Functional Capacity as a Predictor of Everyday Functioning in Patients with Schizophrenia

Anna-Karin Olsson
Functional Capacity as a Predictor of Everyday Functioning in Patients with Schizophrenia

Anna-Karin Olsson
Functional Capacity as a Predictor of Everyday Functioning in Patients with Schizophrenia

Anna-Karin Olsson

DOCTORAL THESIS

Karlstad University Studies | 2019:2

urn:nbn:se:kau:diva-70681

ISSN 1403-8099

ISBN 978-91-7063-833-6 (print)


© The author

Distribution:
Karlstad University
Faculty of Arts and Social Sciences
Department of Social and Psychological Studies
SE-651 88 Karlstad, Sweden
+46 54 700 10 00

Print: Universitetstryckeriet, Karlstad 2018

WWW.KAU.SE
“The ‘rules’ of mathematics say that bumblebees can’t fly
Their wings are just not big enough to launch them to the sky
Their bodies are too large in relation to their power
So the rule makers concluded that the bumblebee’s a liar”

Tony Almond, 1994
Doctorial dissertation in Psychology: Functional capacity as a predictor of everyday functioning in patients with schizophrenia
Anna-Karin Olsson, Department of Psychology, Karlstad University, Sweden

Abstract
The overall purpose of this thesis is to increase knowledge of the concept of functional capacity and how it is related to everyday functioning for adult patients with schizophrenia spectrum disorders. The thesis comprises three papers (Papers I-III) based on empirical data from a clinically representative sample of outpatients. The results in the first study (Paper I) indicated that the Swedish version of University of California San Diego Performance-based Skills Assessment-Brief (UPSA-B) is a reliable instrument, with good psychometric properties in terms of both validity and reliability. UPSA-B is a performance-based instrument used to assess functional capacity, i.e. the patient’s ability to perform certain everyday tasks, necessary for independent functioning, in a controlled setting. In the second study (Paper II), the aim was to investigate if and how demographic variables and illness activities, together with functional capacity, contribute to predicting real-world functioning milestones. Functional capacity was mainly associated with level of education and housing situation. In the third study (Paper III), the aim was to investigate how the patient’s self-rating ability regarding functional performance relates to neurocognitive performance and real-world functional performance. The results showed that 37% of patients overestimate their functional performance. The results also showed that clinicians seem to have greater difficulty assessing patients who overestimate their functioning. In summary, this thesis states that using UPSA-B to measure functional capacity offers considerable advantages and plays an important role in capturing functional outcomes. The importance of taking control of limited self-rating ability in patients with schizophrenic spectrum disorders is also demonstrated.

Keywords: schizophrenia, functional capacity, everyday functioning, self-awareness, assessment instrument.
Doktorsavhandling i psykologi: Funktionskapacitet som en prediktor för hur patienter med schizofreni och schizofreniliknande tillstånd klarar vardagliga aktiviteter.
Anna-Karin Olsson, Avdelningen för psykologi, Karlstad Universitet, Sverige

Sammanfattning

Nyckelord: schizofreni, funktionskapacitet, vardagslivets förmåga, självmedvetenhet, bedömningsinstrument
**Paper I**

**Paper II**

**Paper III**

Contribution in the appended papers

**Paper I**
Main and corresponding author. Translation and adaptation of the instrument. Shared responsibility for data collection, analyses and writing.

**Paper II**
Main and corresponding author. Shared responsibility for planning, data collection, analyses and writing.

**Paper III**
Main and corresponding author. Responsibility for planning, data collection, analyses and writing.
TACK
Jag vill först rikta mitt tack till arbetsterapeuterna på psykiatriska kliniken, NU sjukvården, som med stort engagemang använt bedömningsinstrumentet UPSA-B. Ni har bidragit med många värdefulla synpunkter och generöst delat med er av olika erfarenheter. Likaså vill jag tacka alla patienter som deltar i CLIPS studien och på så sätt bidrar till den viktiga kunskapsutvecklingen inom området schizofreni och vardagsfunktion.
Jag också tacka mina kollegor på Psykiatriska öppenvårdsmottagningen i Henån för er uppmuntran och framförallt er förståelse när jag haft mer eller mindre fokus på våra gemensamma arbetsuppgifter. Vidare vill jag också tacka ledningen på psykiatriska kliniken, NU sjukvården för att jag fått möjlighet och tid att ägna mig åt detta lärorika och spännande arbete. Tack också till Arto Hiltunen, Karlstads universitet, som har hjälpit mig att komma in i den akademiska värden och att söka rätt kurs i rätt tid.
Till mina nära och kära som alltid finns där och erbjuder en oas av viktig vardag, vill jag också rikta ett stort tack, ni betyder allt. Min kära Michaels fantastiska tålamod, uppmuntran och ständigt goda råd ”Ring Lars eller Fredrik” har räddat mig många gånger.
Så till sist vill jag då framföra ett stort TACK till mina handledare Lars Helldin, psykiatriska kliniken NU sjukvården, som inspirerat och väglett mig med sin framåtända, gedigna kunskap och kliniska erfarenhet och Fredrik Hjärthag, Karlstads universitet, som ihärdigt uppmuntrande lotsat mig genom det praktiska arbetet med statistiska analyser och forskningsmetodikens mysterier. Ni har båda under alla år sakkunnigt, ständigt engagerade och med en stor portion tålamod, guidat mig genom samtliga delar i avhandlingsarbetet. Tack för att ni alltid tar er tid att lyssna och diskutera stort som smått.
1 INTRODUCTION

1.1 SCHIZOPHRENIA

1.2 FACTORS ASSOCIATED WITH EVERYDAY FUNCTIONING

1.2.1 Symptoms

1.2.2 Cognition

1.2.2.1 Treatment of cognitive impairments

1.2.3 Gender

1.2.4 Age

1.3 THEORETICAL PERSPECTIVES

1.3.1 General theoretical models describing everyday functioning

1.3.2 General theoretical models describing self-awareness of performance

1.3.3 Theoretical framework

1.4 PRACTICAL PERSPECTIVES

1.4.1 Everyday functioning in schizophrenia

1.4.2 Self-awareness of performance in patients with schizophrenia

1.4.3 Assessing everyday functioning

1.5 IMPLICATIONS FOR RESEARCH

2 THE PRESENT INVESTIGATION

2.1 INTRODUCTION

2.2 PAPER I. PSYCHOMETRIC PROPERTIES OF A PERFORMANCE-BASED MEASUREMENT OF FUNCTIONAL CAPACITY, THE UCSD PERFORMANCE-BASED SKILLS ASSESSMENT – BRIEF VERSION

2.2.1 Aim

2.2.2 Design

2.2.3 Instruments

2.2.4 Procedure

2.2.5 Statistics

2.2.6 Ethics

2.2.7 Results

2.3 PAPER II. PREDICTING REAL-WORLD FUNCTIONAL MILESTONES IN SCHIZOPHRENIA

2.3.1 Aim
2.3.2 Design ....................................................................................... 37
2.3.3 Instruments ............................................................................... 38
2.3.4 Procedure .................................................................................. 38
2.3.5 Statistics .................................................................................... 39
2.3.6 Ethics ........................................................................................ 39
2.3.7 Results ...................................................................................... 40
2.4 PAPER III. OVERESTIMATED FUNCTION IN PATIENTS WITH SCHIZOPHRENIA: A POSSIBLE RISK FACTOR FOR INADEQUATE SUPPORT? ................................... 40
2.4.1 Aim ............................................................................................ 40
2.4.2 Design ....................................................................................... 41
2.4.3 Instruments ............................................................................... 42
2.4.4 Procedure .................................................................................. 45
2.4.5 Statistics .................................................................................... 46
2.4.6 Ethics ........................................................................................ 46
2.4.7 Results ...................................................................................... 46
3 GENERAL DISCUSSION ........................................................................ 48
3.1 THE RELATIONSHIP BETWEEN TWO LEVELS OF FUNCTIONAL OUTCOME: FUNCTIONAL PERFORMANCE AND FUNCTIONAL CAPACITY................................. 49
   3.1.1 UPSA-B as a predictor of real-life functional milestones .......... 50
   3.1.2 UPSA-B as a predictor of functional performance assessed using SLOF ......................................................... 53
3.2 SELF-AWARENESS AND FUNCTIONAL OUTCOME............................ 55
3.3 PSYCHOMETRIC PROPERTIES, TRANSLATION, AND ADAPTATION OF UPSA-B ............................................................................................................... 56
3.4 HOW THE FINDINGS CONTRIBUTE TO INCREASED KNOWLEDGE ABOUT EVERYDAY FUNCTIONING ................................................................. 60
3.5 LIMITATIONS .................................................................................. 63
3.6 FURTHER RESEARCH ...................................................................... 64
3.7 CONCLUSIONS ................................................................................. 66
4. REFERENCES ...................................................................................... 67
1 INTRODUCTION

Despite successful pharmacological treatment for persons with schizophrenia and other psychotic illnesses, many patients who have been diagnosed with these conditions still find it difficult to cope with everyday activities and functioning in society (Carter, 2006). A low level of achieved real-world functional milestones, as could be indicated by unemployment and social impairment, have made schizophrenia one of the most serious and expensive illnesses (Wu et al., 2005).

Impaired everyday functioning in patients with schizophrenia is closely linked to impaired cognitive performance (Green, 1996, Green & Harvey, 2014). Everyday functioning is related to abilities or skills that are essential to an individual’s ability to function independently in the community (Brown & Velligan, 2016; Heinrichs, Statucka, Goldberg & McDermid-Vaz, 2006). A model (see Figure 1) demonstrates how everyday functioning could be measured in different levels of functional outcome: neuropsychological performance, functional capacity and functional performance (Sumiyoshi & Sumiyoshi, 2015). This thesis addresses the concept of functional capacity as a predictor of everyday functioning in patients with schizophrenia.

Figure 1. Levels of functional outcome - a modified version from research conducted by Sumiyoshi and Sumiyoshi (2015).
An individual’s neuropsychological performance level is related to basic cognitive function, and functional capacity refers to an individual’s capability, under controlled conditions, to perform tasks and activities necessary for, or desirable in, everyday life. Functional performance refers to the patient’s ability to manage independent living, engage in work, education, and housekeeping, and to engage in and enjoy leisure pursuits, social activities, and social interaction with other people (Sumiyoshi & Sumiyoshi, 2015).

1.1 Schizophrenia

Schizophrenia is a complex disorder with several different characteristic expressions, poorly understood etiology, and genetic contribution. Environmental factors seem to interact with genetic vulnerability (Jablensky, 2010). In recent decades, premorbid cognitive deficits in schizophrenia have been, interpreted as supporting a neurodevelopmental etiological model (Reichenberg et al., 2010). Around one percent of the population suffers from schizophrenia, and the same percentage can be seen across different countries, cultural groups, and genders. The disorder typically emerges between the ages of 16 and 30 (Mueser & McGurk, 2004). Schizophrenia is characterized by positive and negative symptoms and, cognitive impairments. Persons with schizophrenia have an unusual way of feeling, thinking, and relating to the world. This could lead to a feeling of losing control of emotional and attentional functions and the sense of self (Austin, 2005). The ability to engage in activities is influenced by both symptoms and an illness phase. In the acute phase, patients are clearly limited in their interaction with the outside world (Nagle, Cook & Polatajko, 2002). Substantial changes in personal behavior and impaired role functioning are included as diagnostic criteria for schizophrenia (American Psychiatry Association, 2013). Reduced ability to work, attend school, be a parent, manage social interactions, handle self-care activities, and participate in leisure activities, could be observed several years before the psychotic symptoms (Häfner et al., 1998). Impaired functioning can result in a need for assistance to meet basic living requirements,
1.2 Factors associated with everyday functioning

1.2.1 Symptoms

During the 1950s, antipsychotic medication was introduced. As expected, it reduced the psychotic symptoms for the majority of patients with schizophrenia (Braslows, 1997). Positive symptoms refer to delusions and hallucinations, which are added to the individual’s perceptions and behaviors. Negative symptoms are described as a lack of perception and behavior such as poverty of speech, reduced motivation, and social withdrawal (Austin, 2005). In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), eight dimensions are used to describe different subtypes of schizophrenia: hallucinations, delusions, disorganized speech, abnormal psychomotor behavior, negative symptoms, impaired cognition depression, and mania (American Psychiatric Association, 2013).

Early pharmacological treatment focused mainly on reducing positive symptoms (Marder & Meibach, 1994). It was assumed that reduced psychotic symptoms would lead to increased functioning and ability to integrate and perform activities in the community. However, antipsychotic medication treats symptoms but not cognition (Green & Harvey, 2014). It became more evident that it is the negative symptoms in particular, together with cognitive function, that affect patients’ everyday functioning in society (McGurk & Mueser, 2004). With antipsychotic medication, treatment changed radically. During the 1960s and 1970s, the number of mental hospitals decreased, and patients with schizophrenia moved out into the community and away from lifelong hospitalization. The focus in the health care system shifted from treating patients in institutions to treating them within a community-based health care system (Markström, 2002). Institutionalized patients are today in the minority, and patients with no previous long-term hospitalization seem to demonstrate
improvements in everyday living skills compared to patients who spend extended periods in an institution (Fucetola et al., 2000; Harvey, Reichenberg, Bowie, Patterson & Heaton, 2010). One major goal in the treatment of patients with schizophrenia is to reduce and achieve a stable symptom and function level, what is termed remission. Patients in remission have a better quality of life, prognosis, and function (Helldin, Kane, Hjärthag & Norlander, 2009). A study showed that when patients were in remission, just under 20% had a low functional level compared to about 15% of those not in remission. These results indicate that it is not enough to simply examine the prevalence of symptoms to understand patient’s functional level. There is a need to discriminate between symptomatic and functional remission (Helldin, 2009).

### 1.2.2 Cognition

Since the 1990s, there has been a consensus that cognitive performance is a primary and essential determinant of functional outcome in schizophrenia. Cognition is an important target for treatment as it is believed that cognitive impairments underlie the functional deficits observed in schizophrenia (Green & Harvey, 2014; Wilk et al., 2005). Cognitive dysfunction leads to problems with, concentration, memory, learning, and problem solving (Green, 1996). Studies have revealed that subtle cognitive deficits are already apparent in childhood and adolescence, many years prior to onset of illness (Khandaker, Barnett, White & Jones, 2011: Mollon & Reichenberg, 2018). According to a ten-year follow-up study of first-episode patients the level of cognitive impairment seems to be relatively stable over time (Rund et al., 2016).

