search for meaning can be a trajectory for engaging in certain occupations, a view supported by Ikiugu (2005). Nelson (1995) states that meaning is a person's entire interpretive process when experiencing an occupation, including perceptual, symbolic, and affective experience. According to Townsend and Polatjako (2007) a person creates meaning from his or her experiences, thereby also explaining them, in turn motivating engagement in new occupations. Occupational therapy research and literature thus provides several different explanations as to what "occupational meaning" is, but many of those imply that meaning leads to engagement in further occupations. A vital existential and personal element of importance for meaning making is the previously mentioned so-called spirituality that has been described as "the essence of the person" and a form of spiritual director that guides the individual through life (CAOT, 2002). The concepts of doing, being and becoming, proposed by Wilcock (1998) and further developed by Hammell (2004) are also connected to spirituality and meaning. Hammell describes meaning in terms of *doing*: engaging in purposeful occupations; *being*: taking time to reflect; *belonging*: feeling part of a social context; and *becoming*: picturing a future self. Hammell's definition implies that meaning is influenced by the direct experience of performing an occupation, the context in which it takes place, the competence the occupational performance may bring and the person's ability to visualize a future. Similar ideas were launched by King (2004), proposing that there are three universal routes to acquiring meaning from life experiences: *Belonging* which means experiencing affiliation, connectedness and relationships, *Doing* which includes the experience of competence, self-mastery and achievement, and finally *Understanding*, which is about self-actualization, fulfillment and being. Moreover the experience of flow, as described by Csíkszentmihályi (1997), stresses one aspect of meaning. Flow is defined as a situation when the demands of one occupation are in perfect balance with the skills of the individual, and neither boredom nor stress is experienced. Furthermore the Value and Meaning in Occupations (ValMO) model (Persson, Erlandsson, Eklund, & Ivarsson, 2001), further described below, defines meaning as something that is created when the value experiences from taking part in occupations are integrated with a person's identity and life history. There is thus no clear and common definition of the concept of meaning in occupation. In this thesis the definition of meaning will be based on the ValMO model (Persson, *et al.*, 2001) and also on a more socio-cultural perspective of meaning making (Hasselkus, 2002).

Some studies have focused on the experience of meaning in occupations among people with PD. These results show that occupations tend to give meaning if they facilitate a feeling of autonomy, social belonging, productivity, competence, control and enjoyment as well as when they lead to routines, a chance to take care of oneself to maintain health and to normalize the person's life-world (Gahnström-Strandqvist, *et al.*, 2003; Hvalsoe & Josephsson, 2003; Leufstadius, *et al.*, 2008). Another study (Aubin, *et al.*, 1999) also explored meaning and quality of life, where "meaning" in occupations such as sleep, leisure, work, daily tasks and rest was ranked according to degree of perceived competence, importance and pleasure. The results showed that work was ranked the highest on importance, in line with other studies, which have also emphasized the importance of work and that occupation related to work gives meaning to people with PD (Honey, 2004; Leufstadius, *et al.*, 2009; Strong, 1998). A recent study regarding meaning in everyday life for people with PD, not focusing on occupational engagement in particular, still showed that general engagement in occupation, either work or other regular everyday occupations, was a major part of meaning making (Eklund, Hermansson, & Håkansson, in press).

Although studies have been conducted regarding what brings meaning in everyday occupation, studies are scarce regarding perceived meaning and other subjective experiences from day centre attendance.

### *Occupational value*

Occupational value, which is connected to meaning, is the subjective experience of value a specific occupation may generate (Persson, *et al.*, 2001). The ValMO model describes different aspects of value that may be attached to occupations. The model depicts occupational value along three dimensions; *concrete*, *symbolic* and *self-reward value*. The *concrete value* is about the visible features of occupational value and is characterized by tangibility. The *symbolic value* has to do with what an occupation signifies for a certain person, and the final dimension is the *self-reward value* which has a focus on immediate rewards and enjoyment. There are few studies regarding the way in which people with PD perceive the value linked with their everyday occupations, although a few exist (Eklund & Leufstadius, 2007; Goldberg, *et al.*, 2002). Eklund and Leufstadius (2007), for example, showed that subjective perceptions of occupations were related to aspects of health and functioning. Eklund, Erlandsson and Persson (2003) also found that people with PD scored lower than mentally well people on experienced occupational value, although the difference was moderate in size.

### *Satisfaction with everyday occupation*

Another facet of the subjective experience of occupation is people's satisfaction with everyday occupations. This has been shown to be an important phenomenon in its own right (Eklund, 2004). The concept of satisfaction with everyday occupation has, however, not yet been clearly defined. Kielhofner (2008) associates satisfaction with everyday occupations with meaning and describes satisfaction as general and "simple" and derived from everyday life as a whole. Eakman and Eklund (2011) argue that this view may be in line with the motivation psychology view, particularly those theories that focus on both intrinsic needs, i.e. that behaviour occurs as a result of free choice and without any apparent external rewards, and extrinsic need, i.e. the performance of an activity in order to attain some separable outcomes. According to Ryan and Deci (2000) intrinsic motivation leads people towards seeking new challenges. The seeking of a new challenge would also, according to Eakman and Eklund (2011) be compatible with the basic belief in occupational therapy theory that humans have an innate drive to be active and seek competency and achievements. Another view is presented by Morgan (2010) who states that there are three major conceptions of occupational satisfaction; getting what one wants from occupational pursuit, having a balanced life and the experience of flow. The occupational literature so far thus does not provide a consensus definition regarding satisfaction with occupation, but the present thesis will adhere the reasoning proposed by Eakman and Eklund (2011), that occupational satisfaction is linked to motivation and the satisfaction of certain needs.

## Untangling the concepts of meaning, value and satisfaction

In this thesis, meaning is viewed, as previously mentioned, as a positive subjective experience with a more socio-cultural perspective. Value is closely connected to meaning, being as experiences of occupational value are believed to create the higher-level concept of meaning. Satisfaction with everyday occupation is viewed as a broad and general feeling of being content with occupations in everyday life. The definition also includes that satisfaction with occupation may be framed in the theory of intrinsic and extrinsic motivation and the satisfaction of such needs. This is different from occupational value, which targets more immediate and specific experiences related to meaning when performing an occupation. The three concepts are thus related but differ in that satisfaction is more closely related to general fulfilment of needs for a person (Eakman & Eklund, 2011), while value is more connected to some form of direct positive experience when engaged in an occupation (Persson, *et al.*, 2001), ultimately forming meaning as a positive subjective experience in life. The concepts of value and satisfaction have previously been stated as somewhat different but still connected and complementary to each other (Eklund, 2004). All three concepts are important for the effect occupational engagement will have in the rehabilitation process of people with PD (Eklund & Leufstadius, 2007; Leufstadius, *et al.*, 2008) and therefore research related to those concepts is important.

Previous research indicates that some of the factors that may influence how people with PD perceive their everyday occupations, in terms of meaning, value and satisfaction, are being part of society, including the worker role, and self-mastery (Eklund, 2007; Leufstadius *et al.*, 2009). These factors are thus further described below.

## Social life

Being social is seen as a fundamental need for all people (Townsend & Polatajko, 2007) and social actions and having different social roles, such as a worker role, also give a sense of meaning and belonging in the community (Hammell, 2004; Leufstadius, *et al.*, 2008). Davidson et al (2001) state that social inclusion is difficult for people with PD and outline three dimensions of inclusion; experiencing friendship, feeling worthwhile through meaningful activity and being hopeful.

### Social interaction and social networks

Severe mental illness does not take away the urge to remain in social relationships; in contrast, social relations are of great importance for the possibility to recover (Davidson, 2001; Topor, 2004). According to Lindström *et al.* (2011) socializing creates a tension for the person with PD in that it is both experienced as tiring and difficult, but also as meaningful and rewarding. Further, studies have shown that social interaction and having friends increase well-being (Strömberg, Sandlund, & Westman, 2005) and quality of life (Lundberg, Hansson, Wentz, & Björkman, 2008), are inherent in the experience of meaning (Leufstadius, *et al.*, 2008) and help to avoid mental illness relapses and hospitalization (Becker *et al.*, 1998). Social interaction does, not least, play a major part for community integration for the target group (Munroe, *et al.*, 2007).

In an investigation of four different kinds of social networks for people with PD Klamas (2010) underlines the importance of social interaction and social support. The four network types were; family and relatives, friends, work colleagues and formal supporters. Klamas means that these types of networks provide different types of support. Social support from family and relatives has the greatest focus on getting everyday life to work, based on the recognition that functioning well generates a sense of safety and calmness. The support given from friends is directed towards being more out-going and feeling socially included. Regarding work colleagues, people with PD experienced that they received support from them in coping with their work situation and maintaining the role as a worker. Finally, support from formal support givers tends to be focused on psychiatric difficulties. Klamas means that the fact that these four network modes provide different types of support is a strength and that having support from more than one network is important for the personal recovery process. Klamas also highlights that one specific type of network can not be replaced with another type; all the networks thus complement each other.

Schön (2009) argues that social support is important and that recovery is enhanced especially when having good quality social relationships. Daremo (2010) also highlights the social support from both relatives and professionals as being very important for inpatients in a recovery process. Support from relatives was especially important in that they had knowledge of the person when not having the role of someone with a mental illness, and they would help with practical matters as well as giving emotional and social support. Daremo argues, however, that there could be problems with receiving good support from relatives being as they often had limited knowledge of psychiatric symptoms and how these affect the everyday life of a person with PD. In line with that reasoning, Daremo maintains that relationships can also have a negative impact on the person. She argues that in order to enhance a supportive relationship it is essential to discuss what level of demands may be put on the occupational performance in everyday life of the person with PD.

Social interactions are thus vital for people with PD, and although a study showed that day centre attendees had a larger network than day hospital users (Catty, Goddard, & Burns, 2005), reports still show that many live in social isolation and lack opportunities for engagement in social interactions (Bejerholm & Eklund, 2004; Nilsson & Lögdberg, 2008). Their networks are often limited (Macdonald, Hayes, & Baglioni, 2000) and mainly focused on family members (Sörgaard, *et al.*, 2001). There can be many reasons for this. Although the community-based psychiatric care services are responsible for community integration (National Board of Health and Welfare, 2011) different authors mean that integration is complicated by society still reacting based on stigmatizing attitudes. This creates a lack of social opportunities in the community for the target group, leading to the development of so called "social ghettos" where people with PD because of rejection from society lead an isolated and segregated life together with others with similar problems (Leff & Warner, 2006; Rosenberg, 2009). People with PD thus reside in the community, but are still socially distant and isolated from general community life (Ralph & Corrigan, 2005; Thornicroft, 2006), which is also in line with the previously discussed concepts of day centres acting as secluding in the community (Bryant, *et al.*, 2004).

## The worker role

A way to social integration in the community is having a worker role with all its benefits such as salary, daily structure and social interactions with work colleagues (Boardman, 2003). The concept of role, in role theory, (Biddle, 1986) has been described as a person being a member of a collective, having certain social positions and being expected to uphold specific behaviours, but also expecting certain behaviours from other people. A role has also been stated to include the performance of certain behaviours and activities, which are all influenced by both cultural context and individual values. The worker role can be seen as a function of motivation, life style, capacity and environmental factors, which all interact with each other (Kielhofner, 2008).

Being as work has historically had such a strong impact on, among other things, fitting into society for people with PD (Foucault, 1983), it is not surprising that most societies today still strive to integrate and rehabilitate people with PD by regaining a worker role. In Sweden it is stated in the national guidelines for psychosocial interventions for people with PD (National Board of Health and Welfare, 2011) that work enhances positive self-esteem and social inclusion, and should thus be promoted. Research also shows that people with PD have to a great extent a desire to work (Grove, 1999; Secker, Grove, & Seebohm, 2001) and that having paid work promotes better well-being and quality of life (Bond, *et al.*, 2001; Eklund, Hansson, & Bejerholm, 2001), diminishes social exclusion (Boardman, 2003) reduces hospitalization and medication (Bell, Lysaker, & Milstein, 1996; McKeown, O'Brian, & Fitzgerald, 1992; Reiker & Eikelmann, 1997), and enhances recovery (Morrow, Wasik, Cohen, & Perry, 2009; Sells, *et al.*, 2006) as well as the experience of meaning (Leufstadius, *et al.*, 2009) for the target group. Pinfold (2000) also argues that having paid work reduces the feelings of dependency on the state among people with PD.