In general, patients with schizophrenia perform below healthy controls in various neurocognitive tests (Keefe, 2008). A review of the differences between patients with schizophrenia and healthy controls revealed a deficit of 1.0 to 1.5 S.D. across different domains (Gold & Harvey, 1993). However, a recent study found an average performance deficit of over 2.0 S.D. compared to normative standards
Nevertheless there is considerable neurocognitive heterogeneity in patients with schizophrenia and subgroups and around 20 - 25% of patients perform at the same level as healthy samples (Heinrichs, Miles, Ammari & Muharib, 2013). The neuropsychological literature about schizophrenia, comprises dozens of tasks, and thousands of patients in hundreds of studies. Reviews have revealed divergence in results regarding which cognitive domains are particularly impaired in patients with schizophrenia (Holmen & Juuhl-Langset, 2010; Keefe et al., 2004; Shaefer, Giangrande, Weinberger & Dickinson, 2013). There is compelling evidence that cognitive deficits correlated significantly with impairments in everyday activities (Jablensky, 2010). Leifker, Bowie and Harvey (2009) have shown that patients with higher functioning and cognition scores reach a significantly higher level of employment and residential milestones. They also indicated that other individual differences are needed to predict patients’ real-world performance. It would appear that not all types of cognition are equally important when it comes to the ability to perform everyday activities. Together with general intelligence, cognitive domains such as processing speed, attention, memory, and executive function are commonly present and associated with patients’ functional capacity and everyday functioning (Green, 1996; Green & Harvey, 2014; McClure et al., 2007).

The cognitive domain ‘processing speed’ refers to the speed at which different cognitive operations can be executed. Processing speed is one of the most impaired cognitive domains in patients with schizophrenia, and patients perform approximately 1.5 S.D. below healthy comparisons (Dickinson, Ramsey & Gold, 2007).

The ‘attention’ domain can be divided into three basic concepts: alerting, orienting, and executive control. ‘Alerting’ is defined as the function needed to achieve and maintain alertness and optimal vigilance when performing tasks. ‘Orienting’ is focused on the ability to prioritize and select relevant sensory input. ‘Executive control’ is described as resolving conflicts between responses (Petersen & Posner, 2012). When describing attention impairment in patients with schizophrenia, it is primarily the alerting function that has been
Attention is closely intertwined with working memory - two constructs that dominate in the field of neuropsychological studies (Mayer, Fukuda, Vogel & Park, 2012). Working memory refers to the capacity to keep a limited amount of information in mind, which plays a fundamental role in cognitive processes such as learning, reasoning and decision making (Squire & Dede, 2015). In schizophrenia studies, meta-analyses indicate that impairments in tasks that demand both maintenance and manipulation of information are noticeably greater than in tasks that demand maintenance only (Grot, Potvin & Luck; Lee & Park, 2005).

The definition of memory can be separated in terms of the different kinds of information being processed and the principles employed. A distinction can be drawn between working memory and long-term memory (Squire & Dede, 2015). Long-term memory has in turn been divided into two types: declarative and non-declarative memory. Declarative memory (knowing that) encompasses both episodic memory and semantic memory, and non-declarative memory (knowing how) encompasses simple classical conditioning, non-associative learning, priming, and procedural memory (Finn et al., 2016). Impairments in declarative memory are consistently reported in patients with schizophrenia (Cirillo & Seidman, 2003). Non-declarative memory is suggested as being relatively well preserved, since patients with schizophrenia show normal results or only mild impairments in tests used in relation to procedural learning, such as learning by doing (Altshuler et al., 2004).

Executive functions refer to a variety of higher-order cognitive abilities involved in the regulation of goal-directed behavior that is particularly necessary in novel situations for which automated behavior or routines are not available (Baddeley, 1998). Existing models view executive functions as a construct consisting of several processes, such as cognitive flexibility, working memory, multitasking, and response inhibition, representing the most important sub-processes (Andres, 2003). Many of the clinical features of schizophrenia are similar to those associated with frontal lesions, such as reduced spontaneity, mental rigidity, and impaired social
judgement (Reichenberg, 2010). Although importantly the prefrontal cortex is involved, other areas, such as the parietal and temporal lobes and the hippocampus have been shown to be activated when performing executive functional tasks (Andres, 2003).

1.2.2.1 Treatment of cognitive impairments

Meta-analysis, with a focus on treatments for improving cognition in schizophrenia has revealed that a variety of interventions and methods for measuring cognition are used. Some of the studies show results for specific cognitive domains whilst others focus on the general cognitive level. Most of the studies included revealed improved cognition and that it is preferable to combine pharmacological, psychological and psychosocial methods (Fisher et al., 2013). Positive findings have been reported from psychosocial interventions such as social skills training, psychoeducation, cognitive behavior therapy, cognitive remediation, and family interventions. Cognitive remediation therapy, for example, seems to have an effect on cognitive domains, such as attention, working memory, and executive functioning, as well as on social cognition (Harvey & Bowie, 2012). A two-year follow-up study showed that cognitive rehabilitation training could significantly reduce the relapse rate, prolong the non-relapse time for patients and improve the employment rate (Tao et al., 2015). The purpose of cognitive training and remediation is to enable patients to generalize learned skills in everyday life. However, more research is needed to find out if, for example, improved working memory is directly transferable to an improved ability to cope with everyday functioning in society (Suenderhauf, Walter, Lenz, Lang & Borgwardt, 2016).

A meta-analysis of 29 randomized clinical trials showed that aerobic exercise significantly improved attention, processing speed, long-term memory and executive function (Smith et al., 2010). Consequently, exercise represents a promising new treatment option that may supplement current pharmacological and psychosocial interventions for patients suffering from schizophrenia. Activities that have been
incorporated into studies range from yoga, walking and cycling to team sports, and the results show that moderate to intense exercise appears to be beneficial for improving symptoms, cognition and functioning (Mittal et al., 2017). In several studies dealing with exercise, the results have been affected by high dropout rates. However, one study managed to include more patients in the follow-up than usual, and their training program consisted of both traditional exercise equipment and active-play video games (Kimhy et al., 2015).

1.2.3 Gender

There is no consensus about gender differences in the ability of patients with schizophrenia to perform everyday activities, and often there seems to be more within-gender differences. (Ran, Mao, Chan, Chen & Conwell, 2015). However, a follow-up study conducted two years after the first episode, showed that women had more affective symptoms and a longer duration before treatment, whereas men had more negative symptoms and were more socially isolated (Køster, Lajer, Lindhart & Rosenbaum, 2008). There also seems to be a consensus that male patients develop the disease about five years earlier than female patients (Arango et al., 2008). Male incidence shows a pronounced peak in the age group 15-24 years, whilst female incidence reveals a lower peak in the age group 15-29 years (Häfner, 2015). Some studies show a second peak at menopausal age (40-60 years) which is completely unmatched for men. The hypothesis is that estrogen in some way protects against psychosis (Akhondzadeh et al., 2003; Castel, Able, Takei & Murray, 1995). Studies also indicate that women have a better prognosis than men, and the later onset of illness may explain why women have had more time to develop abilities and functioning. Women thus seem to have better opportunities for social and occupational achievements, and they are more often in regular employment and show superior family and occupational role functioning compared with men (Angermeyer, Kuhn & Goldstein, 1990; Leung & Chue, 2000; Ran et al., 2015). The type of occupation and activities among patients seem to differ
between genders in the same way as in the healthy population. For example, Shimitras, Fossey and Harvey (2003) showed that women are significantly more involved in household or domestic activities. Other possible reasons why women with psychotic disorders have better outcomes could include genetic factors, different brain structures, higher rates of marriage, lower rates of substance abuse, social expectations, and pressure concerning vocational activities (Grossman, Harrow, Rosen, Faull & Strauss, 2008).

Viewed across the entire lifespan, there are no major gender differences in schizophrenia incidence. Results from epidemiological studies reporting higher lifetime risks for men are explained by age differences (Häfner, 2015). However, a Chinese study indicates that there seems to be an unusually high proportion of women with schizophrenia within the country. They suggest that higher rates of mortality, suicide and homelessness in men may contribute to this division. The poor long term prognosis for men may also be because female participants receive better support and care from their family and from society. Many women with the disorder manage to contribute to some of the daily activities and thus have a role in the family (Ran et al., 2015).

**1.2.4 Age**

Schizophrenia is a disorder that affects people of all ages. It has also been shown that patients with schizophrenia compared to the general population have a reduced life expectancy and a higher incidence of premature death. Studies have shown that life expectancy is reduced by approximately 10 years (Tiihonen et al., 2009) to 20 years (Laursen, Nordentoft & Mortensen, 2014). Among the general population in Sweden, life expectancy increased by 2.2 months per year between 2000 and 2010 but there was no major change in the mortality rate for patients with schizophrenia (Ösby, Westman, Hallgren & Gissler, 2016) Another longitudinal study from Sweden confirmed this risk: the mean age at time of death was 60.5 years,
58.6 years for men and 62.9 years for women (Helldin, Hjärthag, Olsson & Harvey, 2015).

Cognitive and functional impairments increase as part of the normal aging process, and elderly people often require some assistance when performing everyday activities. Schizophrenia is a condition marked by functional changes in many of the same areas in which there are commonly detected changes associated with aging (Harvey & Rosenthal, 2018). There is an accelerated aging hypothesis, and future studies need to deal with potentially confounding factors and the fact that schizophrenia is itself a heterogeneous disorder (Kirkpatrick & Kennedy, 2018). To be considered a significant longitudinal change unique to schizophrenia, the change must be distinct from both normal aging and degenerative conditions, such as Alzheimer’s disease. When patients with schizophrenia were compared to patients with Alzheimer’s disease, they were found to be different in several cognitive domains. Patients with schizophrenia performed worse in a naming test (requires the patient to correctly identify 15 line drawings of objects) and constructional praxis test (requires the patient to copy four geometric figures), while patients with Alzheimer’s disease had more impairments in conjunction with delayed word recall and recognition (Davidson et al., 1996). A study concludes that, over the years, negative and depressive symptoms are similar in prevalence for all patients with schizophrenia, whereas positive symptoms decrease with age (Cohen et al., 2008).

Patients with schizophrenia at the age of 26 perform worse than healthy people in their 60s and 70s (Harvey & Rosenthal, 2018). It would seem that their everyday functioning deteriorates most around the time of the first psychotic episode and at around 65 years of age, irrespective of age at onset (Harvey, 2014). Another study showed that everyday functioning deteriorates continuously across adult life but may accelerate as early as the age of 55 onwards. When older patients \( (M = 57\text{ years}, S.D. = 9.0) \) with schizophrenia were followed up over a period of 45 months and were examined one or two times, everyday functioning worsened over time in several domains, including social functioning and everyday activities (Reichenberg et al., 2014).
Age has been found to have an impact on how people with schizophrenia engage in daily activities (Palmer et al., 2002). Gould Bowie and Harvey (2012) suggested that there is probably an age effect that influences performance-based estimates of ability when real-world outcomes are assessed. However, much of the data presented in different studies seem to be from young patients and their first illness episode. In addition, psychiatric disabilities among younger patients are likely to vary to a greater extent compared with those of older patients with a longer illness duration (Green, Kern, Braff & Mintz, 2000).

1.3 Theoretical perspectives

1.3.1 General theoretical models describing everyday functioning

To place functioning in a context, frameworks and theoretical models need to be considered. According to Law and colleagues (1996) and the World Health Organization (WHO, 2001), functioning can be interpreted as the outcome that occurs in the complex and dynamic relationships between the person, the environment, and the activity.

The International Classification of Functioning, Disability, and Health-ICF (WHO, 2001) provides a biological, individual, and social perspective of health that is developed from a biopsychosocial model. It is a framework for describing and measuring health and disability at both the individual and population level. The ICF consists of three key components: Body functions and structures, Activities and participation, and Environmental factors. The functional limitations occur in a context, and the ICF provides a structure for describing how these limitations can be associated with impaired ability to engage in activities and participate in society (WHO, 2001).

The ICF was used to identify the most representative features of functioning in patients with schizophrenia. The categories with a
higher prevalence of impairment in the Body functions component were related to mental functions such as Emotional functions (b152) and Higher-level cognitive functions (b164). Activity limitations and participation restrictions included Solving problems (d175), Handling stress and Other psychological demands (d240), Looking after one’s health (d570) and Informal social relationships (d750). Support from family (e310), Health professionals (e355) together with Medication (e110) were the most common Environmental factors (Barrios, Gomez-Benito, Pino, Rojo & Guilera, 2018).

Another method of describing a person’s ability to perform activities is the Person–Environment–Occupation (PEO) model (Law et al., 1996), a conceptual model that offers a foundation for guiding assessments across all practice settings and client populations. In the same way as the ICF, the PEO model accounts for the interaction between the person and environmental factors, and how this dynamic interaction affects a person’s level of functioning (Figure 2).

![Figure 2. The Person–Environment–Occupation model, based on a diagram by Law et al. (1996).]

The development of the PEO model was primarily influenced by concepts and ideas that offered a theoretical basis for considering variables from both personal and environmental domains when assessing occupational performance (Law et al., 1996). There is a relationship between individual skills and the challenges of an activity. The activity offers a greater feeling of satisfaction when there is harmony between individual skills and activity challenges. Lawton, one of the researchers specializing in environmental-behavioral
theory, pointed out that both adaptive and maladaptive behaviors could be a result of the interaction between the person and environment. He also found that vulnerability to environmental influences increases when personal competence decreases (Law et al., 1996).

In the PEO model, the person is defined as a unique being with a variety of occupational roles to perform in daily living. The personal factor involves psychological, cognitive, physical, and social skills, personal experience, interests, and attitudes. Furthermore, the perception of self in relation to occupation and environment has an impact on how a person observes and explores the world. The environmental domain is defined as the context in which a person engages in an occupation, and this domain includes a broad spectrum of cultural, socio-economic, institutional, physical, and social considerations of equal importance. The occupational domain encompasses what a person actually does, and it covers activity, task, and occupation. Although these words are often used interchangeably, in this model ‘activity’ is defined as the basic unit, e.g. the act of writing. ‘Task’ is defined as several combined purposeful activities, such as writing a report. ‘Occupation’ is defined as a group of tasks and activities, such as a student’s report writing (Law et al., 1996).

1.3.2 General theoretical models describing self-awareness of performance

Self-awareness is used in clinical settings to describe a person’s ability to recognize the discrepancy between the skills they possess, expected performance, and environmental demands (Fragkiadaki et al., 2016). People’s general thoughts and feelings about themselves across different domains (physical, social and emotional for example), is an inherently subjective structure. The insight that you are ill and have impaired awareness of functioning appears to be based on the person’s own frame of reference. This is in turn shaped and influenced by background, culture, family, education, personality and many other variables (Nair, Palmer, Aleman & David 2014). In the
PEO model, self-awareness is comparable with the perception of self, i.e. one of the personal factors (Law et al., 1996). In ICF, self-awareness could be coded as a mental function, orientation to person (WHO, 2001).

In the search for determinants of real-world functioning the term ‘introspective accuracy’ is used. It is defined as the ability to accurately self-assess performance of cognitive and social cognitive tasks, to evaluate the general level of neurocognitive or social cognitive ability, and to evaluate the level of competence in the performance of functional skills. Introspective accuracy focuses on self-awareness of specific skills and abilities (Silberstein, Pinkham, Penn & Harvey, 2018). Introspective accuracy is used to describe wide-ranging self-rating impairments in severe mental illness (Harvey & Pinkham, 2015). The ability of introspective accuracy is not general; a patient might have insight in one domain and impaired insight in another domain (Yahav, Maimon, Grossman, Dahan & Medalia, 2011).

Traditionally, awareness has been defined as knowledge and understanding about one’s strengths and weaknesses. In one of the existing definitions, self-awareness has also been described as metacognition, referring to aspects of the term that integrate a variety of cognitive variables, such as autobiographical memory, semantic knowledge, and self-monitoring of performance (Morris & Mograbi, 2013). Crosson and colleagues (1989) defined self-awareness as, the ability to recognize deficits, understand their functional implications, and establish realistic goals. In the literature, there is a significant degree of overlap and similarities with regard to self-awareness. The term is related to executive function in neuropsychology, and to metacognition in cognitive psychology. In social psychology there is a similar overlap between the concept of awareness and the concept of self-efficacy (Toglia & Kirk, 2000). Due to the complex and multidimensional nature of the term, a widely accepted definition has not yet been developed (Pragkiadaki et al., 2016).

The first multi-dimensional model of self-awareness, called the pyramid model, includes three independent levels: intellectual,
emergent and anticipatory awareness (Crosson et al., 1989). At the bottom of the pyramid is intellectual awareness, i.e. the ability to acknowledge that a specific function is impaired. The second level is emergent awareness, i.e. the ability to monitor performance and recognize problems when they occur. They cannot see the problem before it has already happened, and they need to use general strategies to accomplish tasks and activities. At the top of the pyramid is anticipatory awareness, the ability to have the foresight that a problem is likely to occur as a result of the impaired function. Intellectual and emergent awareness are considered a prerequisite for anticipatory awareness (Crosson et al., 1989).

Another model, where the aim is to capture the complexities of awareness, is the Dynamic Comprehensive Model of Awareness - DCMA (Toglia & Kirk, 2000). This model is based on the concepts in the pyramid model (Crosson et al., 1989) and integrates parallel terms from cognitive psychology, neuropsychology and social psychology. The DCMA does not assume a hierarchical structure, and instead it provides a dynamic relationship between the task demands, beliefs, the person’s knowledge, and the context of a situation. In this model, self-awareness is divided into two concepts: metacognitive knowledge and on-line awareness, to clarify the differences between knowledge and awareness (Toglia & Kirk, 2000).

Metacognitive knowledge exists prior to an actual task or a situation and is based on knowledge about task characteristics, strategies, procedural knowledge and self-knowledge, and beliefs about one’s capabilities and limitations. Past experiences of similar tasks or situations shape our knowledge and beliefs about our abilities. Metacognitive knowledge is closely interrelated with self-efficacy and is comparable with intellectual awareness from the pyramid model. On-line awareness, on the other hand, is activated within tasks and situations and involves judgement about one’s abilities and limitations in relation to the ongoing situation (Toglia & Kirk, 2000).

The concept includes both a self-monitoring and a self-regulatory process. The ability to monitor one’s performance varies as a function of task characteristics Cognitive psychology studies have found that
the ability to anticipate and recognize errors varies depending on the familiarity of the task and the level of difficulty. According to DCMA, declarative knowledge (or metacognitive knowledge) of one’s abilities combines different aspects of intellectual awareness, while on-line monitoring of performance during tasks is related to emergent awareness and anticipatory awareness (Toglia & Kirk, 2000).

In the general population, global self-awareness seems to be quite stable across the lifespan (Ownsworth & Clare, 2006). Awareness deficits following a neurological disorder have been observed clinically for centuries (Fragkiadaki et al., 2016). Awareness deficits limit motivation to learn, treatment and rehabilitation. Persons who are unaware of their limitations tend to choose activities that are too difficult and they do not know when they need help (Toglia & Kirk, 2000).

1.3.3 Theoretical framework

The theoretical framework of this thesis relies on Sumiyoshi and Sumiyoshi’s model (2015) of functional outcomes (see Figure 1), as a model to describe the different levels of assessing patients’ impaired everyday functioning. The present thesis focuses on two levels of everyday functioning: functional capacity and functional performance. The importance of a patient’s self-awareness when assessing everyday functioning is also highlighted. Everyday functioning will be interpreted in a manner similar to the ICF and PEO models, i.e. as an outcome that occurs in the dynamic relationships between the person, the environment, and the activity. Functional capacity is defined as a patient’s ability to perform tasks in a controlled environment. Functional performance is described as functional abilities and achieved real-world functional milestones. Functional abilities, with a more qualitative description, focus on the abilities needed to perform activities in different domains, such as household tasks, transportation, seeking employment, and financial management. Achieved real-world functional milestones include, for example, marriage, employment, and independent living.
1.4 Practical perspectives

1.4.1 Everyday functioning in schizophrenia

Patients with schizophrenia demonstrate a decline in several aspects of functioning (Harvey, 2014). Impaired everyday functioning is a complex phenomenon as there are many factors that contribute to adequate outcomes. Since the deinstitutionalization movement during the 1960s, functional recovery has become an important treatment priority. It is expected that more patients with schizophrenia will manage to live independently in the community (Goering, Wasylenki, & Durbin, 2000). A problem encountered when studying functioning is that variables other than capacity (what a person can do) seem to limit performance in real life (what a person does). The former is referred to as functional capacity and the latter is known as real-world functional performance (Mantovani, Teixeira & Salgado, 2015). Another obstacle is the lack of consensus on the definition of everyday functioning and how to measure functional outcome in patients with schizophrenia (Figueira & Brissos, 2011; McCabe, Saïd & Priebe, 2007; Schennach-Wolff et al., 2009). Functional assessment is challenging and complex since there also is a lack of appropriate terminology and standards to reflect a patient’s individual level of functioning (Mausbach et al., 2008).

1.4.2 Self-awareness of performance in patients with schizophrenia

Impaired insight seems to follow a U-shaped curve, with decreased awareness during the first episode of psychosis, modestly improved or stabilized over midlife, and worsened again in later life (Gerretsen, Plitman, Rajji & Graff-Guerrero, 2014). Among adult patients with schizophrenia, impaired awareness is associated with illness severity, premorbid functioning, global cognitive functioning, memory and executive functioning (Aleman, Agrawal, Morgan & David, 2006; Nair et al., 2014). Patients who underestimated their real-world performance had better cognitive skills than those who overestimated,
while over-estimators were the most cognitively and functionally impaired (Bowie et al., 2007, Ermel et al., 2017; Nair et al., 2014, Siu et al., 2015, Stratton, Yanos & Lysaker, 2013). Patients with schizophrenia without work history overestimated their vocational potential, even compared to patients who are employed full-time. However, patients with an unsuccessful work history seem to underestimate their skills and abilities (Gould, Sabbag, Durand, Patterson & Harvey, 2013). McKibbin, Patterson and Jeste (2004) found high correlations between patient-reported level of disability and subjective reports of health-related quality of life, but that neither of these scores was related to cognitive performance or functional capacity scores. Accurate raters demonstrated greater social skills than both overestimators and underestimators (Bowie et al., 2007). Lack of self-awareness may lead to that patients with schizophrenia not receive the treatment and support they need (Siu et al. 2015).

1.4.3 Assessing everyday functioning

Assessing everyday functioning is complicated due to limited accuracy in reports of functioning from both patients with schizophrenia and other informants. Since everyday functioning is complex and difficult to describe, several sources are often used. There is a range of methods for collecting data about everyday functioning, each of the approaches has unique advantages and disadvantages. However, studies show low levels of correlation between different informants and different methods and rating scales (Bowie et al., 2007; Burns, 2007; Hjärthag, Helldin, Olsson & Norlander, 2012; Kooyman, Dean, Harvey & Walsh, 2007; McCabe et al., 2007).

1.4.3.1 Sources and informants

The methods most frequently used to measure patients' everyday functioning are self-assessments, interview-based reports and
observations from relatives and health professionals (Moore, Palmer, Patterson & Jeste, 2007).

With self-assessment, the patients estimate and report their own levels of functioning. This method provides the patients with an opportunity to describe their view of how they are functioning (Silberstein et al., 2018). It appears to be the simplest way to gather information, and it is economic in terms of time and cost (Patterson & Mausbach, 2010). Patients with schizophrenia have long been known to lack awareness of impairments associated with illness in several areas, including cognitive abilities (Medalia & Thysen, 2008), everyday living skills (Sabbag et al., 2011) and everyday functioning (Bowie et al., 2007). Although self-ratings provide valuable information, they are slightly risky as the answers are influenced significantly by the patients’ self-awareness, cognitive functioning, symptoms, emotional status, and recent events (Atkinson, Zibin & Chuang, 1997; Silberstein et al., 2018). Despite a great deal of research that highlighted the considerable problems associated with self-assessment, these methods are still widely used (Sabbag et al., 2011).

In order to answer self-rating questions, metacognitive knowledge of one’s abilities is needed (Toglia & Kirk, 2000). Self-assessment accuracy seems to be limited in both the clinical population and in healthy individuals. Healthy individuals tend to consistently overestimate their abilities and poor performers seem to have a particularly positive bias (Ehrlinger, Johnson, Banner, Dunning & Kruger, 2008). Individuals with mild depression seem to make the most accurate estimations of their true functioning, whereas individuals with severe depression underestimate their performance, and those with cognitive impairments overestimate theirs performance (Carone, Benedict, Munschauer, Fishman & Weinstock-Guttman, 2005). Studies in this area relating to patients with schizophrenia and depression produce contradictory results. One study showed that higher levels of depressive symptoms within the moderate range in patients with schizophrenia were associated with a lower tendency to overestimate everyday functioning (Saabag et al., 2011). Another study showed that even when suffering from mild
depression, patients still overestimate their everyday functioning (Harvey, Twamley, Pinkham, Depp & Patterson, 2017).

By obtaining information from the patient’s relatives or significant other, knowledge about the patient’s functioning may increase, but it has proved difficult to get the patient to name a relative who can provide this kind of information (Patterson, Goldman, McKibbin, Hugs & Jeste, 2001). In some cases, such as when the informant does not live with the patient, the relatives may not have the opportunity to observe the patient’s full spectrum of behaviors. Even when an appropriate relative is identified, significant discrepancies have been revealed between ratings generated by the relative and how the patient actually performed in the performance-based measures (Sabbag et al., 2011).

The reliability of clinical rating scales used by health professionals to report patients’ functional performance differs. Previous studies have highlighted the advantage of clinicians using several sources to measure functioning, e.g. incorporating observations when judging the patient’s functioning (Gould et al., 2015; Sabbag et al., 2011). In a study by Bowie et al. (2007), clinicians were asked to score using the same everyday functioning rating scale as their patients. In each of the three functional outcomes domains (social, vocational, and residential), the correlations were small (r-values from 0.2 to 0.3). However, Sabbag et al. (2011) showed that the closer the rater is to a high-contact clinician, the better and more accurate the information that is obtained.

Observations of functional performance in patients’ ordinary contexts increase the possibility that the results are a valid reflection of the patient’s functioning. This is particularly important for patients with schizophrenia, who often experience a variety of information-processing deficits. These deficits can include impaired ability to process subtle environmental cues, impaired short-term memory, affected ability to attach meaning to stimuli, or reduced ability to screen out distraction in the environment (Hamera & Brown, 2000). Observation-based assessment, however, is considered to be too expensive, too time-consuming and too personnel-intensive, to be
used in larger studies (Patterson, Goldman et al., 2001). Direct observation may also be impractical and limited because there are few relevant situations that can be assessed (Bowie et al., 2007).

1.4.3.2 Functional capacity

Functional capacity reflects the ability to perform everyday living skills. Whether the patient actually carries out these activities in real life is not certain as they are surrounded by stress or pressure due, for example, to interpersonal relationships or time constraints (Green, Kern & Heaton, 2004; Harvey & Velligan, 2011). However, individuals with unimpaired functional capacity are supposed to have the competence to perform the required activities, and they could do so if an appropriate and supportive environment is provided (Green et al., 2011). Functional capacity is defined as the patient's ability to perform daily activities under optimal conditions. This means that a patient's functional capacity can be assessed at a clinic, in a controlled environment, through role-play and various everyday tasks. In such an environment, the assessment of a patient's functional capacity is not influenced by surrounding factors, such as prevailing cultural beliefs, social welfare systems, access to sheltered housing, or employment (McKibblin, Patterson, & Jeste, 2004; Patterson, Goldman et al., 2001).

Environmental factors, such as health care systems and level of social support for people with mental illness, are highly divergent. To avoid the influence of environmental factors, such as unemployment and availability of sheltered housing, when measuring functional performance, the use of performance-based assessment to measure functional capacity has increased. Studies comparing patients from different countries and cultures show that—despite similarities in symptomatology and cognitive functioning—there are major differences in how patients manage to achieve desired and expected life goals (Harvey et al., 2009; Helldin, Cavallaro & Galderisi, 2012). Environmental conditions in society, such as culture and welfare politics, seem to affect a patient’s ability to manage independent
living, social interaction, and employment. The American-Swedish study by Harvey et al. (2009), showed that 80% of patients in western Sweden lived independently compared to 46% of patients in New York. The differences in living situations were also described in a study focusing on patients from Sweden and Italy. In Italy, most patients lived with their families, whereas patients in Sweden more frequently lived alone (Helldin et al., 2012).