People with PD often lack work (Marwaha, *et al.*, 2007), however, and often also drop out of a worker role due to, among other things, mental relapse (Pinfold, 2000). This might be due to work at times, according to Scheid (1993), being experienced as stressful and even counterproductive. Pinfold (2000) argues that people with PD both have abilities and disabilities, but means that current work places are not able to accommodate, for example, flexible work patterns. Pinfold states that, people with PD instead examine the possibilities of engagement in other forms of valued roles, outside the employment arena. Other studies show that environmental factors such as poor service coordination, negative attitudes (Henry & Lucca, 2004), loss of benefits, stigma and lack of appropriate professional help (Marwaha, *et al.*, 2007), may act as barriers to work. Examples of personal factors acting as barriers to employment are: fear of relapse, limited education and work experience, limited motivation and work expectations, dependency on entitlements (Henry & Lucca, 2004), the person's own acceptance of being unemployed, low self-esteem, low motivation (Marwaha, *et al.*, 2007), negative psychiatric symptoms (Razzano, *et al.*, 2005) and being satisfied with current life circumstances (Catty, Lissouba,*et al.*, 2008).

Fortunately, research has also presented work facilitators showing that a worker role is established and better maintained if the person has a work history and a good relationship with his or her vocational worker (Catty, Lissouba, *et al.*, 2008), appropriate work and social skills, high motivation to work and a strong belief in him/herself (Henry & Lucca, 2004). Skills training and ongoing support, peer support, opportunies for seeing others with PD succeed with employment and developing a positive relationship with a hope giving provider have also been identified as being of importance for employment (Henry & Lucca, 2004). A recent study also showed that empowerment and occupational engagement were correlated with a more positive view of the worker role (Areberg, Björkman, & Bejerholm, 2011).

A positive view of the worker role is believed to enhance the possibility of employment, and to promote self-esteem and social inclusion (National Board of Health and Welfare, 2011). Studies regarding the view of the worker role for people with PD are, however, scarce and there are no studies examining the role of day centre attendance for the development of a worker role, despite the fact that day centres are responsible for community integration (National Board of Health and Welfare, 2011), where being part of a working force is an important cornerstone. The worker role in relation to day centre attendance is thus an important area for further investigation.

## Self-mastery

The concept of self-mastery has been described as the individual's control over life circumstances that significantly affect his or her life (Pearlin, Lieberman, Menaghan, & Mullan, 1981) or the perception of actual power to bring about desired outcomes (Marshall & Lang, 1990). To perceive power and to be able to orchestrate what kind of occupations to perform and engage in are also in the very core of several models of occupational therapy (Kielhofner, 2008; Townsend & Polatajko, 2007). In terms of people with PD, self-mastery has been shown to be of importance to health-related factors such as sense of coherence (Bengtsson-Tops, 2004), hope (Kirkpatrick, Landeen, Woodside, & Byrne, 2001), empowerment and recovery (Bradshaw, Peterson Armour, & Roseborough, 2007; Fava, *et al.*, 2001), and well-being, quality of life and functioning (Bosma, Scheijvers, & Mackenbach, 1999; Eklund & Bäckström, 2006; Rosenfield, 1992). Self-mastery has previously been found to be related to many of the aforementioned factors, such as the subjective experience of occupation and the target group's activity level (Bejerholm & Eklund, 2007; Eklund, 2007; Eklund & Leufstadius, 2007). Self-mastery is thus important to investigate further in relation to subjective perceptions of everyday occupations for people with PD.

Against this backdrop of research it thus seems urgent to further investigate the life situation of people with PD, especially to learn more about their perceptions of everyday occupation and social interaction, including how they look upon the worker role and whether day centre attendance can be important for how these factors are perceived.

# Aim of thesis

The overall aims of the thesis were to generate further knowledge regarding subjective experiences of everyday occupations and the experience of being part of society for people with PD, to explore whether people who attend a day centre differ from non-attendees in those respects, and to investigate factors of importance for the subjective experience of everyday occupation and being part of society.

## Specific aims

### Study I

The aim of Study I was to explore the specific characteristics of everyday occupations that bring meaning among unemployed people with SMI.

### Study II

The aim of Study II was, among people with PD, to investigate factors of importance for subjective perceptions of everyday occupations, operationalized as occupational value and satisfaction with everyday occupations, while also exploring whether or not people who attend day centres differ from non-attendees in these respects.

### Study III

The aim of the Study III was to investigate how people with PD perceived their social interaction and how socio-demographic and clinical factors and subjective experiences from everyday occupations are related to the experience of social interaction. Furthermore, the aim was to study how day centre attendees might differ from non-attendees regarding social interaction.

## Study IV

The aim of Study IV was to investigate how unemployed people with PD envision a future worker role and how subjective experiences of everyday occupations, activity level, day centre attendance, social interaction, self-mastery and clinical and socio-demographic factors were related to their view of the worker role.

Figure I illustrates the phenomena investigated in Studies II-IV.

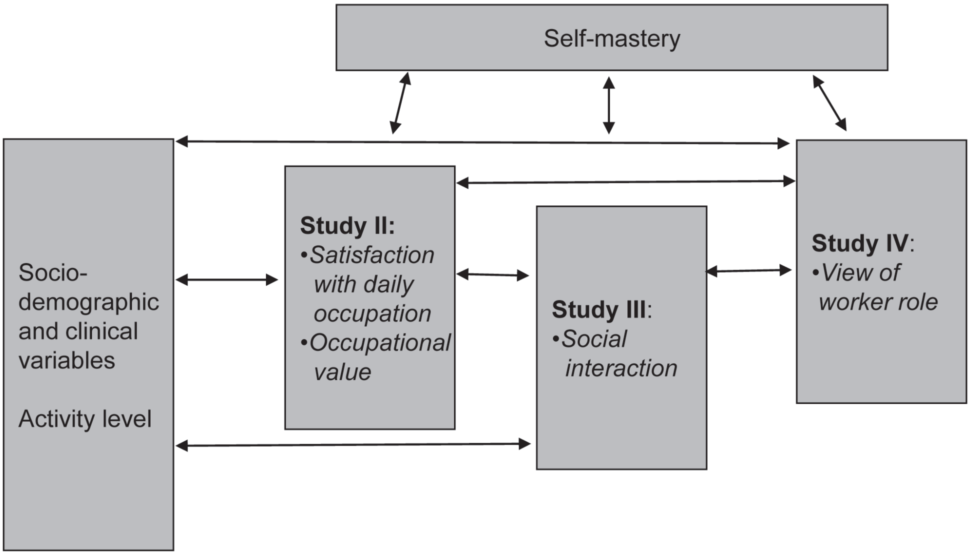

**Figure 1.** The phenomena investigated in Studies II-IV.

# Material and methods

An overview of the design, selection procedures and methods for the four studies of the present thesis are described in Table I.

**Table I.** Design, selection of participants and methodology in Studies I-IV.

| Study | Design | Selection of participants | Method- data collection | Method- analyses |
|---|---|---|---|---|
| **Study I** | Qualitative study | Purposeful selection of 12 unemployed informants with SMI with heterogeneity concerning age, sex, and duration of illness. | Semi-structured interview about 1 hour, with interview guide | Content analysis inspired by Burnard (1991) |
| **Study II** | Cross-sectional comparative design | Randomized selection of 93 participants from day centres and 82 participants from psychiatric outpatient units<br>Selection criteria for both groups: >2 years contact psych. services, age 18-65 years, not engaged in paid work.<br>Selection criterion for day centre group: >4 h/week in day centre<br>Selection criterion for outpatient group: no regular everyday occupation | – Occupational Value (OVal-pd)<br>– Satisfaction with Daily Occupations (SDO)<br>– Self-mastery<br>– Socio-demographic questionnaire<br>– Self-reported diagnosis<br>– Brief Psychiatric Rating Scale (BPRS) | Statistical analyses with SPSS software, version 17:<br>– Mann-Whitney U-test<br>– Kruskal Wallis test<br>– Spearman's correlation test<br>– Logistic regression analysis |
| **Study III** | Cross-sectional comparative design | See Study II. | – Interview Schedule for Social Interaction (ISSI)<br>– Occupational Value (OVal-pd)<br>– Satisfaction with Daily Occupations (SDO)<br>– Self-mastery<br>– Socio-demographic questionnaire<br>– Self-reported diagnosis<br>– Brief Psychiatric Rating Scale (BPRS) | Statistical analyses with SPSS version 17:<br>– Mann-Whitney U-test<br>– Kruskal Wallis test<br>– Chi-Square test<br>– Spearman's correlation test<br>– Logistic regression analysis |

| | | | | |
|---|---|---|---|---|
| **Study IV** | Cross-sectional comparative design | See Study II. | – Worker Role Self-Assesment (WRS)<br>– Occupational Value (OVal-pd)<br>– Satisfaction with Daily Occupations (SDO)<br>– Self-mastery<br>– Socio-demographic questionnaire<br>– Self-reported diagnosis<br>– Brief Psychiatric Rating Scale (BPRS) | Statistical analyses with SPSS version 17:<br>– Mann-Whitney U-test<br>– Kruskal Wallis test<br>– Spearman's correlation test<br>– Jonckheere-Terpstra test<br>– Logistic regression analysis |

## Study design

The first study had a qualitative approach, exploring the meaning found in everyday occupation for people with SMI who were unemployed. Studies II-IV were quantitative in nature and were part of a larger comparative cross-sectional study, based on two samples consisting of day centre attendees and non-attendees, respectively. These studies explored subjective perceptions of occupation (Study II), social interaction (Study III) and the view of the worker role (Study IV) by cross-sectional and comparative designs. Studies II-IV were guided by the results of Study I, where these factors had been shown to be pivotal for experiencing occupational meaning. They were further investigated in an order that seemed logical from the findings in Study I, with subjective perspectives of occupation further explored first, and followed by social interaction. Finally, the view of the worker role was looked upon, as work emerged as an important but complicated facet of the experience of meaning in Study I.

## Study contexts

All studies in this thesis were performed in two types of settings, at community-based day centres and at outpatient clinics, in four municipalities, urban as well as rural, in the south of Sweden. The community-based day centres, varied in character and met different occupational needs among the visitors. Four of the day centres were mainly oriented towards meeting social needs and were thus termed "meeting place-oriented". The remaining three day centres were termed "work-oriented", being as they provided work-like occupations such as assembly work and food catering. The outpatient settings, where the non-attendees were sought, were located separately from the hospital-based inpatient care and the interventions included supportive counselling, different types of psychotherapy, for example cognitive behavioural therapy, and medication. A person with PD could of course be in contact with both types of settings, as they aim to complement each other. Further selection criteria for distinguishing the respective groups of attendees and non-attendees were thus used, which is described under Participants and inclusion criteria. The data for Studies II-IV were collected during spring 2006 to March 2008.

## Participants and inclusion criteria

The inclusion criteria for the participants in all studies were set as being between 18 and 65 years of age, having a psychiatric disability and not being engaged in paid work. Paid work is here defined as an occupation required for subsistence and earning a living, i.e. paid employment (Christiansen, 2005). Another inclusion criterion was that the participant had to be able to understand spoken and written Swedish, being as the interviews and self-rating instruments were in Swedish.