1.4.4 Assessment instruments

There is a long history of measuring functioning. Early clinical observations were reported at the beginning of the 1900s. The assessment-based approach emerged after 1945 and has increased over the past 20 years (Green & Harvey, 2014). The number of instruments used to assess a patient’s functional performance is limited compared to the number of instruments used to assess cognitive functioning (Patterson, Goldman et al., 2001). There has been growing concern regarding everyday functioning in patients with schizophrenia since its inclusion as a criterion in the diagnostic manual of mental disorders (Burns & Patrick, 2007). The purpose of measuring functioning is to increase knowledge of the patient group and the intervention effects, and to inform the patients and set out plans for how to proceed (Wright, 1997). Although there have been some attempts to create a single outcome instrument, a single summary assessment instrument of global functioning is unlikely to capture the true diversity and complexity of a patient’s functioning (Barnes & Pant, 2005).

Another issue that complicates assessment is the heterogeneity in functioning among patients with schizophrenia (Brown & Velligan, 2016). A broad range of reliable, valid, and sensitive instruments is required to improve the quality of treatment in clinical practice and for research purposes. Accurate assessment instruments of everyday functioning are important for both patients and clinicians, and an increasing number of researchers aim to develop and improve scales
for this purpose (Sumiyoshi & Sumiyoshi, 2015). An overview of instruments used to assess everyday functioning is presented in Table 1. By necessity, the presentation is selective due to the multitude of existing instruments.

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Description</th>
<th>Method</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>UCSD Performance-Based Skills Assessment (UPSA)</td>
<td>Assesses multiple functional tasks in five domains: household chores, communication, finance, transportation, and planning recreational activities.</td>
<td>Performance-based</td>
<td>Patterson et al., 2001</td>
</tr>
<tr>
<td>Social Skills Performance Assessment (SSPA)</td>
<td>Assesses social and communication skills using role-play situations with the examiner. Social skills are rated in six domains: Interest/disinterest, fluency, clarity, focus, affect, and social appropriateness.</td>
<td>Performance-based</td>
<td>Patterson, Moscona, et al., 2001</td>
</tr>
<tr>
<td>Medication Management Ability Assessment (MMAA)</td>
<td>Assesses the ability to manage medication using sample pill bottles and instructions. Data recorded include pill type, number of pills taken, and whether they are taken with or without food. The total score is the sum of the correct answers to 25 questions.</td>
<td>Performance-based</td>
<td>Patterson et al., 2002</td>
</tr>
<tr>
<td>UCSD Performance-Based Skills Assessment–Brief Version (UPSA-B)</td>
<td>Assesses functional tasks in two domains: communication and finance—by using 19 items.</td>
<td>Performance-based</td>
<td>Mausbach et al., 2007</td>
</tr>
<tr>
<td>Test of Adaptive Behavior in Schizophrenia (TABS)</td>
<td>Assesses a variety of adaptive skills including shopping, working, and identifying products needed for daily functioning.</td>
<td>Performance-based</td>
<td>Velligan et al., 2007</td>
</tr>
<tr>
<td>Assessment Method</td>
<td>Description</td>
<td>Functional Form</td>
<td>Reference</td>
</tr>
<tr>
<td>------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>----------------------------</td>
</tr>
<tr>
<td><strong>Virtual Reality Functional Capacity Assessment</strong></td>
<td>A computerized virtual reality assessment that contains all the components of a shopping trip. Twelve functional abilities are assessed based on the accuracy of performance and time to complete the tasks.</td>
<td>Performance-based</td>
<td>Ruse et al., 2014</td>
</tr>
<tr>
<td><strong>Functional performance</strong></td>
<td><strong>Strauss Carpenter Scale (SCS)</strong> Assesses functional performance and encompasses 21 items divided into three domains: social situation, history, and psychiatric state.</td>
<td>Interview-based</td>
<td>Strauss &amp; Carpenter, 1972</td>
</tr>
<tr>
<td></td>
<td><strong>Social Functioning Scale (SFS)</strong> Assesses functional performance in seven domains: withdrawal/social engagement, interpersonal communication, independence-competence (the ability to perform a variety of life skills, such as shopping and washing), independence-performance (the actual performance of these skills), recreation, prosocial activities, and employment.</td>
<td>Self-questionnaire</td>
<td>Birchwood et al., 1990</td>
</tr>
<tr>
<td></td>
<td><strong>Specific Level of Functioning (SLOF)</strong> Assesses functional performance and encompasses 43 items divided into six domains: physical functioning, ability to take care of oneself, interpersonal relations, social acceptance, activities, and capacity to work.</td>
<td>Interview and performance-based</td>
<td>Schneider &amp; Struening, 1983</td>
</tr>
<tr>
<td></td>
<td><strong>Camberwell Assessment of Need (CAN)</strong> Assesses functional performance and unmet needs. The instrument comprises 22 items, divided into five domains: health, basic needs, social needs, service needs, and functioning.</td>
<td>Interview-based</td>
<td>Phelan et al., 1995</td>
</tr>
<tr>
<td></td>
<td><strong>Assessment of Communication and Interaction Skills (ACIS)</strong> Assesses social skills and is composed of 20 observational skill items divided into three domains: physicality, information exchange, and relations.</td>
<td>Performance-based</td>
<td>Forsyth et al., 1999</td>
</tr>
</tbody>
</table>

---

24
1.4.4.1 Assessment of functional capacity

Performance-based instruments of functional capacity provide several methodological advantages compared to other assessment instruments. They are, for example, less dependent on the patient’s introspective accuracy and can focus on controlling the capacity that is of importance for rehabilitation in order to live as independently as possible (McKibbin et al., 2004). The limitations of this type of instrument could be that the tasks do not always correspond to how the patient usually carries them out, which means that the test score does not always mirror the actual performance ability (Bellack, Hersen & Turner, 1978).

Functional capacity is a measure of the patient’s ability to perform tasks similar to those in the real world. These tasks are assessed in a controlled environment using structured role-play with props often found in the real world (Patterson & Mausbach, 2010). The tasks can consist of everything from combing one’s hair to more complex tasks, such as participating in social interactions or paying bills (McKibbin et al., 2004). Several scales measuring functional capacity have been developed in recent decades (Sumiyoshi & Sumiyoshi, 2015).

Performance-based instruments were first developed for use in patient groups with cognitive impairments, such as those with Alzheimer’s disease (Patterson, Goldman et al., 2001). These instruments evaluate functional behavior through role-play tasks in a controlled environment. As such, they are independent of patients’ self-awareness and do not require the presence of relatives, friends or other informants (McKibbin et al., 2004). One of the first instruments designed to measure functional capacity in older patients with schizophrenia was the University of California, San Diego, Performance-Based Skills Assessment (UPSA). The instrument encompasses five domains covering community functioning tasks critical for independent living: communicating, finance, using public transportation, household chores (preparing a shopping list), and planning recreational activities. Patients are asked to use props, such as real money or an unplugged telephone, to demonstrate how they would perform each activity in real life (Patterson, Goldman et al.,
The UPSA has been widely used in studies together with cognitive tests and is recommended by Measurement and Treatment Research to Improve Cognition in Schizophrenia-MATRICS (Nuechterlein et al., 2008). The UPSA has shown high correlations with tests measuring cognitive functioning, social and communicative skills, and personal care skills (Bowie, Reichenberg, Patterson, Heaton & Harvey, 2006; Patterson, Moscona et al., 2001). The instrument is also available in a condensed version, the UPSA-Brief (UPSA-B), which was developed through factor analysis of the original instrument. The two subscales loaded most were Finance (factor loading = 0.9) and Communication (factor loading = 0.8). The UPSA-B thus contains two of the original five domains: Finance (counting money and paying bills) and Communication, e.g., making an emergency call, rescheduling a medical appointment (Mausbach et al., 2007).

There is a total of 19 items in the UPSA-B, and by using a standardized calculation of the scores, the total score ranges from 0 to 100 (Mausbach et al., 2007). The UPSA-B is thus more portable and easier to administer than the UPSA. Another advantage of the UPSA-B is that the assessment itself takes no more than 10–15 minutes, which might be positive for both the test administrator and the patient. Certain persons with schizophrenia, for example, have difficulty keeping their attention focused for any length of time (Mausbach et al., 2007). A review by Green et al (2011) concluded that the UPSA-B correlated highly ($r = 0.5$) with neurocognitive performance. According to recent studies, the UPSA-B is one of the instruments that ought to be further used in research to measure the functional capacity of persons with psychotic illnesses in order to increase knowledge of their everyday functioning (Becattini-Oliveira, Dutra, Spenciere de Oliveira Campos, de Araujo & Charchat-Fichman, 2018; Mantovani et al., 2015; Menendez-Miranda et al., 2015).

There are also some new versions of the UPSA in progress: a computerized version of the UPSA (C-UPSA; Moore et al., 2013) and a mobile app (UPSA-M; Moore et al., 2015). The advantages of the C-UPSA compared with the traditional paper and pen version is increased portability, easier administration and scoring, reduced
examiner impact on participant performance, and a recording of participants’ verbal responses for the examiner to listen to, and score, at a later point. A pilot study of a mobile app version, the UPSA-M, shows that it has all the advantages of the C-UPSA and further increases portability. In addition, the use of the touch screen function seems to be more translatable to today’s real-world functional activities compared with paper and pen tasks (Moore et al., 2015).

1.4.4.2 Assessment of functional performance

Functional performance can be considered a measure of what a patient is actually doing in his or her daily life (Horan et al., 2010). Assessment of functional performance can be accomplished through two approaches: descriptions of functional achievements — referred to as real-world functional milestones, such as marriage, employment, and independent living — and through structured rating scales measuring functional abilities and skills (Harvey et al., 2012). Even though achieved functional milestones are important to the patients, their families, and society, using them to measure improvements is impractical due to the low rates of change. Rating scales that capture patients’ functional abilities seem to be more sensitive and they also have the potential to measure changes (Harvey et al., 2012). Assessments of functional abilities and skills measure either qualitative or quantitative data, such as the degree of independence in different household activities versus years of employment (Harvey, 2013). One of the most frequently used instruments is the Global Assessment of Functioning (GAF; Luborsky, 1962), which is a clinician-rated measure of a patient’s overall functioning. The scale contains 100 steps, where a score of 1 represents the most severe illness condition, and a score of 100 means that the person is completely free from functional disability and symptoms (American Psychiatric Association, 1994).

The Validation of Everyday Real-World Outcomes (VALERO) study (Harvey et al., 2011) suggested that the Specific Level of Functioning (SLOF) scale should be used as it provides qualitative information.
regarding functional performance. It is a multidimensional behavior assessment instrument that assesses functional abilities based on ratings by health professionals or relatives. The instrument contains skills items related to daily living, divided into six domains: physical functioning, ability to take care of oneself, interpersonal relations, social acceptance, activities, and capacity to work (Schneider & Struening, 1983).

Other assessment instruments are designed to enable health professionals to systematically rate the quality of functional performance by assessing specific skills. Here, skills refer to what a person does during actual performance and not to his or her underlying capacity. One example is the Assessment of Communication and Interaction Skills (ACIS). In this assessment, skill items such as gazes (uses eyes to communicate and interact with others), articulates (produces clear, understandable speech), and conforms (follows implicit and explicit social norms), are rated by an occupational therapist after observing the patient’s participation in social interaction (Forsyth et al., 1999).

1.5 Implications for research

Functional capacity seems to mediate the relationship between neuropsychological functioning and functional performance (Bowie et al., 2006, 2008; Ho et al., 2013; Mantovani et al., 2015). Measures of cognitive performance account for about 25% of the variance in functional performance (Fett et al., 2011), whereas gender, ethnicity, and age have traditionally been the most important demographic factors for predicting abilities in everyday functioning (Gould et al., 2012).

Many personal and environmental factors could be defined as being contributors to the discrepancy between functional capacity and functional performance in the real world. Some studies have investigated the correlation between functional capacity, measured using the UPSA-B, and personal factors such as age and illness.
activity. Above all, these studies have elucidated the correlation between functional capacity and age: The younger the patients, the higher the scores on the UPSA-B, which indicates a higher functional capacity (Mausbach et al., 2007; Gould et al., 2012). A study assessing patients aged 18–34 years ($M = 25$, $S.D. = 3.3$) with recent-onset schizophrenia found that age, even within this age group, has an impact on functional capacity (Vesterager et al., 2012). Studies have also indicated that patients’ age at illness onset may have an impact on functional capacity. However, this correlation was not significant (Mausbach et al., 2010). The assessment instrument Positive and Negative Syndrome Scale (PANSS) is often used in studies to describe patients’ symptoms of psychosis (Kay, Fiszbein & Opler, 1987). Previous studies have mainly demonstrated statistically significant correlations between UPSA-B and PANSS negative symptoms, where patients with more severe negative symptoms often score lower on the UPSA-B than those with less severe negative symptoms (Mausbach et al., 2007; Mausbach et al., 2010; Vesterager et al., 2012).

It seems as if there is still a large difference between actual everyday functioning and what patients with schizophrenia achieve based on their premorbid potential. The conceptual and empirical basis for reported everyday functioning varies, overlaps, and is influenced by environmental factors, such as cultural, socioeconomic, physical, or political considerations. It is important to clarify the interaction and impact between functioning and personally related domains, such as symptom severity, remission status, relapse, and rehospitalization (McCabe et al., 2007). Nevertheless, a great deal remains to be known about the relationship between functional outcome and patients’ environmental and personal factors (including cognitive ability, self-awareness and illness severity).

The overall purpose of this thesis is to increase knowledge about the concept of functional capacity and the way it is related to everyday functioning for adult patients with schizophrenia spectrum disorders.