### Study I

Attendees at both meeting place-oriented and work-oriented day centres, as well as clients at out-patient units, were asked to participate in the study. The inclusion criterion of unemployment was set in order to address meaningfulness in occupations not related to work. All 12 informants who were asked agreed to participate and there were no drop-outs. Three of the informants were visitors to meeting place-oriented day centres and four visited work-oriented day centres. The remaining four informants were non-attendees and visited outpatient units. Of the informants who were not attending day centres, three attended one or more groups per week at the outpatient unit, together amounting to 1-3 hours, and one was engaged in voluntary work. The ages of the informants ranged from 25 to 62 years, with a mean age of 47.5 years. Four of the informants were living with a partner and/or children, and 6 of the 12 informants were men. Ten had schizophrenia or other form of psychosis and two had mood disorders, according to a self-report inventory.

### Studies II-IV

For Studies II-IV attendees at both meeting place-oriented day centres and work-oriented day centres in the south of Sweden were asked to participate. Clients engaged at outpatient units, forming a comparison group, were also asked to participate in the study. A specific criterion for inclusion in the day centre attendee group was to attend a day centre for more than four hours a week. For the comparison group recruited from the outpatient units, a specific criterion was not to be involved in regular and structured everyday occupation, such as a day centre, for more than four hours per week. Of 195 persons approached in the day centre group, 93 accepted and participated, and of

168 eligible persons in the non-attendees group, 82 accepted to participate. The participation rates were thus 48 % and 49 %, respectively. Most of the participants were single and lived without housing support. The two groups were similar on most socio-demographic characteristics but there were significant differences in that the outpatient group had a higher education level (p<0.001) and there was also some differences in clinical variables, for example did the outpatient group more often report having a diagnosis of schizophrenia and other psychoses. Socio-demographic and clinical factors for the groups are presented in Table II.

**Table II.** Description of socio-demographic and clinical factors for the day centre group and the comparison group.

| **Characteristics** | **Number of subjects** | |
|---|---|---|
| | **Day centre group (N=93)** | **Comparison group (N=82)** |
| Gender: male/female | 55 (59 %)/38 (41 %) | 36/45 (44 %/56 %) |
| Age; mean (min – max) | 46 (22-63) | 47 (24-65) |
| Type of housing | | |
| Own apartment/house without support | 58 (64 %) | 58 (71%) |
| Own apartment/house with support | 27 (30 %) | 16 (20 %) |
| Sheltered living | 6 (7 %) | 8 (10%) |
| Civil status | | |
| Married/cohabiting | 17 (19 %) | 18 (22 %) |
| Single | 72 (81 %) | 63 (78 %) |
| **Education level** | | |
| Not completed nine-year compulsory school | 5 (6 %) | 2 (3 %) |
| Completed nine-year compulsory school | 35 (41 %) | 10 (13 %) |
| Completed 6th form college | 41 (47 %) | 42 (53 %) |
| University or college degree | 6 (7 %) | 25 (32 %) |
| Living with children | 10 (12 %) | 13 (18 %) |
| BPRS negative symptoms mean (min-max) | 2.1 (1-4.5) | 2.4 (1-5) |
| BPRS positive symptoms mean (min-max) | 1.7 (1-3.8) | 1.8 (1-4.2) |
| BPRS depressive symptoms mean (min-max) | 2.7 (1-5) | 2.6 (1-6) |
| BPRS general psychopathology mean (min-max) | 2 (1.2-4.8) | 1.9 (1-3.5) |
| **Self reported diagnosis %** | | |
| Schizophrenia and other psychosis | 43.5 | 81.8 |
| Mood disorders | 22.4 | 5.2 |
| Anxiety, phobia and stress disorders | 18.8 | 5.2 |
| Other disorders | 15.3 | 7.8 |

# Data collection

Different methods and instruments were used in order to meet the specific aims of this thesis and to be able to elucidate depth and nuances among the participant's experiences, but also to study patterns of associations in a larger group.

## Qualitative interview

The interviews in Study I were conducted by using a semi-structured interview guide. The questions focused on the meaning the informants experienced when engaged in everyday occupations, and relied on themes considered relevant in order to understand the experience of meaning. These themes concerned, for example, the person's values, roles, skills, motivation and occupational life. The questions served to elicit the specific experience of meanings generated from engagement in various everyday occupations. The questions were discussed and revised between the authors of Study I to improve their specificity and to ensure that they were easy to understand. A test interview was also conducted with a healthy unemployed 65-year-old man. The interviewer (EA) started with a broad question about the everyday occupations the person usually performed during a day and a week and then proceeded to ask questions about the specific criteria in everyday occupations that gave meaning. Probing was used in order to deepen the conversation to better understand the interviewee's experiences. The interviewer also aimed to have a dialogue with the interviewee in order to create a relationship and to gain a deeper understanding of the interviewee's life situation and the phenomena studied, in line with recommendations by Kvale (1996).

## Instruments

### *Subjective perceptions of everyday occupations*

The instrument Occupational Value with pre-defined items (OVal-pd) (Eklund, *et al.*, 2003) was used to measure the participants' perceptions of the occupational value linked with everyday occupations in Studies II-IV. OVal-pd is a self-rating instrument and has been developed in order to measure three different value dimensions of occupations. These three dimensions are; concrete, symbolic and self-reward value, which together form occupational value, as proposed by Persson *et al.* (2001). In this thesis a revised version of the instrument was used (Eklund, Erlandsson, Persson & Hagell, 2009). The participant answers questions regarding how often he or she has perceived different kinds of value when engaging in occupations during the last month. A scale ranging from 1 (not at all) to 4 (very often) is used. The OVal-pd renders a minimum of 18 and a maximum of 72 points. The instrument has been shown to have good validity and reliability (Eklund, Erlandsson, Persson & Hagell, 2009).

In order to measure another facet of the subjective experience of occupation the instrument Satisfaction with Daily Occupations (SDO) Eklund, 2004) was used In Studies II-IV. The SDO, specifically targeting people with mental illness, measures the individual's perception of satisfaction with everyday occupations and is conducted as a structured interview. The SDO consists of nine questions regarding different occupational areas such as work, leisure, home maintenance and personal care. The participants answer whether or not they perform a certain occupation and then rate their level of satisfaction with performing or not performing that certain occupation. The ratings are made by using a scale from 1 (lowest possible satisfaction) to 7 (highest possible satisfaction) and the total sum gives a minimum of 9 points and a maximum of 63. The SDO has shown good internal consistency, good test-retest reliability, good validity and acceptable ability to discriminate between different psychiatric samples (Eklund, 2004; Eklund & Gunnarsson, 2008).

### *Activity level*

The SDO was also used when measuring the participants' activity level. The number of occupations rated, in which the participant is engaged (Studies II-IV), gives a score of the person's present level of activity. One score point is given to each affirmative answer to whether the person performs a certain occupation, which gives a minimum zero and a maximum of nine points. A higher score indicates a higher activity level (Eklund, 2004). The measure of activity level within the SDO has been shown to have good test-retest reliability (Eklund & Gunnarsson, 2008).

### *Social interaction*

In order to measure the quantitative and qualitative aspects of social interaction for the participants a shortened self-report Swedish version (Undén & Orth Gomér, 1989) of the instrument Interview Schedule for Social Interaction (Henderson, Duncan-Jones, Byrne, & Scott, 1980) was used in Studies III and IV. The Swedish version used is termed Interview Schedule for Social Interaction – Self Rating version (ISSI-SR). The ISSI-SR has been shown to have satisfactory psychometric qualities for people with different psychiatric conditions (Eklund & Hansson, 2007) and good reliability and validity in other samples (Henderson, *et al.*, 1980; Undén & Orth Gomér, 1989). The instrument targets different facets of social integration and attachment and holds 30 items divided into four subscales. Firstly *quantitative aspects* of social interaction are measured using two subscales. These are; Availability of social integration, which examines the participant's amount of social contacts, and Availability of attachment, which addresses the actual access to emotional relationships. Both of these subscales have a maximum score of six. Further *qualitative aspects* of the social interaction are examined, also using two subscales. Adequacy of social integration investigates the level of satisfaction the participant experiences regarding his or her social contacts, and Adequacy of attachment targets the satisfaction experienced with emotional relationships. For Adequacy of social integration the maximum score is eight and for Adequacy of attachment it is ten. It is possible to focus on the item level in the ISSI-SR, which was done in this thesis when comparing day centre attendees with non-attendees.

### *The worker role*

When examining the respondents' view of the worker role for the participants the Worker Role Self-assessment (WRS) (Wästberg, Haglund, & Eklund, 2009) was used in Study IV. The instrument has been developed as a self-rating alternative to the Swedish version of the Worker Role Interview (Ekbladh & Haglund, 2000). A somewhat modified version of the WRS, with fewer reversed items, was used in this thesis. A reliability analysis was thus conducted, showing a Cronbach's alpha of 0.84. The modified WRS contains 14 statements about the worker role and the participant is asked to rate his or her degree of agreement with those statements. The participant's assessment is made on a four-point ordinal rating scale where a higher rating gives the picture of a more positive view of the worker role. A minimum score of 14 and a maximum score of 56 may be obtained. Good content validity and utility, as perceived by both clients and occupational therapists, have been shown for the instrument. Internal consistency and test-retest reliability have also been found satisfactory (Wästberg, *et al.*, 2009).

### *Self-mastery*

The term self-mastery is used to denote the experience of control over things that happen in one's life. When measuring this experience the Swedish version (Eklund, Erlandsson & Hagell) of the Pearlin Mastery Scale (Marshall & Lang, 1990) was used in Studies II-IV. This instrument is a self-report assessment with seven statements regarding control in life. The participant is asked to rate his or her agreement with the statement ranging from 1 (strongly disagree) to 4 (strongly agree). The Pearlin Mastery Scale gives a total score of 7 to 28, where a higher score indicates a higher degree of perceived self-mastery. The instrument has shown satisfactory psychometric properties concerning both validity and reliability (Pearlin, *et al.*, 1981).

### *Socio-demographic factors*

A questionnaire was created specifically for this study in order to gather information about different socio-demographic factors in Studies II-IV. Questions asked concerned gender, age, type of housing, civil status, educational level and whether or not the respondent was living together with someone.

### *Clinical factors*

Psychiatric symptoms were assessed by using the 18-item version of the Brief Psychiatric Rating Scale (BPRS) (Kolakowska, 1976; Overall & Gorham, 1962) employed in Studies II-IV. The participant takes part in an interview and is observed by the interviewer who later on ranks the severity of symptoms on a scale from 1 to 7, where a higher score indicates more severe symptoms. Symptoms included are those of for example, disorganization, disorientation and depression. The symptoms may be divided into four sub-scales; positive, negative, and depressive symptoms and general psychopathology. BPRS has been shown to possess good inter-observer and intra-observer reliability (Kolakowska, 1976). Better psychometric properties have been obtained when the interviewer acquires training for conducting the interview and the rating (Andersen, *et al.*, 1989) and when the interviewer uses a structured interview guide (Crippa, Sanches, Hallak, Loureiro, & Zuardi, 2001). Three raters performed the BPRS interviews for this thesis and both a structured interview guide and specific training were used which by a test of inter-rater reliability resulted in alpha coefficients of 0.80 or more. The day centre attendees' diagnoses were not available. All participants were thus asked to fill in their self-reported diagnosis as part of the socio-demographic questionnaire. This procedure was seen as reasonable, considering that all participants had received a diagnosis at some point when in contact with the psychiatric care services. These diagnoses were later "translated" by an experienced psychiatrist into ICD-10 diagnoses (World Health Organization, 1993) and grouped into the four categories of Schizophrenia and other psychoses, Mood disorders, Anxiety, phobia and stress disorders and Other disorders.

## Procedure

### Study I

Study I was based on semi-structured interviews with four persons from each of three settings; meeting place-oriented day centres, work-oriented day centres and out-patient units. These twelve persons where selected by purposive sampling, seeking variation in sex, age, educational level and cultural background. All of the potential informants were first contacted by the staff, who gave oral and written information about the study. After having given his or her written consent, the informant was contacted by the researcher for booking the interview.

### Studies II-IV

For studies II-IV data were gathered using different instruments. In both the outpatient settings and the community-based settings a contact person served as a link between the research group and the participants. The contact person was informed about the aim of the study and the inclusion criteria and then forwarded this information to eligible participants. The contact person then asked the informed persons if they would like to participate in the study and those who were interested received written information about the study. Upon agreement the particiants gave their written consent and the data collection was then carried out in a private room at the day centre or outpatient unit. The data was collected by project assistants, who were occupational therapists trained in using the instruments. When needed the participant received help from the project assistant who could clarify questions and assist with noting the responses. The data collection took about 1 ½ hours to complete.

## Methods for analyzing the data

### Qualitative analysis

For Study I the data analysis was inspired by Burnard's thematic content analysis (Burnard, 1991). Content analysis has its focus on describing, interpreting and understanding a person's story and is used when the researcher is aiming to find patterns in a person's story. Content analysis has also been described as "a detailed and systematic examination of the contents of a particular body of materials for the purpose of identifying patterns, themes, or biases" (Leedy & Ormrod, 2001, p. 155). The various steps of the analysis were carried out as an iterative process by the three authors involved. In order to make the researchers conscious and open, and also to strengthen the analysis process, a naive reading of the transcribed interviews was performed and codes were identified that were close to the text. Different types of preliminary categories were freely generated and then gradually merged to broader themes. Related subthemes where then generated. The analysis was subsequently refined in dialogue between all three authors until consensus was reached concerning themes and subthemes. A main theme was also identified, based on the understanding of the result as a whole. The fact that the interviewer had a pre-understanding of the target group, after having worked for several years in mental health care, was considered as a potential risk for influencing the analysis. With the aim of avoiding this risk, and also for validation of the analysis, the second author (CH) of Study I, who had no experience of mental health care, read some of the transcripts and served as an independent co-analyser (Graneheim & Lundman, 2003) in the analytic process.

### Statistics

The data used for Studies II-IV were of an ordinal and categorical nature and thus nonparametric statistics were used. Comparisons between the day centre attendees and the non-attendees were based on the Mann-Whitney U-test (for ordinal variables) and Chi-squared test (for categorical variables). For comparisons between more than two groups the Kruskal Wallis test or the Jonckheere-Terpstra test was used. Calculations of relationships between variables were made by the Spearman's rank correlation test. In order to analyze which of the investigated factors could explain the independent variables in Studies II–IV, namely the degree of perceived satisfaction and value in everyday occupations, social interaction and view of the worker role, logistic regression analysis was used. Dichotomous variables were created, according to a median cut for all variables measured by ordinal scales. The age variable was divided into three intervals; 22-40, 41-51 and 52-65 years of age, each comprising approximately equal numbers of participants. The variables showing a relationship with the dependent variables with a p-value $\leq 0.10$, were used for the logistic regression analyses. The logistic regression models were based on the forward conditional model and the data analyses were performed with the SPSS software, version 17.0.

## Ethical considerations

All studies included in this thesis were approved by the regional ethical review board in Lund, Sweden, and were performed in accordance with the principles of informed consent and voluntary participation. Some arrangements were made in order to facilitate for the informants to feel comfortable during the interview procedure in Study I. Precautions were also taken in order to give the informants support, both during and after the interview, if needed. All interviews in Study I took place in familiar environments, and breaks for tea or coffee were included. All participants in Studies I-IV received information that they were free to terminate their participation in the project at any time and that withdrawal from the study or not participating at all would not influence their rehabilitation in any way. Finally, the participants were informed that the data collected during the project would be treated confidentially and stored safely.

# Results

## The experience of meaning in everyday occupations

The experience of meaning in everyday occupation was described with a main theme and four themes with related sub-themes. The main theme was termed *Feeling competent and having a balance between different meaningful occupations helped having control over mental illness*. Within this main theme it was shown that the informants expressed a desire to be seen as competent and to be accepted by society. To have a balance between different types of meaningful occupations was also emphasized in order to avoid a relapse, since this often meant a loss of control and decreased independence and ability to be socially engaged.

The first theme, Being socially engaged and feeling competent and accepted by society, was composed of descriptions about occupations that were meaningful since they led to contact with others and an acceptance by society so that life now resembled how it had been prior to the onset of mental illness. To experience fellowship with others with PD or close friends or relatives were also seen as meaningful. Furthermore to be able to help and support and to be needed by others was important. To attain social approval and confirmation by others were deemed important in order to be accepted by society and gain a feeling of being competent. The second theme found was Creating routines and being productive. The informants felt the importance of having routines and a role that meant being productive, because it helped keep a balance between being active and resting. The informants formed daily and weekly routines that much resembled those of working people, i.e. getting up at a certain time and filling the day with work-like occupations with breaks for lunch and also being more relaxed during weekends. Different types of occupations that were regarded as productive and accepted by society, such as being involved at a day centre or in volunteer work, doing home maintenance work or taking care of relatives were seen as meaningful and also replaced a former worker role. The third theme of meaningfulness was Being creative and seeking knowledge. This theme included the informants' urge to picture a positive future self and the will to learn and experience new things, such as reading a new book, visiting the library or attending courses. Meaning was also connected to the experience of having just the right challenge, i.e. when the occupation performed was in perfect balance with the informants' skills. Being creative and achieving a nice result were also seen as meaningful. The fourth and final theme, Taking care of body and mind, illuminated taking care of oneself by occupations meeting the individuals' basic needs, such as eating and sleeping. Knowledge of the importance of self-care was usually gained from the informants own experiences of how to avoid a relapse. Being physically active and also to become diverted by engagement in different occupations helped to experience meaning. Enjoying relaxation was experienced as meaningful to the informant.

Study I and its findings guided the aims of the further studies of the thesis. Aspects connected to meaning, such as valued and satisfying occupation, occupation as actual doing, social inclusion and the perception of work, were singled out as important for further research, as were factors that seemed to affect meaning, such as control (self-mastery).

### Subjective perceptions of everyday occupations

A number of factors were, through logistic regression models, shown to influence the subjective perception of everyday occupation, operationalized as occupational value and satisfaction with everyday occupations (Study II). Regarding occupational value, as indicated by an odds ratio close to four, the strongest predictor of a high level of this subjective perception of occupation was having less depression. Furthermore having a high activity level more than doubled the chance of perceiving a high level of perceived occupational value. Perceiving a high level of self- mastery also doubled the chance of reporting a high level of occupational value.

Perceiving a high level of self-mastery was also associated with a fourfold chance of belonging to the group with a high level of satisfaction with everyday occupation. Moreover, as compared to the youngest age group, being in the oldest age group (52-65 years) increased the chance of perceiving a high level of satisfaction with everyday occupations, by more than four times. Finally, having less general psychopathology more than doubled the chance of experiencing a high level of satisfaction with everyday occupation.

## Social interaction

The result in Study III showed that the most common supportive and close person for the participants was a family member. For example "someone you are very close to" was in most cases (63 %) a family member. However, several still reported to be without such a close and supportive person.

Independent factors that had been shown to be related ($p<0.10$) to different dimensions of social interaction in initial correlations or group comparisons were included in logistic regression analyses in order to assess these factors' contributions to social interaction. Five different logistic regression models were performed, for each subscale of ISSI-SR, and for ISSI-SR as a total.

Regarding the perception of having a high level of Availability of social integration, that is the quantitative aspect of social integration, cohabiting was the strongest indicator, with an odds ratio of above three. Another strongly related factor was perceiving a high level of satisfaction with everyday occupations, with an odds ratio of more than two. Moreover, having a high level of perceived occupational value was associated with a more than doubled chance of experiencing a high level of Availability of social integration. The strongest indicator for having a high level of Availability of attachment was cohabitating. Another indicator was the perception of a high level of satisfaction with everyday occupation, which was associated with a more than doubled chance of belonging to the group with a high level of Availability of attachment. The strongest indicator for a high level of Adequacy of social integration, which is the qualitative aspect of social integration, was the perception of a high level of self-mastery, with an odds ratio above two, while a high level of satisfaction with everyday occupation also contributed to the chance of perceiving a high level of Adequacy of social integration. Regarding Adequacy of attachment, which denotes the qualitative aspect, an odds ratio of close to four indicated that having a low level of depressive symptoms was related to belonging to the group with a high level on this aspect of social interaction. Furthermore, having fewer positive symptoms showed a more than doubled chance of being in the group with a high level of Adequacy of attachment. Finally, and in line with the models regarding Availability of social interaction and Availability of attachment, to be married or cohabiting was the strongest indicator for being in the high score group on the total ISSI-SR, as revealed by an odds ratio of above four. Less severe depressive symptoms also indicated a more than fourfold chance of belonging to the group with a high level of the total ISSI-SR, while perceiving a high level of satisfaction with everyday occupation increased the odds by being in the group with a high level of the total ISSI-SR.

## The worker role

The view of the worker role was according to bivariate correlations associated with occupational value. Being active and experiencing high levels of self-mastery and availability of social attachment were also correlated with higher ratings of the worker role. Furthermore being young, having less severe negative and depressive symptoms and to have less general psychopathology were associated with a more positive perception of the worker role.

Three sets of different logistic regression analyses were performed to explore the contribution of all factors related to (≤ 0.10) perceptions of the worker role. The first set included occupational factors as independent variables. This model showed that having a high activity level was the strongest indicator of a more positive view of the worker role, as shown by an odds ratio above two. Moreover having a high level of self-mastery doubled the chance of having a positive view of the worker role. In the second model, exploring socio-demographic and clinical factors influence on the view of the worker role, being younger (22-40 years) was a strong predictor of having a positive view of the worker role, with a more than tripled chance of perceiving the worker role as positive. Moreover, having less severe depressive symptoms was an indicator, with an odds ratio of 2.7. When combining the significant factors from the two regression models in a final model, having a high level of self-mastery became insignificant and the total proportion of variance explained by the remaining variables, being younger, being active and having less severe depressive symptoms, was 20 %.

Results from Studies II-IV are shown i Figure 2.