The primary purpose of this thesis is to investigate a Swedish version of the UPSA-B to explore whether the instrument would be useful as an easy, quick, and effective assessment of functional capacity in
patients with schizophrenia and other psychotic illnesses. It is important to find out if the instrument is considered useful not only for clinics when planning for rehabilitation, but also for researchers who—in clinical studies—need to measure improved functioning. The aim of the first study is twofold: to further explore the psychometric properties of the UPSA-B, and to ensure that the Swedish version can be used in clinical practice and for research purposes.

A secondary purpose of this thesis is to further investigate how the levels of everyday functioning (functional capacity and functional performance) and personal factors interact and relate to each other. The aim of the second study therefore is to identify which variables of functional capacity and personal factors (e.g., age, gender, and illness activities) contribute to predicting patients’ ability to achieve functional milestones (i.e., education level, current work situation, housing situation, marital status, and social contacts).

The third and final purpose is to learn more about how observed functional capacity is related to self-awareness of functioning. More specifically, the part of self-awareness referred to as metacognitive awareness or introspective accuracy. The aim of the third study is to investigate how patients’ self-rating ability regarding functional performance relates to neurocognitive performance and real-world functional performance.
2 THE PRESENT INVESTIGATION

1.2 Introduction

In this section the aims, designs, instruments, procedures, statistics, and results of the three papers included in this thesis will be discussed. All data collected and analyzed in Paper I, Paper II and Paper III come from a broader research project carried out at the Psychiatric Department at the NU Hospital Group [NU-sjukvården] in western Sweden. The name of the project is Clinical Long-term Investigation of Psychosis in Sweden (CLIPS). It started in 2000, and data are still being collected to follow up patients with schizophrenia spectrum disorders. The aim of CLIPS is to describe each patient’s illness, functional capacity, and living situation under ordinary, naturalistic conditions. Patients participating in the project were rated annually in several domains, including demographic and function variables (e.g., age, gender, social function, capacity to work, ability to live independently) and clinical variables (e.g., psychiatric symptoms and remission status). During the period of 2000–2004, just one center collected the data. Since 2005 data has been collected from all outpatient centers in the area by local clinicians (case managers, psychologists, and occupational therapists) who have in-depth knowledge of the patient, and who are highly skilled in assessment methodology.

2.1.2 Patient population

In an average year, around 850 patients with schizophrenia spectrum disorders come into contact with the Psychiatric Department at the NU Hospital Group. Since the start of CLIPS, 509 patients have been rated on at least one occasion. Since 2007, 263 out of 389 patients available in the study have been assessed by occupational therapists (20 in total) according to the guidelines in the Swedish UPSA-B manual. Patients were excluded when data for outcome variables was missing from the same assessment session. Patients were also excluded when UPSA-B items were missing. In Paper I, 211 patients
were included, in Paper II, 235 patients were included, and in Paper III, 222 patients were included.

2.2 Paper I. Psychometric properties of a performance-based measurement of functional capacity, the UCSD performance-based skills assessment – brief version

2.2.1 Aim

The purpose of this study was to explore the psychometric properties of the UPSA-B to ensure the Swedish version was good enough to use in clinical practice and for research purposes.

2.2.2 Design

Account has been taken of the need for the degree of difficulty to be as similar as possible to the original instrument when translating and adjusting the instrument to create the Swedish version. The first part of the UPSA-B, for example, consists of tasks that require financial skills such as counting money and paying a bill. Consequently, the amount for all the counting assignments in the Swedish version include as many bills and coins as in the original instrument, and each task requires an equivalent number of steps in the calculation process.

The psychometric properties of the UPSA-B were examined by studying both its validity (concurrent and discriminant validity) and reliability (homogeneity and the result after a test-retest). The dependent variable was the total UPSA-B score. Well-established assessment instruments for measuring function, with known psychometric properties, were selected to study concurrent validity. Discriminant validity was studied by comparing UPSA-B scores for different diagnosis groups and different remission status groups.
2.2.3 Instruments

UCSD Performance-Based Skills Assessment – Brief (UPSA-B). This instrument is a shortened version of the UCSD Performance-based Skills Assessment (UPSA), which was developed to assess how persons with psychotic illnesses cope with everyday tasks. The tasks are performed in a controlled environment (Patterson, Goldman et al., 2001). The UPSA-B showed satisfying psychometric properties, predicted ability for independent living, was sensitive to changes, and only took 10–15 minutes to administer (Mausbach et al., 2007).

Strauss-Carpenter Scale (modified version). The original Strauss-Carpenter scale (Strauss and Carpenter, 1972) was modified by Lindström, Eriksson, Hellgren, von Knorring, and Eberhard (1995). The modified version includes questions related to living conditions, social contacts, ability to work, and number of days in sheltered housing. The first three questions have four fixed response alternatives each, and the exact number of days should be stated for the last two questions. Information is collected via medical notes, and from interviews with patients, relatives, and medical staff.

Positive and Negative Syndrome Scale (PANSS). The instrument is an interview and observation-based with 30 items, divided into three domains: positive symptoms (7 items), negative symptoms (7 items), and general symptoms (16 items). The scoring system uses a seven-point scale, where low ratings signify a low degree of symptom severity, and high ratings signify a high degree of symptom severity (Kay et al., 1987). Patients were interviewed by nursing staff using a Swedish translation of the Structured Clinical Interview – Positive and Negative Syndrome Scale (SCI-PANSS; Lindström, Wieselgren, & von Knorring, 1994). By using eight specific items from the PANSS (three positive symptoms, three negative symptoms, and two general symptoms), the patients who are considered to be in remission could be identified. These items were chosen because they represent the most central symptoms of schizophrenia according to DSM-IV and ICD-10. Symptom remission means that the patient has been in a stable phase for the past six months and has not had more than moderate symptoms (i.e., no more than three points out of a possible
The eight items defining remission are delusions, conceptual disorganization, hallucinatory behavior, blunted affect, passive/apathetic social withdrawal, lack of spontaneity and flow of conversation, mannerisms/posturing, and unusual thought content (Andreasen et al., 2005; Lasser et al., 2007; van Os et al., 2006).

**Global Assessment of Functioning Scale (GAF).** This instrument assesses global mental health based on mental, social, and functional capacity (Luborsky, 1962). GAF consists of two scales (one for symptoms and one for function). Each scale has 100 steps, where a score of 1 represents the most severe illness condition and a score of 100 means that the person is completely free from functional disability and symptoms, i.e. that is, not only free from mental dysfunction (American Psychiatric Association, 1994). In the present study, only scores from the scale measuring function are used.

**Specific Level of Functioning Assessment Scale (SLOF).** This instrument was developed by Schneider and Struening (1983) and was used to describe the observable roles and functions of patients. The instrument is a rating scale that can be filled out by the patient, a case manager, or a relative. The instrument consists of 43 statements within the following domains: physical functioning, ability to take care of oneself, interpersonal relations, social acceptance, activities, and capacity to work. The statements are assessed on a five-point scale, where high scores signify that the patient can cope more independently, and low scores signify that the patient is more dependent on help. The reliability of the instrument has been tested via a homogeneity test that showed acceptable values (from 0.59 to 0.83; Schneider and Struening, 1983). In the present study, both the patient's case manager and a relative filled out the questionnaire.

**Assessment of Communication and Interaction Skills (ACIS).** This is an observational instrument rating a person's communication and interaction skills with other persons in some form of activity or social interaction. The Swedish version of the ACIS has been tested and been shown to have good validity and reliability (Kjellberg, Haglund, Forsyth & Kielhofner, 2003). The role assumed by the individual, and the environment in which the interaction takes place,
are two of the things that affect communication and interaction skills. In the present study, the assessment situation was a dyadic interaction between the patient and the occupational therapist, where the patient was asked to describe an ordinary day. The occupational therapist participated in the conversation by asking follow-up questions to simulate an everyday conversational situation.

2.2.4 Procedure

Data were collected within the framework of the CLIPS. Within the project, clinicians assessed patients each year to evaluate, for example, mental status, psychiatric symptoms, side effects, social functioning, satisfaction with care provision, and quality of life. In addition, the patient was offered an opportunity to see an occupational therapist for further examination using the UPSA-B. A total of 211 patients were assessed using the UPSA-B, 80 of whom were reassessed using the same instrument after approximately one year.

2.2.5 Statistics

In order to explore the psychometric properties of the Swedish version of the UPSA-B, the concurrent validity was examined by correlating (Pearson’s $r$) UPSA-B scores and the measuring instruments Strauss-Carpenter, GAF, SLOF health care staff, SLOF relatives, and ACIS. The discriminant validity was examined using a one-way ANOVA with the UPSA-B score.

2.2.6 Ethics

The CLIPS research project was approved by the Ethical Research Committee at the University of Gothenburg, Sweden (Approval
numbers Ö537-99, 507-04, 438-10, 423-14), and the investigation was carried out in accordance with the latest version of the Declaration of Helsinki.

Participants were given verbal and written information about the study, contents, and purpose. They were also informed that they could withdraw from the study without explanation. All participants provided signed informed consent. To assure participant confidentiality, the data were stored securely at the research unit at the Psychiatric Department at the NU Hospital Group in Sweden.

2.2.7 Results

The results indicate that the Swedish version of the UPSA-B is a reliable instrument with good psychometric properties relating both validity and reliability. The concurrent validity, examined by comparing UPSA-B scores with other instruments measuring functioning, showed significant correlations with acceptable \( r \)-values: GAF \((r = 0.30, p = 0.01)\); ACIS \((r = 0.37, p = 0.01)\); SLOF by health professionals \((r = 0.41, p = 0.01)\); and SLOF by relatives \((r = 0.50, p = 0.01)\). The results also show significant correlations \((r = 0.25 \text{ to } 0.27, p = 0.01)\) between the total score on the UPSA-B and housing, ability to work, and social contacts, as measured using the Strauss-Carpenter scale. The discriminant validity was examined with the aid of UPSA-B scores and patients’ remission status. The analysis showed a significant difference, where patients in remission had a higher mean value on the UPSA-B. The discriminant validity was also studied by comparing the three different diagnostic groups; schizophrenia, schizoaffective disorder and delusional disorder. The analysis revealed a significant difference, where patients diagnosed with schizophrenia had a lower mean score on the UPSA-B compared to patients diagnosed with schizoaffective disorder. The reliability test for the UPSA-B showed significant test–retest correlations, and the homogeneity test showed acceptable values.
Since there was an uneven gender distribution (a larger proportion of men in the schizophrenia group, 75% compared to 40% in the schizoaffective disorder group), a number of separate, non-published analyses was carried out. An independent t-test for each of the diagnostic groups was conducted to compare UPSA-B scores. There were no significant differences in scores between males and females in any of the diagnosis groups. To further examine gender differences, a chi-square test for independence (with Yates Continuity Correlation) indicated that there was no significant association between males and females in any of the 19 UPSA-B tasks. The results from gender analyses were not included in the published study (Paper I).

2.3 Paper II. Predicting real-world functional milestones in schizophrenia

2.3.1 Aim

The aim of this study was to identify which variables of demography and illness activity, together with functional capacity, predict patients’ ability to achieve real-world functional milestones. The aim was also to investigate how these variables contribute to explaining the five functional milestones: Education level, Current work situation, Housing situation, Marital status, and Social contacts.

2.3.2 Design

The study had achieved real-world functional milestones as independent variables. The dependent variables in this study consisted of outcomes from different measures, rating scales, and questionnaires used to collect data about patients’ demographic, illness activity, and functional capacity variables. Information about these variables was collected by trained clinicians with considerable knowledge of the patient. They used performance-based measures, as
well as information from medical records, and interviews with patients, relatives, and clinicians.

2.3.3 Instruments

**Strauss-Carpenter (modified version)**. Three items from the Strauss-Carpenter scale (Strauss & Carpenter, 1972) were used to assess real-world functional milestones. The chosen items, and three response alternatives, were Current work situation (sickness benefit/unemployed, part-time job, or full-time job), Housing situation (sheltered housing, living with parents, or independent housing), and Social contacts (infrequent contact with others, contact with others once a week, or contact with others more than once a week). Other items included were Education level (primary, secondary, or higher education) and Marital status (single, separated, or married/cohabiting; Helldin, Kane, Karilampi, Norlander & Archer, 2007). Information was collected via medical records and from interviews with patients, relatives, and clinicians.

**Positive and Negative Syndrome Scale (PANSS)**. This instrument was also used in Paper I. For further details regarding PANSS and remission, see section 2.2.3.

**UCSD Performance-Based Skills Assessment – Brief (UPSA-B)**. This instrument was also used in Paper I. See section 2.2.3 for more detailed information regarding the UPSA-B. The total score for the 19 UPSA-B items ranges from 0 to 100, and a standardized calculation of the scores is used.

2.3.4 Procedure

Data collection took place within the CLIPS research project. See section 2.2.4 for further details about the collection of data as this procedure coincides with the procedure followed in Paper I. The
assessments of demographic and illness activity variables were administered by a case manager skilled in assessment methodology and with knowledge of the patient. An occupational therapist measured the patient’s functional capacity.

### 2.3.5 Statistics

The analysis was conducted in two steps. In the first step, the covariance between each of the five functional milestones (Education level, Current work situation, Housing situation, Marital status, and Social contacts) and the independent variables (demographics, illness activity, and functional capacity) were analyzed. The Chi-Square test ($\chi^2$) and the Kruskal-Wallis test (H) with multiple comparison tests were used to analyze differences in demographic and clinical variables between independent categories of functional milestones. Correlations between continuous variables were determined using Spearman’s rho. In the second step, ordinal logistic regression analyses were carried out to predict the association between the demographic, illness activity, and functional capacity variables and each of the five functional milestones. Only the variables that in the previous step showed significant results (correlations or significant group differences) for each of the functional milestones were included in the ordinal regression analysis. The results are presented as odds ratios and with 95% confidence intervals.

### 2.3.6 Ethics

The ethical considerations in this study are the same as in Paper I; see section 2.2.6 for more detailed information.
2.3.7 Results

The analysis showed significant group differences for several of the functional milestones. Differences were found between the lower and higher levels of functioning. The results also highlighted the fact that the functional milestones were associated in different ways with the patients’ demographics, illness activity, and functional capacity. Level of education was associated with age and functional capacity. Younger patients with a higher UPSA-B score had reached a higher level of education. Housing situation was associated with gender, general symptoms, and functional capacity. Male patients, patients with more severe symptoms, and patients with a lower UPSA-B score, lived in supported housing to a greater degree. Marital status was associated with gender, age, and positive symptoms. Male patients were more often single, and patients who were single had a lower mean age and more severe positive symptoms compared with those who were married or separated. Frequency of social contact was associated with age and negative symptoms. Patients who had more contact with other people and who met friends and/or families more than once a week, had a lower mean age and less severe negative symptoms. These findings show that dividing real-world functioning into separate domains offers advantages, and should be preferable to combined global functioning scores.