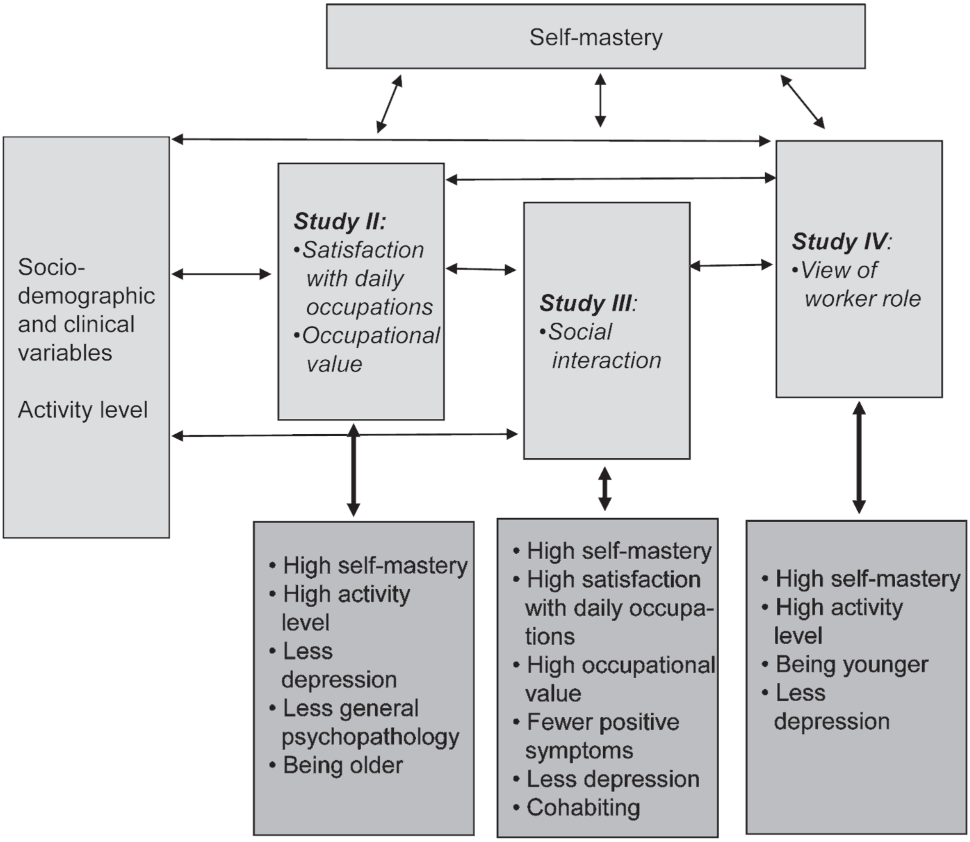

**Figure 2.** Results from Studies II-IV.

## Comparing day centre attendees with non-attendees

In the three quantitative studies (Studies II-IV), the importance of day centre attendance for subjective perceptions of everyday occupations, activity level, social interaction and the view of the worker role was explored. The day centre group experienced a higher level of occupational value than the non-attendees did (p=0.005). There was also a difference (p<0.001), showing that the day centre attendees were more active than the non-attendees. No difference was found between the groups regarding satisfaction with everyday occupations. When examining aspects of social interaction it was shown that the day centre attendees reported having a close friend more frequently than the non-attendees (p=0.010). There was no differences between the group on the sum variable of the ISSI-SR. On the sub-scale level, difference was found in Availability of social integration (the quantity of social contacts), where the attendees scored higher than the non-attendees. On item level of the ISSI-SR, it was shown that the day centre attendees met more people per week and had a larger number of people they could ask to borrow things from compared to the non-attendees. There was also a significant difference at the item level in between the attendees and the non-attendees in that the attendees were less satisfied with the number of people who could help them, and wanted more of such persons, than the non-attendees. The attendees seemed more content than the non-attendees regarding satisfaction with the total number of people in one's social network. There was no significant difference between the day centre attendees and non-attendees regarding who these supportive persons generally were (family member, friend or staff). Finally, with respect to the view of the worker role, differences between non-attendees, attendees at meeting place-oriented day centres and attendees at work-oriented day centres were examined. The results showed that there were no significant differences regarding the sum variable of the WRS. However, at the item level, there were significant differences on the questions that concerned "I believe that work will be part of my life in the future" and "I have goals I want to attain in relation to work", showing that the attendees at work-oriented centres scored higher than those at the meeting place-oriented centres, and the latter rated their worker role better than the group of non-attendees.

Figures 3a and 3b indicate some results and differences regarding the day centre attendees and the non-attendees.

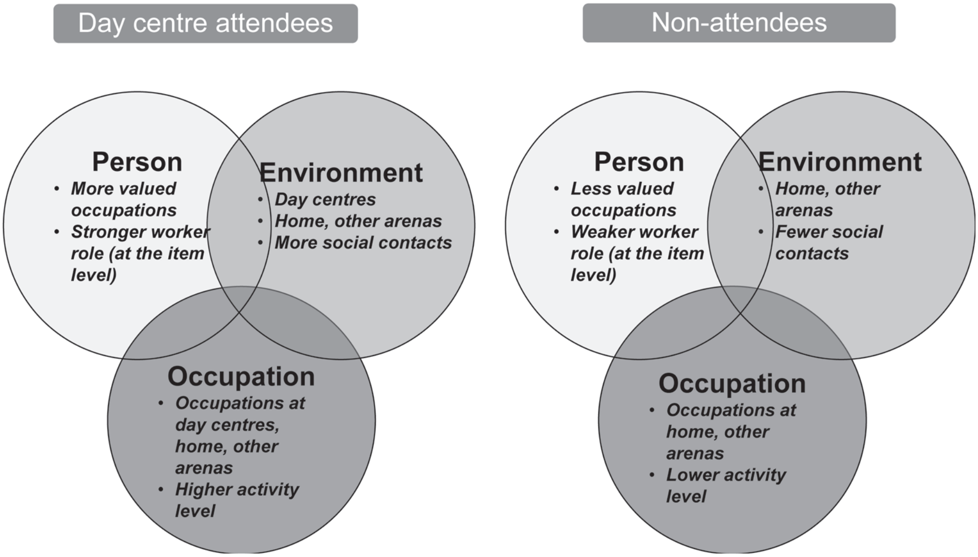

**Figure 3a and 3b.** Some results for the day centre attendees and the non-attendees.

# Discussion

The overarching aim of this thesis was to investigate the subjective experience of everyday occupation, social interaction and the view of the worker role among people with PD, while also addressing the importance of day centre attendance. A certain focus on the experience of meaning in occupation was accomplished through Study I, the findings of which guided the aims of Studies II-IV, which highlighted whether day centre attendance was of importance for how the addressed phenomena were perceived. In Study II a further investigation of the concept of subjective perceptions and related factors were made. Since social interaction was seen as a prominent factor for the experience of meaning, this aspect was then investigated in Study III. Finally, as work and work-like occupations had shown to be of importance for the experience of meaning in Study I, the view of the worker role was investigated in Study IV.

## Factors influencing meaning, value and satisfaction in everyday occupations

Meaning in occupation, occupational value and satisfaction with everyday occupation were the different forms of subjective experiences of occupations addressed in this thesis.

An identified facet of occupational meaning in Study I concerned having control over ones mental illness by feeling competent and having a balance between different meaningful occupations. Control was described as a means of coping with mental illness and staying well, but also important for having friends and a well-functioning everyday life. Earlier studies that explore the concept of meaning in occupations have also shown that having control gives meaning (Hvalsoe & Josephsson, 2003). In Study II self-mastery was shown to be strongly related with both occupational value and satisfaction with everyday occupations, which supports the findings in previous research (Eklund, 2007). The important role of self-mastery shown in these studies makes it one of the key factors in achieving positive subjective experiences in everyday occupations.

To have routines and be productive was further experienced as meaningful by the informants in Study I, which has also been shown to enhance meaning in previous research (Leufstadius, *et al.*, 2008). Being creative and achieving pleasing results also gave meaning where the latter could be connected to the concrete value presented in the ValMO model (Persson, *et al.*, 2001). The theme of meaning in terms of being creative and seeking knowledge is also in agreement with both Hammell's (2004) term doing when performing an occupation and the term becoming which is about facilitating a view of a positive future self. Both of these phenomena have also been shown to enhance recovery (Anthony, 1993; Sutton, 2008). By being creative the informant at times experienced just the right challenge, which was experienced as giving a respite from worrying thoughts. This type of experience has been reported as having a form of healing power (Csíkszentmihályi, 1997) and has also in previous studies been shown to give meaning (Leufstadius, *et al.*, 2008). The meaning generating theme of taking care of body and mind was closely associated with staying mentally well. Such occupations as generators of meaning have been reported in other studies as well (Aubin, *et al.*, 1999; Leufstadius, *et al.*, 2008; Nagle, *et al.*, 2002).

Furthermore, activity level in general was important for the experience of value, where performance of more everyday activities was associated with higher levels of occupational value (Study II). However, activity level did not seem to have any significant relationship with the experience of satisfaction with everyday occupation. This might be due to differences between the constructs of perceived occupational value and satisfaction with everyday occupations, where value targets a more specific experience from an occupation. Besides, the instrument assessing occupational value asks for the frequency with which valued occupations are performed, which intuitively should be linked with activity level. Still, in Study I, based on qualitative methodology, the importance of being active in order to achieve meaning was highlighted, in terms of the informant striving to have a balance between rest and activity. This is in line with the thoughts of Sutton (2008), who argues that different modes of doing resulted in a sense of meaning for people in a recovery process. A recent study examining aspects of meaning in life (Eklund, *et al.*, in press) showed that among the things in life that gave meaning, engagement in occupation was prominent, which further substantiate those findings. Taken together, the results from this thesis and those from previous research indicate that being active enhances occupational meaning and value. Its importance for satisfaction with everyday occupations needs to be further investigated.

Symptoms seemed to impact on the experiences of occupational satisfaction and value in Study II. Less severe depressive symptoms gave higher levels of value while lower levels of general symptoms gave more satisfaction in everyday occupations. This result might indicate that people with PD, as well as perceiving deteriorating mental health problems, tend to decrease their engagement in social contacts and everyday occupations, as reported elsewhere (Munroe, *et al.*, 2007). This in turn decreases their positive subjective experiences. Symptoms were also mentioned in Study I, where the avoidance of relapses and associated symptoms were seen as vital for experiencing meaning.

The studies in this thesis concurred rather well concerning factors of importance for occupational meaning, value and satisfaction, where high levels of self-mastery and activity level, and less severe psychiatric symptoms stood out. There were, however, also some differences. This might be due to actual differences, but might also be a result of use of different methods. For example, meaning was in this thesis investigated with a qualitative method (Study I), which would presumably provide results with more depth than the quantitative studies. The concepts of value and satisfaction, however, were examined in a total of three quantitative studies, first as dependent variables (Study II) and later as independent variables (Studies III-IV) in order to see associations with other factors, found to be of importance to meaning in Study I. These subjective perceptions were thus investigated by different methods. Furthermore, some factors, not specifically examined for their relationships to the concepts of occupational value and satisfaction in Study II, were of more importance for the experience of meaning in Study I. For example, establishing routines, being creative and seeking knowledge were sources of meaning according to the informants in Study I. A factor that influenced the quantitatively measured subjective perception of occupation but was not highlighted in the qualitative study was that of age; being older gave more satisfaction.

Being social and feeling needed by someone seemed related with different aspects of meaning and satisfaction, which corroborates previous research (Erdner, 2006; Hvalsoe & Josephsson, 2003; Leufstadius, *et al.*, 2008; Rebeiro, 1999), and this will be further discussed below.

## Social interaction and belonging

Social interaction has been said to be important for people with PD, both for the process of recovery and the experience of meaning (Davidson, 2001; Leufstadius, *et al.*, 2008; Schön, 2009; Topor, 2004), and this was verified in the present thesis. Study I showed that being social was a prominent factor for the experience of occupational meaning, largely influenced by the social context of the person, including a milieu that allowed feelings of competence and acceptance. This is in agreement with previous studies of people with PD and their experience of meaning (Gahnström-Strandqvist, *et al.*, 2003; Hvalsoe & Josephsson, 2003; Leufstadius, *et al.*, 2008; Nagle, *et al.*, 2002; Rebeiro, 1999). Feeling needed also created meaning and could, for example, entail taking care of or helping family members or friends, as well as looking after one's cat or dog. Several other studies have also shown that being needed and getting acknowledgement from others promote the experience of meaning. Study I further highlighted the importance of engaging in relations where the informants felt accepted, whether it was with relatives, close friends, others with PD or others with similar interests. Study III also pointed to the importance of supportive relationships, where relatives were the most important group, which concurs with reports from previous studies (Daremo, 2010; Pernice-Duca & Onaga, 2006). Daremo (2010) argues that in order to create supportive relationships it is important to discuss and clarify what occupational demands are reasonable to put on the person with PD. As shown in both previous research (Pernice-Duca & Onaga, 2006) and the present thesis (Studies I and III), family members have a major supportive social role for people with PD. Some aspects of social interaction seemed to be influenced by symptoms, as indicated by the results in Study III, which showed that fewer psychiatric symptoms seemed to be related to more social interaction. This would be in line with another study, indicating that a larger social network helps to avoid hospitalization (Albert, Becker, McCrone, & Thornicroft, 1998). Self-mastery also seemd associated with social interaction, as earlier reported (Eklund, 2006).

Some theoretical reasoning concerning social interaction and meaning seems to be corroborated by the results of Study I, showing that the social context had a role in shaping occupational meaning. Also, Study II showed connections between social interactions and subjective perceptions of occupations. Hammell's (2004) view of belonging as an aspect of meaning making through social interaction was confirmed by the informants' description in Study I of mutual social interaction as vital for the experience of meaning. Belonging was, for example, experienced when socializing with people who also had PD since this gave a more unique and special connection than socializing with mentally well people. Further, the theoretical reasoning regarding symbolic occupational value, defined by Persson and colleagues (2001) as influenced by, for example, the social environment's expression of whether or not a specific chosen occupation is acceptable and in line with cultural norms or ideologies, seems to match the result that the informants felt confident and perceived meaning when being with people who were accepting, such as close friends or relatives. Social situations where the informants felt left out or stigmatized did not generate meaning and having to socialize with others with mental illness has also been reported to at times be difficult (Lindström, *et al.*, 2011) and even a reason for avoiding to attend, for example, a day centre (Andersson, 2009). Although social integration and the counteracting of stigma are the most important aspects in the context of rehabilitation they are also the most complex and difficult ones, as shown in previous research (Kilian, Lindenbach, Lobig, Uhle, & Angermeyer, 2001; Yilmaz, Josephsson, Danemark, & Ivarsson, 2009).

## The worker role – its correlates and importance for meaning

Work-like occupations seemed to play a great part for the experience of meaning for people with severe mental illness (Study I) and the view of a future worker role was also linked with subjective experiences of occupation. In Study I, productive occupations, such as taking care of a household or being at a day centre, served as substitutes for paid work. To feel competent and capable through work-like occupations has also previously been shown to be important for both well-being and the development of an identity (Henry & Lucca, 2004), and also for the experience of meaning (Kennedy-Jones, *et al.*, 2005; Kirsh, 2000; Leufstadius, *et al.*, 2009). A substitute for paid work such as voluntarism has also been shown to generate meaning since it is a valued and socially acceptable occupation (Rebeiro, 1999). A recent study of unemployed people with PD also showed that envisioning a future worker role was experienced as meaningful (Eklund, *et al.*, in press). Study I highlighted that the informants sometimes had felt stigmatized at former work settings, however, and also showed that the meaning of paid work varied with the individuals' perceptions of their mental illness. Competitive work was often seen as too stressful to be an alternative to the present everyday occupations. Instead, engagement in day centres or voluntarism gave meaning and served as substitutes for paid work, in line with the results of Rebeiro (1999) and Kennedy-Jones and colleagues (2005). These occupations gave the person a role as a productive member of society, because they were seen as valued and socially acceptable, which strongly agrees with how paid work was regarded in a previous study of how people with PD found meaning in work (Leufstadius, *et al.*, 2009).

Study IV showed that having less severe depressive symptoms increased the chance of having a strong worker role, which is in line with previous research (Razzano, *et al.*, 2005). Less severe negative and general symptoms were also correlated with a positive view of the worker role, which concords with other research showing that symptom reduction was correlated with work engagement (Marwaha, *et al.*, 2007) and negative psychiatric symptoms and poor functioning were associated with employment failures (Razzano, *et al.*, 2005).

Activity level and self-mastery was an inprtant correlate to the view of the worker role, as similar reported by Arberg *et al.* (2011). That self-mastery was related to a stronger worker role seems as an expected finding being as it concerns feelings of being in control of one's life situation and future.

The logistic regression models in Study IV did not identify a relationship between valued everyday occupations and the view of the worker role. That a relationship was not found in the logistic regression models may be explained by the related phenomenon of satisfaction, discussed by Catty and colleagues (2008). They reported that unemployed persons who were generally satisfied with life tended to have a diminished interest or motivation for changing their life situation, by, for example, applying for work.

Paid work without support may not be the only main road in achieving meaning, but it does give the security of a stable income, as reported by the informants in Study I. Leufstadius *et al.* (2009) also reported having an income and contributing to society as positive consequences as well as meaningful aspect of the engagement in paid work for people with PD. A limited income at one's disposal has further been shown to reduce opportunities to participate more fully in the community (Bradshaw, *et al.*, 2007). These aspects of work were not explicitly studied in this thesis, but deserve further attention in future research.

## Day centres – important arenas for the experience of meaning and community integration or not?

Those informants in Study I who attended day centres reported that to socialize with people who also had PD created meaning, since this type of socialization gave a particular feeling of connection and belonging to a certain social group. This aspect of meaning highlights the importance of meeting places, such as day centres, as opportunities for people with PD to connect with one another, as previously reported (Mannerfelt, 2000). Study I also highlighted the opportunity to create meaning through occupations, among others those performed at day centres, which gave structure to the day and were seen as creative and/or work-like, as seen in other research (Leufstadius, *et al.*, 2008).

Day centre attendance seemed to positively influence the experience of value but not the experience of satisfaction with everyday occupations (Study II). Being as occupational value is experienced when performing certain occupations, for example, at a day centre, the higher level of perceived occupational value among the day centre attendees might not be so surprising. Study II also showed that day centres attendees were more active which may seem as natural as they received activity-based support. The experience of occupational value might also be connected to the higher level of activity, being as opportunities for perceiving value occupations are broadened in pace with increased activity levels. Furthermore, Mannerfelt (2000) reports that day centre attendees experienced immediate meaning when engaging in occupations at the day centre but that attending day centres did not create a general feeling of meaning since the outcome of the attendance was unclear. The fact that the day centre group did not experience any higher level of occupational satisfaction may thus indicate that the day centres might not meet all the varying needs of the attendees, as previously proposed by Eklund *et al.* (2004). In a more recent article on day centre attendees and non-attendees (Eklund & Sandlund, 2011) it was also assumed that being as non-attendees had higher education levels they might choose not to attend day centres because these centres did not offer activities with sufficient intellectual stimulation. Andersson (2009) further reported that some people chose not to attend day centres due to meeting others with a mental illness could create anxiety and could reinforce the person's own mental illness. Another explanation for the the lack of a difference in terms of satisfaction may be that both groups described satisfaction with everyday occupations in general, where day centre occupations were only a part. Any satisfying day centre occupations might thus have been overshadowed by not being satisfied with resuming a dull everyday life at home. Alternative interpretations might thus be that the day centre group and the non-attendees were equally able to engage in satisfying occupations when they were on their own or that they both had the type of daily structure they desired.

Study III revealed in terms of social interaction that the day centre attendees more frequently reported to have a close friend. As indicated by the ISSI subscales they met more people but did not as a whole have more close social contacts than the non-attendees. Analyses on the item level showed, that the day centres attendees saw more people on a weekly basis, had more people to ask to borrow things from and generally had a greater availability of social interaction, which is in line with findings by Catty *et al.* (2005). However, the day centre group seemed to have a somewhat greater need for closer contacts for helping actions, which also may be the reason why they chose to visit day centres.

Study IV showed that a positive view of some aspects of the worker role was related to day centre attendance, especially attendance at a more work-oriented day centre. Previous studies have also shown that employment-focused services yield better employment outcomes for people with PD than interventions without such a focus (Bond, Drake, Becker, & Mueser, 1999; Bond, *et al.*, 2001). However, Study IV did not detect a stronger worker role in general when comparing those who attended a day centre with those who did not. The differences identified were only on the item level. Perhaps the work orientation was not strong enough at the studied day centres to produce differences when the attendees were compared to non-attendees regarding the overall worker role. One reason for that might be that the staff feared to jeopardize the clients' social benefits. Such considerations have previously been shown to hinder the clients' rehabilitation towards work (Henry & Lucca, 2004). It might also be that things outside the day centre arena influenced the worker role. Study IV showed, for example, that having a general high activity level contributed to a stronger overall worker role, but the participants' activity level was probably affected by circumstances both within and outside the day centre. It is also likely that factors that were not targeted in this thesis were of importance for perceptions of the worker role and led to few differences between the groups, such as possible stigmatising attitudes in work places and employment agencies.

It has been questioned if alternatives such as community-based day centres, which aim to provide meaningful occupations and integrate people with PD into the community (National Board of Health and Welfare, 2011), actually provide enough possibilities in these respects (Catty, Goddard, White, & Burns, 2005; Rosenberg, 2009). The present thesis indicates that day centres do seem to give structure to the day and serve as substitutes for paid work. They also seem to enhance some aspects of occupational meaning social interaction and, on item level, parts of the view of the worker role. However, the findings also indicate that not all occupational needs seem to be met in day centres, such as satisfaction with daily occupation, further qualitative aspects of social interaction and some aspects of the worker role. That not all occupational needs are met in day centres has also been reported by Mannerfelt (2000), Catty *et al.* (2005) and Eklund and Sandlund (2011). Community-based care should thus further concentrate on enhancing meaning-generating occupations and community integration for people with PD, by for example supporting the attendees' self-mastery and giving possibilities for further social and occupational opportunities, both within the day centre settings and in the outside community. These strategies would hopefully also diminish the risk of day centres sometimes acting as secluding (Bryant, *et al.*, 2004; Catty, Goddard, White, *et al.*, 2005; Kilian, *et al.*, 2001).

## Recovery and its relationship with the findings

The concept of recovery was not in focus in this thesis and was not specifically investigated, but the results still indicate that recovery may be seen as a factor that links all four studies together. This is not surprising, being as recovery has been associated with factors such as occupational performance (Alphonce, 2004), meaning in occupation (Sutton, 2008) and occupational therapy theory in general (Rebeiro, 2005), which are central to this thesis. Creating new meaning in life and experiencing hope are fundamental cornerstones in the process of recovery (Anthony, 1993), and meaning, and to some extent hope, were in focus in Study I. Related concepts such as occupational value and satisfaction were further addressed in Study II, and social interaction, which was central in Study III, has been shown to be an important aspect of recovery (Schön, 2009). Moreover, the view of the worker role, addressed in Study IV, has links with both work per se, shown to enhance recovery (Morrow, *et al.*, 2009) and the ability to picture a positive future self, also included in the thoughts of recovery (Deegan, 1988). Moreover, self-mastery, which showed to be of relevance for all investigated occupational factors in this thesis, is also of great importance for recovery (Topor, 2004). Thus, recovery and the assumptions within that view are highly relevant for this thesis, whose findings, in turn, lend support to the recovery paradigm and its constituents.

## Methodological considerations

### Study I

A qualitative approach was chosen for Study I since the aim was to investigate the person's own perception and experience of his or her personal lifeworld (Kvale, 1996). Informants were selected with the aim of getting a varied and rich picture of the meaning in everyday occupations. The final informants varied in terms of sex and whether or not they were connected to a day centre, a variation that should be seen as enhancing the credibility of the study results (Graneheim & Lundman, 2003). The variation in age was, however, less than intended being as most of the informants were middle-aged. A larger number of young informants might have altered the picture of meaning for people with PD. The interviewer (EA) used probing during the interview in order to improve the trustworthiness of the study and also to validate the topics described by the interviewees. The interviewer's previous work in mental health care, and the pre-understanding she had acquired, was seen as potentially influencing the analysis of the data (Burnard, 1991). However, measures were taken to bracket the pre-understanding, such as continuous awareness and by discussions between the first author and the co-authors regarding alternative categorizations. This is a method that has previously been shown to strengthen a study's credibility (Graneheim & Lundman, 2003). In order to achieve credibility meaning units that were neither too broad, for example, several paragraphs, or too narrow, for example a single word, were selected. According to Graneheim and Lundman meaning units that are too broad may be difficult to interpret being as they can contain many different types of meaning. Meaning units that, on the other hand, are too narrow can constitute a risk for fragmentation Furthermore, representative quotes from the different informants were given in the results and a clear and distinct description of the informants and the analysis process was given in order to enhance trustworthiness of the study (Graneheim & Lundman, 2003; Guba, 1981). Unfortunately, no member check of the results was performed, which would have strengthened the credibility of the study (Guba, 1981). The result of the study was, however, presented for people with PD and day centre staff at two seminars held within the project, and they could confirm the relevance of the results and conclusions.

## Studies II-IV

### *Design and selection of participants*

Studies II-IV had a comparative and cross-sectional design and could therefore not reveal any causal relationships. The variables set as independent factors influencing the dependent factors might thus also have been influenced by the dependent factors, and there may also be circular relationships, where for example, subjective perceptions of occupation may influence social interaction, which in turn may have an impact on how occupations are perceived. The scenario of independent and dependent variables assumed in the studies was, however, much in line with the theory behind the different investigated factors. The concept of self-mastery is for example seen as a self-variable (Pearlin, *et al.*, 1981), which according to theory should be less influenced by different external life events. The studies had a naturalistic design which provided a way of studying the target group without manipulating or intruding into the participants lives more than necessary (Medical Research Center, 2003), which is seen as a strength.