2.4 Paper III. Overestimated function in patients with schizophrenia: a possible risk factor for inadequate support?

2.4.1 Aim

The aim of this study was to investigate how patients’ self-rating ability regarding functional performance relates to neurocognitive performance and real-world functional performance.
2.4.2 Design

The study was conducted in three steps. In the first step, we divided the 222 patients into four groups based on their self-rating ability, i.e. on their UPSA-B results and their self-rated functioning.

The four groups were called Unimpaired function-ae, Underestimators-uf, Overestimators-if and Impaired function-ae (see Figure 3). The cut-off percentage for inclusion of a group for further analysis was set at a minimum of 10% of the 222 participants.

To investigate the patients’ self-rating ability with regard to functional performance, they answered four short questions before the UPSA-B was administered. The questions were based on tasks included in the UPSA-B: Can you manage everyday tasks such as 1) counting money, 2) paying bills, 3) making phone calls, and 4) rescheduling appointments? Each ‘Yes’ answer carried 1 point, and the total for self-rated function ranged from 0–4 points.

<table>
<thead>
<tr>
<th>Functional capacity</th>
<th>Self-reported function</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Underestimators-Unimpaired function</strong></td>
<td></td>
</tr>
<tr>
<td>UPSA-B, 16–19 points</td>
<td></td>
</tr>
<tr>
<td>Self-rated function, 0–3 points</td>
<td></td>
</tr>
<tr>
<td><strong>Unimpaired function-Accurate estimators</strong></td>
<td></td>
</tr>
<tr>
<td>UPSA-B, 16–19 points</td>
<td></td>
</tr>
<tr>
<td>Self-rated function, 4 points</td>
<td></td>
</tr>
<tr>
<td><strong>Impaired function-Accurate estimators</strong></td>
<td></td>
</tr>
<tr>
<td>UPSA-B, 0–15 points</td>
<td></td>
</tr>
<tr>
<td>Self-rated function, 0–3 points</td>
<td></td>
</tr>
<tr>
<td><strong>Overestimators-Impaired function</strong></td>
<td></td>
</tr>
<tr>
<td>UPSA-B, 0–15 points</td>
<td></td>
</tr>
<tr>
<td>Self-rated function, 4 points</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 3. A model of the study groups’ self-awareness, divided according to functional capacity and self-reported functioning.*
In the second step, the performance-based assessment of neurocognitive abilities was compared between the groups. Analyses were made between unimpaired and impaired function, and between accurate and non-accurate estimators. In a third step, the groups’ differences and similarities regarding real-world functional performance were examined using the SLOF scale.

### 2.4.3 Instruments

**UCSD Performance-Based Skills Assessment – Brief (UPSA-B).** This instrument was also used in Paper I and Paper II; see section 2.2.3 for more detailed information regarding the UPSA-B. The total UPSA-B score ranges from 0 to 19, with a higher score signifying better functional performance. In the present study, a cut-off level for ordinary function was set at 16 points; hence 16-19 points is presented as unimpaired functional capacity, and 0-15 points as impaired functional capacity.

**Neuropsychological tests.** The patients included in the CLIPS research project were assessed using a semi-computerized neuropsychological test battery. It consists of seven well-known neuropsychological tests, six of which measure aspects of cognition known to be reduced during the time of the illness, and one of which estimates the participant’s premorbid level of functioning. This battery was constructed for use in the CLIPS, with support from Michael F. Green, Philip D. Harvey and Håkan Nyman. It contains almost the same cognitive domains measured in, for example, the well-known MATRICS Consensus Battery (Nuechterlein et al., 2008).

**Continuous Performance Test-Identical Pairs (CPT-IP 450).** CPTs are a family of neuropsychological measures originally developed to assess sustained attention and vigilance (Rosvold, Mirsky, Sarason, Bransome & Beck, 1956). The CPT-IP is a computerized version, with a visual stimulus, in the form of a four-digit number displayed on the screen at a constant rate of one per second and with a 50-millisecond onset interval. When the same stimulus appears twice in a row (an
identical pair) on the screen, the participants were instructed to respond as quickly as possible by lifting a finger from the mouse button. The test is constructed in three equal-sized sequences, each with 150 trials, given in one session (Cornblatt, Risch, Faris, Friedman & Erlenmeyer-Kimling, 1988). In the present study, the total $d'$ prime score (which is calculated as the participant’s ability to discriminate targets from non-targets) for the 450 trial was used as a measure of vigilance. A higher $d'$ score indicates better performance.

**Trail Making Test A (TMT-A) and B (TMT-B).** The Trail Making Test was originally part of the Army Individual Test Battery and was subsequently incorporated into the Halstead-Reitan Battery (Reitan & Wolfson, 1985). TMT is commonly used to assess motor processing skills, complex visual scanning, and cognitive flexibility. The test is highly sensitive to attentional and executive impairments (Laere, Tee & Tang, 2018). Processing speed is assessed using TMT-A, and the participants are required to connect an ascending series of 25 randomly distributed circles containing numbers. Cognitive flexibility is assessed using TMT-B, where the participants are required to alternate between two sets, numbers and letters (i.e., 1-A-2-B-3, etc.), and the same number of circles on a separate worksheet. The goal is to connect the circles as quickly as possible by drawing a line between them, without lifting the pencil from the paper. TMT-B is significantly more difficult compared with TMT-A (Drane, Yuspeh, Huthwaite & Klingler, 2002). In the present study, the test results are presented as time to completion in seconds. Lower scores represent better performance.

**Rey Auditory Verbal Learning Test (RAVLT).** Commonly used for evaluating verbal learning and episodic memory, including proactive and retroactive inhibition, retention, encoding versus retrieval, and subjective organization (Schmidt, 2004). RAVLT measures immediate memory span, provides a learning curve, reveals learning strategies, and elicits interference tendencies and indications of confusion or confabulation in memory tasks. The test consists of a 15-item word list that is presented five times (trials 1-5), always in the same order, with an assessment of recall immediately after each presentation. After the five trials had been completed, a new list of different words
was presented in the same way as before. Likewise, a free recall trial would immediately follow for all the words in the new list. Immediately after, the participants were asked to freely recall the first list of words (trial 6). Finally, a delayed recall test is presented after 20 minutes, where the participant was again asked to freely recall the list of words (trial 7). The number of words remembered for each condition constituted the test score. In the present study, we used the number of words correctly recalled after trial 1 (RAVLT 1) as an indication of immediate verbal memory, the number of words correctly recalled in trial 1 to trial 5 (RAVLT 1-5) as an indication of learning, and the number of words correctly recalled after 20 minutes (RAVLT 7) as an indication of retention memory. Higher scores indicate better performance.

**Letter Number Sequencing (LNS) a supplementary subtest in the Wechsler Adult Intelligence Scale – Third edition.** The test requires the participants to listen to a scrambled list of letters and numbers read to them by the administrator, and then repeat back the numbers in ascending order, followed by the letters alphabetically. The combination is presented in increasing order of difficulty (Gold, Carpenter, Randolph, Goldberg & Weinberger, 1997). The participants can either pass or fail each item. The number of correct recalls in 21 items was used in the present study to measure auditory working memory.

**Vocabulary, a subtest from Wechsler Adult Intelligence Scale - Revised.** This verbal subtest is a test of language skills and includes questions about the meaning of words (e.g., what does winter mean?) It captures language processes such as the ability to acquire, recall, and express word meaning. The test measures recollection of knowledge, i.e. crystallized intelligence, and has been identified as the single best measure of both verbal and general mental abilities (Lezak 1995). The subject is asked the meaning of 40 words, arranged in order of difficulty, and their explanation is given a score of 2, 1 or 0 points. The test is discontinued after five consecutive failures, with responses scored as zero (Wechsler 1981). The total test score, where better vocabulary is indicated by a higher test score, is used in this study as an estimate of premorbid cognitive functioning.
**Wisconsin Card Sorting Test (WCST).** The WCST is one of the most widely used neurocognitive measures to evaluate executive function. It was developed in 1948 to measure perseveration, set shifting, and abstract thinking. The WCST has been employed increasingly as a clinical neuropsychological instrument. The test consists of three factors: perseveration, failure to maintain set, and idiosyncratic sorting. There are different versions of the WCST, e.g. with 64 or 128 cards, and the test can be performed on a computer or manually using cards. (Heaton, Chelune, Talley, Kay & Curtiss, 1993). An increased number of perseverative errors have been associated with frontal lobe dysfunction. When performing the WCST, the participant is presented with four reference cards and one response card. When performing the task, participants need to match response cards to reference cards according to three possible rules: color, number, or shape. The sorting rules are not given to the participants - they are simply instructed to match each response card from the deck with one of the reference cards by pressing a computer key. A message on the screen tells the participant whether each response is right or wrong. Initially unaware of the correct rule, participants sort the cards randomly or formulate a hypothesis for sorting and test it by trial and error. Once the participant has made a specified number of consecutive correct matches to the initial sorting principle, the sorting principle is changed without warning (Heaton et al., 1993). The computer program calculates the test scores. In the present study (the computerized version with 128 response cards) the number of completed categories was used as a measure of executive functioning.

**Specific Level of Functioning Assessment Scale (SLOF).** This instrument was also used in **Paper I**. For further details regarding SLOF, see section 2.2.3.

### 2.4.4 Procedure

Data collection took place within CLIPS research project in Sweden. See section 2.2.4 for further details about the collection of data, as this
procedure is the same as for data collection in Paper I. Just before the UPSA-B was administered, the same occupational therapist interviewed the patients about their functioning with the aid of four short questions. The neuropsychological tests were administered by a psychologist and real-world functioning, measured using SLOF, was administered by a case manager who had knowledge of the patient and who was also skilled in assessment methodology.

2.4.5 Statistics

A descriptive analysis of the variables included was performed using mean ($M$) and standard deviation ($S.D.$). Comparisons were conducted using the Kruskal-Wallis ($H$) test. Stepwise discriminant analyses were performed to test how well the cognitive domains and SLOF domains differentiated the functional groups. Significance was determined at the 0.05 level.

2.4.6 Ethics

The ethics considerations in this study are the same as in Paper I. See section 2.2.6 for more detailed information.

2.4.7 Results

The underestimators-uf group was excluded due to the low number of patients with this profile. To achieve two comparable impaired functional capacity groups (overestimators-if and impaired function-ae), the patients were matched according to UPSA-B scores, age, and gender. The analysis showed that patients with impaired functional capacity perform at a similar cognitive level, regardless of their self-rating of their functioning. A comparison between the unimpaired function group and the two impaired function groups (accurate
estimators and over-estimators) revealed differences in two cognitive domains: premorbid functioning and executive functioning. Patients with impaired functional capacity had a poorer premorbid functioning and more impaired executive functioning. According to the Specific Levels of Functioning Scale (SLOF), there were statistically significant differences across the three groups in all domains except social acceptability. The difference between the impaired function-ae group and the unimpaired function-ae group was also statistically significant. Patients with unimpaired function had a higher SLOF score. The SLOF domains: activities, physical functioning, and interpersonal relationships – correctly classified the outcome in 75% of cases. The results also reveal that clinicians seem to have greater difficulty assessing function for patients who over-estimate their functioning. Consequently, when clinicians assessed the patients using SLOF there were no significant differences between patients with unimpaired functional capacity and patients who overestimate their function.
3 GENERAL DISCUSSION

This thesis states that using UPSA-B to measure functional capacity has advantages and plays an important role in capturing functional outcomes. The main purpose was to increase knowledge of the concept of functional capacity and its relationship to everyday functioning in a large, naturalistic sample of adult patients with schizophrenia spectrum disorders. In Paper I, the psychometric properties of the Swedish version of the UPSA-B were examined, and in Paper II the functional capacity, together with personal factors associated with real-world functional milestones, was studied. In Paper III, the patients’ self-rating ability with regard to functional performance and how this is related to cognitive performance was investigated.

To summarize, the findings from the present studies indicate that the Swedish UPSA-B version is a reliable instrument, comparable with the original version, and with good psychometric properties in terms of both validity and reliability. The analysis also revealed that there were no gender differences, neither in the total score nor at the item level (Paper I). The findings also indicate that patients’ personal factors, such as demographics and illness activity, together with functional capacity and environmental factors, are associated with different functional milestones in different ways (Paper II). The challenges of using several sources, both questions and observations, to capture the complexity of functioning is particularly important since several patients with schizophrenia have impaired self-rating ability (Paper III). These results support and contribute to the ongoing effort to create a gold standard for measuring functioning in patients with schizophrenia. The Swedish version of UPSA-B is a valuable instrument that could be used in clinical practice as well as in future cross-national studies. The significant association between functional capacity and cognitive performance, as well as its ability to predict certain aspects of functional performance, has made the UPSA-B one of the most widely used instrument in this field.
Several methods are used to measure functional outcome in the struggle to capture a true picture of the patient’s real-life situation. To measure functional performance, i.e. the patients’ ability in real life, data is often based on observation and interviews. Although observations of functional performance in the patients’ regular life contexts is considered to be one of the best methods (Hamera & Brown, 2000; Gioia & Brekke, 2009), the second-best alternative could be to observe the patient using a performance-based measure (Patterson et al., 2001; Mausbach et al., 2007). This method is not as dependent on the patients’ self-awareness. According to Harvey and Pinkham (2015), accurate information can also be collected by health professionals who have regular contact with the patients. To ensure the collection of information is as reliable as possible, the data in all the papers were obtained in the patients’ normal out-patient setting by their regular clinicians through the use of rating scales.