The participation rate was just below 50 %, which can be viewed as low but is similar to that of other studies of people with PD (Bengtsson-Tops, *et al.* 2005). Random sampling was used after collecting participants from different outpatient settings. This, however, was not feasible at one unit, but being as it was seen as valuable to include this unit in order to get data from all the selected geographical areas, the waiting room principle was applied. This should not have affected the outcome of the study, but led to difficulties in calculating the non-participation rate, which must be seen as a limitation. Moreover, the participants in both the day centre attendees and the non-attendees showed only moderate levels of psychopathology on a group level. This indicates that people with PD who had greater psychiatric difficulties tended not to participate in the research project, which means that the investigated people with PD might not fully represent the target group. Moreover, the day centre attendees less often reported a diagnosis of schizophrenia, but since the results did not indicate that diagnosis explained any of the variance in the dependent variables this difference in self-reported diagnosis should not jeopardize the validity of the findings.

### *Data collection and statistical procedures*

All instruments used in the studies were well tested and should have produced valid and reliable data. The limited knowledge of the non-attendees' occupational life was a drawback, however. There might be a possibility that the non-attendees filled their days with meaningful occupations similar to those of the attendees, which would diminish the occupational differences between the groups and be the reason why they did not seek occupational support. Few alternatives to day centres were, however, available in the studied areas, which makes it more likely that the non-attendees did things that were different in character but which might give equally positive experiences. An additional drawback, in relation to Study IV and the participants' view of their worker role, was that no employment history among the participants was collected. It would have been valuable to know how close the participants were to a former worker role. Probably work and what it entails for the worker role is something the participants could imagine even if their own work experience was way back in time, or even lacking, since work and the associated lifestyle are something that permeates society. The importance of the participants' work history would, however, have been interesting to study in this thesis.

The statistics used in Studies II-IV were non-parametric, being as most data were on ordinal scales. The sample size for attendees and non-attendees was deemed large enough to detect statistically significant differences of clinical interest (Wampold, 2001), corresponding to an effect size of about 0.5. No specific power calculations were made, however, due to lack of research in the specific fields and with the instruments used. When analyzing data with the logistic regression models several of the variables were dichotomized at the median cut, which meant that variation within these variables was lost. Logistic regression analysis was, however, viewed as the most appropriate statistical regression method since most of the variables investigated were of ordinal nature (Altman, 1991). A further limitation is the large number of statistical analyses that were performed in the studies. With a p-value of $<0.05$ a risk occurs that 5 % of the statistical findings is obtained by chance. This should be considered when drawing conclusions from the studies. The findings should thus not be regarded as definite answers to the research questions but may serve to generate hypotheses for future research.

# Conclusions and clinical implications

The results from the studies are concluded below, together with implications when forming rehabilitation strategies, mainly in community-based settings for people with PD:

- Self-mastery was an important factor for all investigated factors and should hence be highligthed in psychiatric care. Being in control over one's mental illness gave meaning and meaning was also achieved when the informants engaged in occupations that gave a feeling of competence and of having a balance between meaningful occupations. Enhancing self-mastery and developing and providing tools for how to use meaningful occupations to control mental illness should thus be in focus, proceeding from the client's own unique experience of mastering his or her illness. Motivating and encouraging the client to be active in his/her own rehabilitation process is vital, in order to enhance feelings of competence.

- The findings concerning subjective experiences of occupation converged in some respects. Being active and creating routines were, for example, seen as meaningful and activity level emerged as a significant factor for the perception of occupational value. These results suggest the importance of stimulating to activity in general. Thus, providing the client with opportunities for being active and taking part in varied sorts of occupations should be highlighted. Occupations should be individually adjusted to each person's specific occupational and vocational needs. Helping to explore creative and challenging occupations that are motivating and on an appropriate skills level, helping to create daily and weekly routines and to find a balance between work-like and restful occupations in everyday life are also of importance.

- In terms of social life, people with PD received their main social support from family members, but still often lacked close and supportive social contacts. Together with previous research regarding social interaction this indicates that the emphasis of rehabilitation should be on the quality rather than on the quantity of social interaction. The subjective experiences of occupation seemed vital since they were of importance for both quantitative and qualitative aspects of the social network. Valued and satisfying everyday occupations could play an important role in social support, particularly as the latter aspect has also previously been shown to be related to social interaction. Social interaction seemed to be enhanced by reduced psychiatric symptoms, underlining the importance of not neglecting strategies to reduce symptoms. The possibilities for social interaction within day centres should thus be enhanced in general, but particularly regarding needs for close social contacts. This could mean taking actions such as initiatives for user involvement, peer support, social interactions outside the community based setting and also cooperation with consumer-run organisations within community-based settings in order to create opportunities for both cotrol and closer and more helpful relationships in general. Being as many social interactions were with close relatives, offering informal caregiver support from professionals in the psychiatric care services is important, in order to create functional supportive relationships that enhance recovery for the person with PD.

- Paid work was desired but had been replaced by compatible and socially acceptable occupations, since work was often experienced as too stressful or to difficult to receive. Factors that seemed to influence the view of the worker role in a positive direction were a high activity level and high levels of self-mastery, being younger and having less severe depressive symptoms. Possibilities for engagement in work-like occupation that take notice of these aspects should be highlighted as a part of the municipalities' services, since these types of occupation create meaning. Even though paid work was not investigated in this thesis, previous research has shown that paid work with support is an important strategy to enhance recovery.
- Although some criticism is raised in the literature regarding meeting place-oriented day centres, these should not be underestimated being as they have shown to provide opportunities for daily structure, a general higher activity level and social interactions. The day centres attendees also perceived more valued everyday occupations than the non-attendeed. However, there was no difference regarding satisfaction with everyday occupation, indicating that the day centres met some, but not all, of the visitors' occupational needs. In order to avoid the creation of seclusion, assisting people with PD in finding valued and satisfying occupations both within day centres and in the actual community is important in order to boost the attendees' subjective perceptions of occupation. Furthermore, an emphasis is needed on providing a structure for everyday life and social opportunities both within community-based day centres and in the community, the latter preferably with mobile support.

## Implications for future research

The result of this thesis adds to the body of existing knowledge of subjective experiences from occupation, social interaction, the view of the worker role and day centre attendance for people with PD. However, in order to further the understanding regarding meaningful occupations for people with PD in the community and in society at large, more research focusing the subjective perceptions of occupation and how it may be promoted should be undertaken. Different forms of community-based rehabilitation and day centre attendance as a way of enhancing community integration is another important topic that deserves attention in future research. Research regarding day centre attendees' former worker role would also be of importance. Furthermore, being as research in general indicates that work and work-like occupations are favoured and seen as meaningful by the target group, the effect of work-promoting rehabilitation strategies, such as supported employment, on positive subjective experiences should be investigated. Additionally, investigations regarding the experience from engaging in consumer-run organizations should be highlighted in future research.

# Svensk sammanfattning/ Swedish Summary

## Bakgrund

I Nationell psykiatrisamordnings slutbetänkande 2006 anges att personer med långvarig psykisk sjukdom i anmärkningsvärt stor utsträckning står utanför både deltagande vid daglig sysselsättning och lönearbete, vilket bedöms vara ett hinder för integrering i samhället (SOU, 2006 100). Då flertalet personer med psykiskt funktionshinder saknar arbete, och därmed den sociala roll och de aktiviteter som tillhör ett arbete, vilar ett stort ansvar för kommunen att organisera och erbjuda en välfungerande psykiatrisk rehabilitering och meningsfulla aktiviteter på exempelvis sysselsättningsenheter (Tjörnstrand, *et al.*, 2011). Att vara på en daglig sysselsättningsenhet och ta del av de aktiviteter och den sociala miljö som erbjuds där kan påverka en persons vardag, vilket i sin tur influerar hur personen upplever och värderar sina vardagliga aktiviteter. Forskningen om effekterna av deltagande i daglig sysselsättning är dock begränsad (Catty, *et al.*, 2007), men en tidigare studie kunde inte finna några signifikanta skillnader gällande upplevelsen av värde och tillfredsställelse i aktivitet mellan personer med psykiskt funktionshinder som deltog i sysselsättning och de som inte gjorde det (Eklund, *et al.*, 2004). Således behöver både personer som deltar i daglig sysselsättning och de som inte gör det studeras vidare beträffande vad som ger dem positiva aktivitetsupplevelser och en tillfredsställande vardag.

Tidigare forskning visar att en persons dagliga aktivitetsmönster förändras när denne insjuknar i psykisk sjukdom. Till exempel tenderar personer med långvarig psykisk sjukdom att få problem med att organisera sin tid och tillbringar stor del av dagen med att sova och vila (Bejerholm & Eklund, 2004; Nagle, *et al.*, 2002). Personer med psykiskt funktionshinder har generellt få sociala kontakter och uppger sig även i stor utsträckning sakna mening i sitt liv (Bejerholm & Eklund, 2004; Krupa, *et al.*, 2003; Leufstadius, *et al.*, 2006; Minato & Zemke, 2004). Forskning har visat att olika aspekter av att ha ett avlönat arbete ger ökad tillfredställelse och mening (Leufstadius, *et al.*, 2009) och har positiva effekter på återhämtning från psykisk sjukdom (Dunn, *et al.*, 2008), vilket indikerar att lönearbete skulle vara en viktig del i den psykiatriska rehabiliteringen. Forskningen visar dock att lönearbete ej enbart upplevs som positivt utan även kan upplevas som stressande för personer med psykiskt funktionshinder (Scheid, 1993). Detta, tillsammans med det faktum att en stor del av personer med psykisk sjukdom saknar avlönat arbete (SOU, 2006 100), antyder att alternativa sysselsättningsformer är viktiga. Trots betydelsen av meningsfull aktivitet för målgruppen är forskning begränsad gällande denna subjektiva upplevelse och de specifika aspekter av aktivitet som ger mening för personer med psykiskt funktionshinder som saknar lönearbete (Gahnström-Strandqvist, *et al.*, 2003; Hvalsoe & Josephsson, 2003) vilket gör detta till ett område som är viktigt att beforska.

## Subjektiv upplevelse av aktivitet

För att kunna förstå den subjektiva upplevelsen av aktivitet, i termer av mening, värde och tillfredsställelse, har olika teoretiska modeller och teorier tagits fram (Law, *et al.*, 1996; Townsend & Polatajko, 2007), vilka trycker på att det är individen själv som definierar vilken aktivitet som är meningsfull (Persson, *et al.*, 2001). För upplevelsen av mening i samband med aktivitet finns idag ingen generell och enhetlig definition då författare tar olika utgångspunkter. En definition som kan lyftas är den av Hammell (2004) som definierar begreppet mening som en känsla eller upplevelse, invävd i individens identitet. Hon beskriver fyra dimensioner av mening; att göra, att vara, att tillhöra och att bli. Den subjektiva upplevelsen av värde beskrivs av Persson et al (2001) i modellen the Value and Meaning in Occupations (ValMO). Värde ses här som en komplex upplevelse med flera olika dimensioner. Modellen belyser de tre dimensionerna *konkret* (synbar produkt), *symbolisk* (individuellt och indirekt värde) samt *självbelönande värde* (aktiviteten i sig är belönande). Ytterligare ett sätt att se på subjektiv upplevelse av aktivitet är genom den tillfredsställelse en aktivitet kan ge. Tillfredsställelse med daglig aktivitet har visat sig vara ett separat fenomen jämfört med värde (Eklund, 2004) men ses som kopplat till begreppet mening såsom en generell känsla gällande dagligt liv i sin helhet (Kielhofner, 2008). Tillfredsställelse ses även här främst som kopplat till tillfredsställelse av olika behov (Eakman & Eklund, 2011). Forskning på ämnet upplevelse av värde, mening och tillfredsställelse för personer med psykiskt funktionshinder är begränsat men Eklund et al (2007) har visat att dessa fenomen är viktiga i rehabiliteringsprocessen och därför viktiga att beforska. En individs subjektiva upplevelse av aktivitet är beroende av en rad faktorer, av vilka en del undersöks i denna avhandling. Dessa beskrivs närmre nedan.