3.1 The relationship between two levels of functional outcome: functional performance and functional capacity

Efforts to assess everyday functioning in schizophrenia have progressed substantially in recent years. Functional performance and functional capacity measure different levels of everyday functioning and have been remarkably consistent, with only modest correlations across different samples of patients with schizophrenia (Bowie et al., 2008; Bowie et al., 2010; Gupta, Bassett, Iftene & Bowie, 2012; Keefe, Poe, Walker & Harvey, 2006; Leifker, Patterson, Bowie, Mausbach & Harvey, 2010; Mendendez-Mirana et al., 2015). According to the PEO model (Law et al., 1996), functional performance reveals patients’ abilities when carrying out real-life activities and takes place in the complex and dynamic relationships between personal factors, environmental factors, and everyday activities. However, functional capacity emerges mainly in the interaction between personal factors and tasks. These tasks are performed and assessed in a laboratory setting with minimal influence from environmental factors. Mendendez-Mirana et al. (2015) showed that functional capacity and functional performance explain 17% of each other’s variance.
Similarly, the results in **Paper I** reveal acceptable \( r \)-values, with a range of approximately 0.2 to 0.5 between the total score on the UPSA-B and the total score for the other instruments used to measure functional performance.

### 3.1.1 UPSA-B as a predictor of real-life functional milestones

It would seem that different personal factors predict functional outcome, and that functional capacity and functional performance contribute differently. In **Paper II**, we decided to examine the association between patients’ personal factors and achieved functional milestones. The personal factors chosen were demographic and illness activity variables together with functional capacity measured using UPSA-B. The aim was to identify factors predicting functional performance related to achieved real-world functional milestones, and to identify the specific variables that contribute to the prediction of each of the different milestones.

The results in **Paper II** show that patients’ functional capacity was primarily associated with education level and housing situation. These findings are well in line with previous results (Gould et al., 2012; Mausbach et al., 2007; Mausbach et al., 2008; McIntosh et al., 2011). Younger patients manage to achieve a higher level of functioning in education level, marital status, and social contacts. The demographic variable age, correlated with all functional milestones except current work situation. Palmer et al. (2002) also stated that age has an impact on how patients with schizophrenia engage in daily occupations, and that disabilities increase with age. We also found that women needed less support with regard to housing, and they achieved a higher marital status level compared to men. However, none of the predictors were significantly associated with current work situation: 27 patients work part-time or full-time, whereas 208 patients are on sickness benefit or are unemployed. This could be seen as a result of environmental factors due to high unemployment rates and the health insurance system in Sweden, which permits early retirement.
The analyses made using Kruskal Wallis tests, with functional milestones as independent variables, showed differences in several demographic and illness activity variables. The social contacts milestone, for example showed significant differences in age, duration of illness, positive, negative, and general symptoms, remission status during the past three years, and functional capacity. The regression analyses revealed that only age and negative symptoms could be regarded as predictors for the level of social contacts (Figure 4).

Figure 4 presents results from Paper II, which were conducted in two steps. Variables with significant differences are listed in black. From the second step, the grey lines show which variables were significantly associated predictors of real-world functional milestones in regression analyses.

These findings support the need, when assessing patients with schizophrenia, to evaluate the different levels of functional outcome, functional performance (e.g. achieved real-world functional milestones), and functional capacity. They also highlight the existence of different factors underlying each functional milestone. The results in Paper II support the suggestion put forward by Harvey (2013), that real-world functional performance should be measured using clearly differentiated scales for social, vocational, and residential functioning.

The results in Paper II also indicate that some of the real-world functional milestones are more associated with and sensitive to environmental support and access to resources in society. Due to the patients’ impaired functioning, they suffer more when faced with
obstacles and problems in society. Likewise, as pointed out earlier, current work situation is dependent on the unemployment rate, and education level is dependent on the availability of education and the costs for the individual and her/his family. These results support earlier studies that compare patients from different countries and cultures. They also show that there are major differences in how patients manage to achieve desired and expected life goals (Harvey et al., 2009; Helldin et al., 2012). In Paper II, functional capacity also predicts the housing situation, a milestone that is also dependent on residential environment and societal resources. Housing situation is dependent on the availability of sheltered accommodation and the support required to live independently. These results highlight the situation in which societal influences may lead to false positive or false negative results in the outcome of functional measures. Even with similar symptoms and similar functional and cognitive abilities, patients may have full-time employment in one country and be unemployed in another due to a higher level of unemployment. Similarly, the lack of sheltered housing forces patients with severe disabilities to live independently, and these patients would consequently be recorded with a false positive result when everyday functioning is reported.

Bowie et al., (2008) presented a study that used cognitive and symptom domains, together with functional capacity, as direct and indirect predictors of real-world functional performance. Some of the SLOF domains were used as the criterion variables, and the result showed, for example, that the activity domain was directly predicted by social skills, functional capacity and the severity of positive symptoms. Processing speed predicted activities directly and indirectly through its effects on both social skills and functional capacity. Attention/working memory, verbal memory and executive functioning influenced activities through their relationship with functional capacity. Both Bowie et al. (2008) and Paper II measure functional outcome for the functional performance level, but using different assessments. In Paper II, the patients’ achieved real-life functional milestones are used as criterion variables. Although they measure different levels of functioning, they both show that symptom domains and functional capacity associate differently depending on
the selected milestone or the functioning domain. The results in **Paper II** showed that functional capacity predicted milestones such as education level and housing situation but not marital status, social contacts or current work situation. In the study by Bowie et al. (2008), functional capacity predicted work skills and activities but not interpersonal relationships. One conclusion is that social milestones, such as marital status and social contacts, may be more dependent on the patient’s own resources. Hence, these milestones may be better predicted using assessment instruments such as Social Skills Performance Assessment-SSPA (Patterson, Moscona et al., 2001) and Assessment of Communication and Interaction Skills-ACIS (Forsyth et al., 1999).

### 3.1.2 UPSA-B as a predictor of functional performance assessed using SLOF

UPSA-B has been used in several studies together with the SLOF assessment scale (Gould et al., 2012; Harvey et al., 2009; Mausbach et al., 2010). The study by Mausbach et al. (2010) showed significant correlations, with *r*-values ranging from approximately 0.3 to approximately 0.6 between the UPSA-B total score and the SLOF domains (i.e. personal care skills, social acceptability, activities, and work skills). **Paper I** also showed significant correlations between the UPSA-B and SLOF total scores: *r* = 0.4 when SLOF was assessed by a health professional, and *r* = 0.5 when assessed by a relative. These results show that UPSA-B and SLOF assess areas that are close to each other on the scale of everyday functioning. The results also indicate that both health professionals and relatives who have rated patients' function using SLOF have considerable knowledge of the patients' functional performance. Nevertheless, the results in **Paper III** indicate that clinicians tend to consider patients who overestimate their performance to achieve a higher level of functioning, comparable with patients who had an unimpaired functional capacity. Consequently, when clinicians assessed patients using SLOF, no significant differences were found between the group with unimpaired functional capacity and the group with patients who
overestimate an impaired function. This was found despite the fact that clinicians had good knowledge of their patients, and it indicates that the clinicians’ assessments were largely based on patient self-reports. These results show that future analyses between UPSA-B and SLOF would benefit by taking control of the effect of impaired self-awareness and decreased self-rating ability.

In Paper I, when SLOF was assessed by a relative the results do not support a study by Sabbag et al. (2011), who found a similar correlation when SLOF was assessed by a health professional, but not when the rating was done by a friend/relative (Paper I $r = 0.5$, $p = 0.01$, compared to $r = 0.1$, n. s.). The sample size in the two studies, and the fact that all the patients are receiving treatment through the outpatient service, do not explain the differences. The only difference that could be noticed is that Sabbag et al. (2011) only use a total score from three of the six SLOF domains. The patients in Paper I are about ten years older on average, and they have a slightly higher UPSA-B score. The studies might indicate some cultural differences regarding the view held by a relative, or that data in Paper I are collected from friends or relatives with closer contact, such as a caregiver role. It is relevant to take the divergent results of these two studies into consideration for future research and in the discussion about reliable methods of collecting data related to functional outcome.

Understanding the factors predicting the discrepancy between what one could do (capacity) and what one actually does (performance) is a critical step in the process of helping patients with schizophrenia move toward increased everyday functioning. As it is most likely that functional performance is influenced by a host of factors in addition to ability, it should be considered in the light of its complexity and thus be assessed carefully.
3.2 Self-awareness and functional outcome

Numerous studies have shown that patients with schizophrenia are poor at judging their everyday functioning. Awareness of one’s psychiatric symptoms and level of functioning has been linked to higher rates of depression and more impaired cognition (Bowie et al., 2007; Ermel et al., 2017; Siu et al., 2015). Previous studies have shown divergent results, mostly with low or non-existing correlations between the patients’ reports of their everyday functioning and the clinicians’ performance-based measures (Bowie et al., 2007). Only a few other studies report a similar result as in Paper III, with about 50% accurate estimators (Gould et al., 2015; Siberstein et al., 2018). One possible explanation for the divergent results is that the instruments used to capture self-awareness have made different demands on the patient’s ability to understand the statements and evaluate their capacity.

The Wisconsin Card Sorting Test (WCST) is one of the most used measures of executive functioning in the literature on schizophrenia (Heaton et al., 1993). Patients are required to solve the tasks in the test through performance feedback, to retain the strategy when responses are correct, and to discard the strategy when the responses are incorrect. In the Dynamic Comprehensive Model of Awareness (Toglia & Kirk, 2000), these kinds of tasks require on-line awareness, which is activated within tasks and situations. Self-evaluating experiences and answering questions about one’s functioning through interviews or self-rating assessments require a metacognitive knowledge of one’s abilities. Metacognitive knowledge exists prior to an actual task or situation. It consists of self-understanding of one’s capabilities and limitations, as well declarative knowledge (facts and events) that are stored in one’s long-term memory (Toglia & Kirk, 2000). Paper III includes a brief interview in which patients were asked to answer ‘Yes’ or ‘No’ to short questions about if they are able to handle four different daily activities. This kind of questionnaire is probably less demanding for the patients compared with other self-awareness assessment instruments, such as SLOF, which has 43 items that need to be assessed on a 5-point Likert scale (Bowie et al., 2006). The latter probably demands a higher level of, for instance, attention
and introspective abilities. The results from Paper III confirm the importance and difficulty of producing objective and valid reports in the field of functional outcomes. To capture the complexity of functional outcomes, multiple measures may be required. However, it could be discussed in terms of validity, which should be preferable—a short and easy instrument with a risk of missing information, or a longer and more complete instrument that encompasses more of the concept.

3.3 Psychometric properties, translation, and adaptation of UPSA-B

Beyond the psychometric properties of a test, it is important to take in consideration the practical application, i.e. how people perform in real-world settings. Ecological validity refers to the extent to which the test score relates to observation of naturally occurring behavior. This is an important and often neglected aspect of laboratory-based testing such as neuropsychological and functioning testing (Chaytor & Schmitter-Edgecombe, 2003; Gioia & Brekke, 2009). A performance-based measure that evaluates the patients by observing their behaviors in the real world, is supposed to show the best ecological validity (Bromley, Mikesell, Mates, Smith & Brekke, 2012). UPSA-B was designed in the United States to measure performance in a number of domains of everyday activities for older, severely mentally ill outpatients with schizophrenia (Mausbach et al., 2007). It was important to take into consideration where and for whom the original instrument was developed as a part of a translation process. Variations in cultural and education background of subjects from different countries may impede translation during the validation process. Cultural adaptation is therefore an essential part of the cross-cultural validation of the instrument, and it should have been considered in the case of large countries with regional cultural variation (Harvey et al., 2011; Velligan et al., 2012). Consequently, even if the demands of everyday life, and the skills required to meet them, seem similar in several Western countries, cultural adaptation is an essential part of the translation and validation process.
In **Paper I**, the translation and adaptation procedure is described and the psychometric properties of the Swedish version of UPSA-B are examined. The results show that the Swedish version of UPSA-B is a reliable instrument with good psychometric properties in terms of both validity and reliability. The manual was easy to adapt to Swedish conditions as UPSA-B tasks are relevant and similar to the ones performed in ordinary everyday activities. However, the manner in which the tasks are supposed to be performed in UPSA-B does not always reflect how the tasks are performed in today's technology-driven world. At present, most people pay their bills online instead of using a bank transfer form (a check in the original instrument). Even so, the information about patients' ability to fill out a form is useful. This could be corrected partially with the aid of new computer-based versions (Moore et al., 2013 and UPSA-M; Moore et al., 2015).

Another issue is that bills and coins have generally been replaced by new ones. The similarity with real money thus disappears as the UPSA-B tasks still use the now invalid bills and coins.

In studies from different countries, the results of the UPSA-B mean value vary from 67.6 to 77.5 points when patients in dependent residential living and patients from China were excluded (see Table 2). The result in **Paper I**, where the patients’ mean UPSA-B value was 69.8, is considered a good, equivalent result. Hence, the instrument is useful and comparable in cross-country studies. In China, both patients with severe mental illness and healthy controls had lower UPSA-B scores compared to reports from other countries' samples. It is assumed that the reason why the mean value is lower for the Chinese population is the lower level of education. Individuals with very low levels of education who live in developing countries perhaps do not use telephones or bank accounts as often (McIntosh et al., 2011). Low results could probably be expected since they are supposed to manage tasks in test situations that they never or very seldom did before in real life. This is a challenge when developing, translating, and cross-culturally adapting everyday functioning assessments. The possible influences of cultural or socio-economic backgrounds need to be taken into consideration.
To date, several studies have presented data for healthy controls (Garcia-Portilla et al., 2014; Leifker et al., 2010; Mantovani et al., 2015; McIntosh et al., 2011; Sumiyoshi et al., 2014). According to these reports, the total UPSA-B scores range from 60 to 89 points for healthy controls. To score 80 points on UPSA-B, you need to correctly manage 17 out of 19 tasks.

UPSA-B shows good psychometric properties in the different versions. In addition to an English version (Mausbach et al., 2007) the instrument has been adapted to Brazil (Mantovani et al., 2015), China (McIntosh et al., 2011), Denmark (Vesterager et al., 2012), India (Velligan et al., 2014), Japan (Sumiyoshi et al., 2014), Spain (Garcia-Portilla et al., 2014) and Sweden (Paper I). The convergent validity has shown moderate to strong correlations between UPSA-B and cognitive test batteries, such as Measurement and Treatment Research to Improve in Schizophrenia Consensus Cognitive Battery ($r = 0.35$; Sumiyoshi et al., 2014) and the Brief Assessment of Cognition in Schizophrenia ($r = 0.74$; Sumiyoshi et al., 2016). The Wechsler Adult Intelligence Scale (WAIS-III) correlation value with the financial domain was $r = 0.58$ and 0.61 with the communication domain (Kim et al., 2017). In Paper III, the cognitive tests; RAVLT, CPT-IP, TMT (A+B), LNS, Vocabulary subtest WAIS and WCST were used to compare cognitive differences between impaired and unimpaired functional capacity. The results showed group differences in several cognitive domains except for retention memory (RAVLT 7) and working memory (LNS). A stepwise discriminant analysis showed that premorbid functioning (WAIS vocabulary) and executive function (WCST, categories complete) significantly predicted functional capacity.