## Self-mastery

Self-mastery eller egenkontroll har beskrivits som individens kontroll över de livets omständigheter som på ett betydelsefullt sätt påverkar personens liv. För personer med psykiskt funktionshinder har olika studier påvisat en koppling mellan egenkontroll och olika hälsorelaterade faktorer såsom känsla av sammanhang (Bengtsson-Tops, 2004), hopp (Kirkpatrick, *et al.*, 2001) samt välbefinnande och livskvalitet (Rosenfield, 1992).

Bengtsson-Tops (2004) fann även att en persons psykopatol0gi influeras mer av individens grad av egenkontroll än behovet av stöd, socialt nätverk, arbetsstatus samt inkomst. I en studie av Eklund (2007) undersöktes upplevd kontroll i relation till dagliga aktiviteter för personer med psykiskt funktionshinder. Studien visade en relation mellan upplevd kontroll och både aktivitetsnivå och tillfredsställelse med aktivitet. Detta indikerar att upplevelsen av egenkontroll är av vikt för utförandet av aktivitet likväl som för hur en aktivitet uppfattas, vilket antyder att stärkandet av en persons känsla av egenkontroll skulle vara en viktig intervention i psykiatrisk rehabilitering.

## Social interaktion

Social gemenskap ses som ett fundamentalt behov hos alla människor (Townsend *et al.*, 2007) och att vara social och ha olika sociala roller ger mening och en känsla av tillhörighet i samhället (Hammell, 2004; Leufstadius *et al.*, 2008) samt ökar möjligheten till återhämtning (Davidson, 2001; Topor, 2004). Enligt Lindström *et al.* (2011) kan sociala situationer upplevas som meningsfulla, men även som tröttande och svåra, för personer med psykiskt funktionshinder, vilket gör att ett spänningsfält mellan positiva och negativa upplevelser skapas. Studier har dock visat att social interaction och att ha vänner ökar både välbefinnandet (Strömberg *et al.*, 2005) och livskvaliteten för gruppen. Inte minst spelar social interaktion en stor roll i integrering i samhället för personer med psykiskt funktionshinder (Munroe *et al.*, 2007). Klamas (2010) menar att olika typer av sociala nätverk ger olika typer av stöd till personer med psykiskt funktionshinder, exempelvis gav familjemedlemmar ett större stöd i att få vardagen att fungera. Även om social interaktion är viktig för gruppen visar forskning att personer med psykiskt funktionshinder ofta har begränsad möjlighet att delta i sociala sammanhang (Bejerholm & Eklund, 2004); deras nätverk är ofta begränsade (Macdonald *et al.*, 2000) och främst fokuserade på familjemedlemmar (Sörgaard *et al.*, 2001). En av orsakerna till svårigheter med social integration för gruppen är enligt Rosenberg (2009) at det finns stigmatiserande attityder i omgivningen.

## Synen på arbetsrollen

Att ha en arbetsroll ökar möjligheten till sociala interaktioner och en arbetsroll roll ger, förutom möjligheten till sociala relationer med arbetskollegor, även fördelar såsom lön och daglig struktur (Boardman, 2003). Eftersom arbete historiskt sett har varit ett medel för att få personer med psykiskt funktionshinder att passa in i samhället (Foucault, 1993) är det inte överraskande att många samhällen idag strävar mot att integrera och rehabilitera personer med psykiskt funktionshinder genom arbete. I Sverige står det att läsa i de Nationella riktlinjerna (2011) för gruppen att arbete ökar personens självkänsla och möjligheten till social interaktion och därmed bör befrämjas i rehabilitering. Även om arbete kan upplevas som stressande (Scheid, 1992) så visar forskning att personer med psykiskt funktionshinder vill arbeta (Grove, 1999; Secker, Grove & Seebohm,

2001) samt att lönearbete främjar välmående, livskvalitet (Bond *et al.*, 2001; Eklund, Hansson & Bejerholm, 2001; Eklund, 2009), upplevelsen av mening (Leufstadius *et al.*, 2009) samt möjligheten till återhämtning (Morrow *et al.*, 2009). Arbete har även visats ge en struktur på vardagen (Leufstadius, *et al.*, 2009). Att studera synen på arbetsrollen hos personer med psykiskt funktionshinder samt deras upplevelse av värde och tillfredsställelse i samband med aktivitet är av vikt för att vidare kunna forma insatser för att öka målgruppens tillfredsställelse med vardagslivets aktiviteter och stärka deras arbetsroll.

## Syfte

Det finns ett stort behov av forskning inom ämnet subjektiva upplevelser i samband med aktivitet för gruppen med psykiskt funktionshinder, inklusive vad deltagande i daglig sysselsättning betyder i termer av upplevelser av aktivitet. Få studier är även gjorda på gruppens meningsupplevelser i samband med aktiviteter, särskilt de som inte är kopplade till arbete. Ytterligare kunskap behövs inom detta område för att kunna utveckla en god och evidensbaserad rehabilitering för målgruppen. Avhandlingsarbetet syftar således till att ge en ökad förståelse för hur personer med psykiskt funktionshinder som saknar arbete upplever mening, värde och tillfredsställelse i aktivitet samt att ge en bild av gruppens grad av aktivitetsnivå, sociala delaktighet och hur de upplever arbetsrollen. Studierna studerar även skillnader mellan personer som deltar i kommunal dsglig sysselsättning och de som ej gör det.

## Urval, metod och resultat i avhandlingens fyra delstudier

Samtliga deltagare i projektet kontaktades först av personal, som förmedlade muntlig och skriftlig information. Efter skriftligt samtycke kontaktades deltagaren av projektanställd personal för bokning av intervju.

Den första delstudien var en kvalitativ intervjustudie med 12 personer med psykiskt funktionshinder, och som var i arbetsför ålder men inte hade arbete. Definitionen psykiskt funktionshinder innefattar att ha svårigheter att utföra aktiviteter inom viktiga livsområden, vilket kan vara en följd av en psykisk störning. Svårigheter ska ha funnits under en tid eller ses som möjliga att bestå under en längre tid (SOU, 2006:5). Att ha ett funktionshinder innebär även att man ser till den begränsing en funktionsnedsättning ger en individ i dennes aktuella miljö (National Board of Health and Welfare, 2009), vilket stämmer väl med arbetsterapeutisk teori om samspelet mellan person, miljö och aktivitet (Law *et al.*, 1996). Därmed ses den aktuella termen som lämplig att använda i denna avhandling. Studien undersökte vad som gav upplevelsen av mening i dessa personers dagliga aktiviteter. Resultatet visade att många av vardagen sysslor gav upphov till en meningsupplevelse – såsom att umgås med och känna sig accepterad av andra, göra saker man var duktig på och ta hand om sin hälsa. Synen på arbete var dubbelbottnad – man saknade arbetsgemenskap och status, men var samtidigt lättad över att slippa stress och krav. Delstudierna II-IV genererades från en och samma större studie, som var en komparativ tvärsnittsstudie med en grupp som gick i daglig sysselsättning (93 personer) och en jämförelsegrupp som rekryterades från öppenvårdsmottagningar för personer med psykiskt funktionshinder (82 personer). Samtliga var i arbetsför ålder, och för jämförelsegruppen var det ett exklusionskriterium att ha arbete och/eller gå i daglig sysselsättning. Olika självskattnings- och intervjubaserade instrument användes.

Delstudie II undersökte subjektiva upplevelser av aktivitet och faktisk aktivitetsnivå i båda subgrupperna, samt studerade faktorer av betydelse för den subjektiva upplevelsen av aktivitet. Subgruppen som gick i daglig sysselsättning hade oftare aktivitetsupplevelser som de fann värdefulla och hade också högre aktivitetsnivå än de som tillhörde jämförelsegruppen. Hög nivå av egenkontroll (self-mastery) var relaterad till högt skattade subjektiva aktivitetsupplevelser i samplet som helhet. Även högre ålder och mindre symptombelastning var associerad med en subjektiv aspekt av aktivitet, nämligen tillfredsställelse med dagliga aktiviteter. Delstudie III hade fokus på social interaktion i de studerade subgrupperna. Syftet var att undersöka hur personer som besökte en daglig sysselsättnings enhet skilj-de sig från jämförelsegruppen avseende olika aspekter av social interaktion samt att undersöka faktorer av betydelse för social interaktion i samplet som helhet. Socialt stöd fick deltagarna främst från informella vårdgivare och familjemedlemmar. Subgruppen som gick i daglig sysselsättning hade en större mängd sociala relationer totalt sett. De faktorer som identifierades som betydelsefulla för hög nivå på social interaktion var högt skattade subjektiva upplevelser av aktivitet, att vara gift/sambo, hög grad av egenkontroll och låg nivå av psykiatriska symptom. Delstudie IV syftade till att undersöka synen på en framtida arbetsroll i gruppen som helhet, samt vilka samband som fanns till faktisk situation gällande daglig aktivitet, subjektiva upplevelser av aktivitet, egenkontroll, social interaktion och sociodemografiska variabler. Vissa aspekter av arbetsrollen var positivt relaterade till att delta i dalig sysselsättning, särskilt sådana enheter som hade arbetsinriktad orientering, men totalt sett utifrån skattningen av arbetsrollen fanns ingen skillnad mellan grupperna. Hög nivå av upplevd egenkontroll, att vara yngre, ha högre aktivitetsnivå samt att ha låga nivåer av depressiva symptom var positivt korrelerade med en positiv syn på en framtida arbetsroll.

## Kliniska implikationer

Resultatet från studierna I-IV i denna avhandling leder till följande förslag på interventionsstrategier som kan tillämpas av arbetsterapeuter samt övriga professioner inom olika kommunala rehabiliteringsverksamheter riktade mot personer med psykiskt funktionshinder:

- Då kontroll visat sig vara en viktig faktor för samtliga undersökta faktorer fokusera stöd för att ge möjligheten att skapa och tillhandahålla redskap för att använda meningsfulla aktiviteter för att kontrollera psykiskt sjukdom med hjälp av klientens unika erfarenhet. Motivera och uppmuntra klienten att vara aktiv i hans/hennes rehabiliteringprocess, för att öka känslan av kompetens.

- Då resultatet visade att det var viktigt att vara aktiv är det också av vikt att hjälpa till att stimulera till aktivitet och dagliga och veckoliga rutiner, finna en balans mellan arbetsliknande och avslappnande aktiviteter samt finna kreativa och utmanande aktiviteter som är motiverande och har lagom svårighetsgrad.

- Ge stöd och hjälp i att etablera och vidga ett fungerande socialt nätverk, bland annat genom att använda rehabiliteringsinsatser såsom brukarstyrda aktiviteter och peer support och genom samarbete med burkarstyrda organisationer. Även professionellt stöd till informella vårdgivare bör betons, då dessa är viktiga i återhämtningsprocessen.

- Ge arbetsfokuserade sysselsättningsenheter samt arbetsrelaterad rehabilitering större fokus i den kommunala psykiatrin. Dock bör även träffplatsorienterad aktivitetscentran främjas till viss del då den kan leda till ökad aktivitetsnivå och upplevelser av utföra värdefulla aktiviteter.

- Använda värderade och tillfredsställande aktiviteter inom sysselsättningsenheter, men även stimulera till sådana ute i samhället för att utöka klientens aktivitetsrepertoar. Ge hjälp till att strukturera det dagliga livet och erbjuda social interaktion både inom den specifika sysselsättningsenheten och i den aktuella kommunen generellt, det senare med olika former av mobilt stöd.

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