Although there is a correlation with both everyday functioning and neuropsychological test performance, UPSA-B still has some limitations regarding ecological validity. There is probably a need for several different types of assessment to capture the complexity of current everyday tasks that are important to independent living.
<table>
<thead>
<tr>
<th>Country</th>
<th>Sample</th>
<th>UPSA-B M/S.D.</th>
<th>Age M/S.D.</th>
<th>Psychometric properties of UPSA-B</th>
<th>Supporting articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>99 (indep.-liv)</td>
<td>72.5/18.8</td>
<td>50.6/9.4</td>
<td>Construct validity: UPSA-B was significantly correlated with UPSA, $r = 0.91$, and cognitive functioning, symptoms, age, and education. UPSA-B predicted residential independence and was sensitive to change. At a cutoff score of 60, 70% of the residentially independent living sample were identified.</td>
<td>Mausbach et al., 2007</td>
</tr>
<tr>
<td></td>
<td>335 (non indep. liv)</td>
<td>54.5/22.9</td>
<td>50.2/7.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>272</td>
<td>37.6/26.1</td>
<td>45.5/12.4</td>
<td>UPSA-B discriminates between diagnoses: lowest scores for patients with schizophrenia, followed by major depression, bipolar disorder, and healthy controls.</td>
<td>McIntosh et al., 2011</td>
</tr>
<tr>
<td></td>
<td>284 (hc)</td>
<td>64.3/23.3</td>
<td>47.9/11.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td>211</td>
<td>69.8/3.73</td>
<td>49.2/11.6</td>
<td>Concurrent validity, $r = 0.37–0.50$. Discriminant validity: Patients in remission score higher on FC. Homogeneity, Alpha scores 0.59–0.77, Test-retest, $r = 0.73$ (p &lt;0.01)</td>
<td>Paper I</td>
</tr>
<tr>
<td>Denmark</td>
<td>117</td>
<td>77.5/13.3</td>
<td>25.0/3.3</td>
<td>Working memory, negative symptoms, and social cognition accounted for 41% of the variance in UPSA-B. FC was only modestly associated with measures of real-world functional performance.</td>
<td>Vesterager et al., 2012</td>
</tr>
<tr>
<td>India</td>
<td>160</td>
<td>67.6</td>
<td>32.5/9.1</td>
<td>Homogeneity: Alpha scores 0.77, Test-retest, $r = 0.72$. Significant correlation with cognitive tests, but not with measures of symptoms. UPSA-B did not correlate significantly with SLOF.</td>
<td>Velligan et al., 2014</td>
</tr>
</tbody>
</table>
3.4 How the findings contribute to increased knowledge about everyday functioning

To understand the factors that predict the discrepancy between what one can do (capacity) and what one actually does (performance) is a critical step in understanding everyday functioning in schizophrenia. The complexity of everyday functioning and the need for several variables to understand and describe everyday functioning is clarified in Papers I-III.

Figure 5 illustrates this complexity and provides a structure for the personal factors that support and/or prevent the activity in interaction with environmental factors. Some of the personal factors
that have been found to be associated with functional outcome are symbolized by the body of a bumblebee. One of the wings of the bumblebee represents the patient’s functional capacity and the other represents self-awareness. These are the main factors that were investigated in the present thesis. How well the bumblebee manages to fly (i.e., everyday functioning) depends on these factors and on the support and obstacles in the environment.

Figure 5. Personal factors that support and prevent everyday functioning in the interaction with environmental factors.

The results from Paper I show that different assessment instruments used to measure everyday functioning correlated well, but in different ways, with UPSA-B. These findings indicate that UPSA-B is firmly anchored within the everyday functioning realm. The earlier discussion about difficulties in measuring functioning could depend partly on the fact that different levels of everyday functional outcomes are compared. It is important to realize that the different levels of functional outcomes contribute new information to the realm and are useful for capturing as realistic a picture as possible. Paper III focuses on the importance of using observation-based assessments and the meaning of evaluating patients’ self-awareness. This is particularly important when patients have a reduced ability to
evaluate their functioning to avoid overestimation by those who provide support and/or treatment. Our findings in Paper II extend the arguments for using several achieved functional milestones. It also became clear that variables such as age and symptoms can be used to a greater degree than functional capacity to predict some of the milestones. Even if there are certain issues concerning the level of achieved functional milestones, such as environmental influences and difficulty changing, they are important to use. Functional milestones are also helpful to demonstrate similarities and differences between countries, and to compare the patients’ situation with a healthy population.

Assessing functional outcome (how well the bumblebee in Figure 5 managed to fly) needs to be done at different levels of functional outcome. To provide a structure for categorizing and comparing assessment instruments, an extended version of the model presented by Sumiyoshi and Sumiyoshi (2015) is suggested (Figure 6).

![Figure 6](image_url)

**Figure 6.** An extended and modified version of the model presented by Sumiyoshi and Sumiyoshi (2015) illustrates the factors that need to be taken in consideration when measuring everyday functioning in patients with schizophrenia.

Functional performance can, for example, be assessed using instruments such as SLOF, and functional capacity can be assessed using instruments such as UPSA-B. The higher the level of functional outcome, the stronger the influence from environmental factors and
the patient’s self-awareness. There are definitely several environmental factors and societal aspects, such as access to money, phone and education, that influence the patient’s conditions for passing the test. However, in the actual test situation of neuropsychological performance and functional capacity, patients are not greatly affected by environmental factors. The model can be complicated further by incorporating interview based methods to assess the patients’ neuropsychological performance and functional capacity. In assessments such as Cognitive Assessment Inventory (Ventura et al., 2013) and Schizophrenia Cognition Rating Scale (Keefe et al., 2006) the patient is asked to make judgements about cognition and degree of severity of impairments in a variety of cognitive domains. Using these instruments, the results will probably be influenced by impaired self-awareness in a similar way to other interview-based assessments, regardless of the functional outcome level that is being assessed.

In assessments at the higher levels of functional outcome, functional performance is based to a greater degree on the patient’s ordinary everyday activities. Moreover, neuropsychological performance and functional capacity, which are almost at the same level, could be assessed in laboratory settings and in institutional settings. The model (Figure 6) may be useful to interpret results when different instruments are compared. The benefits of using a performance-based instrument such as UPSA-B are also clarified, since both self-awareness and environmental factors do not influence the results.

3.5 Limitations

This study has certain limitations. As it has a naturalistic study design, it is difficult to know how representative this specific sample is for the patient population in general. A previous study from the CLIPS project reported that 670 patients met the inclusion criteria and were invited to join the project (Heldin, Kane, Karilampi, Norlander & Archer, 2008). Today, 18 years later, approximately 500 patients are included in the study. As over time new patients have
developed the illness, the number of total available patients is uncertain. However, the population represents the vast majority of patients with the disease. Using retrospective data, such as age at illness onset and illness duration, extra caution must be observed. This could be due, for example, to the patients’ difficulty recalling past events. To reduce such bias, these retrospective data were collected from, and compared with, different sources, such as medical records, patients, relatives, and clinicians. On the other hand, a strength of the CLIPS is that data is collected longitudinally and prospectively. The participants in this study are in a stable phase of their illness when the assessment is made, which means that symptom severity decreases, which in turn makes greater demands on the data in order to detect differences. Apart from symptoms, the patient’s motivation, cognition and emotional state could also have had an impact on the results.

### 3.6 Further Research

When evaluating results from previous studies and new studies it is important, for example, to consider which level of functional outcome has been assessed, which source was used to collect the data, and whether the patient’s self-awareness has been taken into account. The use of Figure 6 could be helpful to clarify the chosen methods. The more these variables resemble each other, the greater the consistency we should expect.

Although **Paper I** shows that the Swedish version of UPSA-B is trustworthy and useful, there is a need for further development of this instrument. Translating and adapting the computer-based versions, (Moore et al., 2013) and/or the mobile application version (Moore et al., 2015), may be the next step in the process of measuring functional capacity. Moreover, there is a need for more challenging tasks when developing a new version of the functional capacity assessment instrument. This is needed, among other things, to avoid a ceiling effect.
The examinee’s level of engagement in the testing situations seems to be important to understand more fully the dynamics of assessment of functional performance. Personality researchers have long been interested in determining how personality is associated with cognitive functioning (Bush et al., 2005; Mohn, Olsson & Helldin, 2018). Although it is probably similar variables that are associated with functional performance, this requires further research. Efforts that provide motivation to engage in the test situation are likely to affect the patients’ functional performance. Other personal factors, such as self-efficacy and grit, may also play a significant role (Hill & Aita, 2018). According to self-efficacy theory, performing well in real-world circumstances is a function of having both the skills and the self-belief to utilize them (Bandura, 1977).

It is also important to continue the process of analyzing the variation in the patient group, where some patients are better at describing their situation than others. **Paper III** highlighted the advantages of using short and simple questions. The results may have been even more refined if more questions were added. The method could be further developed by using both spoken and written questions. The questions about functioning can be set before, during or after performance of the tasks.

Mental health literacy involves knowledge and beliefs about mental disorders that aid their recognition, prevention, or management. Such knowledge allows patients to take action to improve their own mental health (Jorm, 2012). Hence, mental health literacy is important as it helps when seeking appropriate treatments, facilitates early intervention, and consequently support prevent intensified and worsening symptoms and impaired everyday functioning. Functional recovery has become an important treatment priority in schizophrenia, and efforts have been made to evaluate treatment success beyond symptom remission (Gupta et al., 2012). Because patients with schizophrenia have an average lifespan that is approximately 20 years shorter than the normal population, it is vital to increase our knowledge in this area (Helldin et al., 2015). Constantly replicated findings, such as negative symptoms, cognitive
impairment, and low functional capacity, have a considerable impact on functional performance and merit further research into how this information is used in the planning process, and for optimal treatment and support.

3.7 Conclusions

The clinical implications generated by this thesis refer to factors that may be of importance to the crucial task of understanding the complexity of measuring and describing everyday functioning in patients with schizophrenia. There is a growing interest in developing remission criteria for functional performance similar to those that exist for symptoms. This thesis indicates that UPSA-B is a promising contributor in this area. It is a particularly suitable method as it is time-consuming and generates valuable information that correlates with neuropsychological performance. By assessing functional capacity with UPSA-B, and by asking certain brief questions about functioning, a basis is created for capturing the patients’ self-awareness of functioning.

The results also imply that several variables and different levels of everyday functioning need to be assessed, as they provide additional information. Because the predictive factors of achieved functional milestones vary, the support and treatment strategies required to improve them also need to be diversified. How the information about patients’ functioning is used in decision-making related to treatment and support is a question that ought to be examined in future studies.
4. References


specific neuropsychological and functional capacity measures. 
*Biological Psychiatry, 63*(5), 505-511.

Bowie, C. R., Depp, C., McGrath, J. A., Wolyniec, P., Mausbach, B. T., 
world functional disability in chronic mental disorders: a 
comparison of schizophrenia and bipolar disorder. *American 
Journal of Psychiatry 167*(9), 1116-1124.

treatment in the first half of the twentieth century.* Berkeley: 
University of California press.

related to assessing functioning in serious mental illness. 
*Dialogues in Clinical Neuroscience, 18*(2), 135-144

A video ethnography approach to assessing the ecological 
validity of neurocognitive and functional measures in severe 
mental illness: results from a feasibility study. *Schizophrenia 
Bulletin, 38*(5), 981-991.


measure in schizophrenia studies. *Acta Psychiatrica 
Scandinavica 116*(6), 403-418

Bush, S. S., Ruff, R. M., Troster, A. I., Barth, J. T., Koffler, S. P., 
assessment: practice issues and medical necessity NAN policy & 

outcome in schizophrenia. *American Journal of Psychiatry 
163*, 356-358.

Carone, D. A., Benedict, R. H., Munschauer, F. E., Fishman, I., & 
discrepancies of reported cognitive symptoms in MS. *Journal 
of the International Neuropsychological Society, 11*(5), 574- 
583.

differences in schizophrenia: hormonal effect or subtypes?


Gould, F., Sabbag, S., Durand, D., Patterson, T.L., & Harvey, P.D.


functional skills in people with schizophrenia. *Innovations in Clinical Neuroscience* 8, 15-18


McKibbin, C., Patterson, T. L., & Jeste, D. V. (2004). Assessing disability in older patients with schizophrenia: result from the WHODAS-II. *Journal of Nervous & Mental Disorders 192*(6), 405-413.


Moore, R. C., Harmell, A. L., Ho, J., Patterson, T. L., Eyler, L. T.,


Cognition, 1(1), e47-e52.


Sumiyoshi, T., Nishida, K., Niimura, H., Toyomaki, A., Morimoto, T.,


Functional Capacity as a Predictor of Everyday Functioning in Patients with Schizophrenia

The overall purpose of this thesis is to increase knowledge about the concept of functional capacity and the way it is related to everyday functioning for adult patients with schizophrenia spectrum disorders. UCSD Performance-based Skill Assessment-Brief (UPSA-B) is a performance based instrument used to assess functional capacity, the patient’s ability to perform certain everyday tasks in a controlled setting. The result in Paper I indicated that the Swedish version of UPSA-B is a reliable instrument with good psychometric properties. The aim in Paper II was to investigate if and how, demographic variables and illness activities together with functional capacity contribute to predict real-world functioning milestones. Functional capacity was mainly associated with education level and housing situation. In Paper III the aim was to investigate how the patient’s self-rating ability regarding functional performance relates to neurocognitive performance and real-world functional performance. The results showed that 37 % of patients overestimate their ability of functional performance. In sum, this thesis states that using UPSA-B to measure functional capacity has great advantages and plays an important role in capturing functional outcomes.