Apathy, Vocational Rehabilitation and Functional Outcome in persons with Schizophrenia Spectrum Disorders

Doctoral Thesis

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Abbreviations

AES	Apathy Evaluation Scale
CBT	Cognitive Behavior Therapy
CDSS	Calgary Depression Scale for Schizophrenia
CR	Cognitive Remediation
DSM-IV	Diagnostic and Statistical manual of Mental Disorders-IV
GP	General Practitioner
IPS	Individual Placement and Support
IQ	Intelligence Quotient
JUMP	Job Management Program
M.I.N.I	Mini International Neuropsychiatric Interview
NIMH	The National Institute of Mental Health
OT	Occupational Therapist
PANSS	Positive and Negative Syndrome Scale
SCI-PANSS	Structured Clinical Interview for the Positive and Negative Syndrome Scale
SE	Supported Employment
SFS	Social Functioning Scale
SPSS	Statistical Package for the Social Sciences
VR	Vocational rehabilitation
WBI	Work Behavior Inventory

List of papers

Paper I

Bull H., Ueland T., Lystad J.U., Evensen S., Friis S., Martinsen E.W., Falkum E. (2015). Validation of the Work Behavior Inventory *Nordic Journal of Psychiatry*, 2015 May; *69(4), 300-306. doi: 10.3109/08039488.2014.973902*

Paper II

Bull H., Ueland T., Lystad J.U., Evensen S., Martinsen E.W., Falkum E. (2016). Vocational Function in Schizophrenia Spectrum Disorders - Does Apathy Matter? *Journal of Nervous and Mental Disease doi: 10.1097/NMD.0000000000000504*

Paper III

Bull H., Mueser K., Ueland T., Lystad J.U., Evensen S., Martinsen E.W., Falkum E. (2016). The Impact of Apathy on Vocational and Social Functioning in persons with Schizophrenia Spectrum Disorders – A two-year follow-up. (Submitted)

Summary

Working holds an important role in society and is the considered normal thing to do. While the majority of people with schizophrenia would like to work, employment rates remain consistently low. This discrepancy indicates the need for improved vocational services for this group. Low employment rates may be due to illness-related or societal factors. Societal and structural factors such as low expectations, stigma and discrimination, and limited access to services contribute to low employment rates. Negative symptoms in general and apathy in particular, have been identified as important predictors of impaired vocational functioning.

The main aim of this thesis was to examine the impact of apathy on vocational functioning in the context of the Job Management Program (JUMP). The JUMP study is a vocational rehabilitation program including close collaboration between health and vocational services, providing participants with ongoing support, psychoeducation and either cognitive remediation or cognitive behavior therapy applied in the work setting.

In order to assess work performance, we validated the Work Behavior Inventory (WBI), an on-site assessment of work behavior developed specifically for people with severe mental illness.

Paper I examined the psychometric properties of a Norwegian version of the WBI. The original scale has five subscales. We found that a three-factor model best represented the data, resulting in three subscales: social skills, work quality and complying with work norms. The model had acceptable psychometric properties, indicating that the WBI has good cross-cultural properties, and may be used to assess work behavior for people with schizophrenia in Norway.

In Paper II we examined whether baseline apathy predicted vocational outcome defined as the average number of hours worked per week during the study, work behavior and employment status (working or not working) at post treatment (including competitive employment, work placement and sheltered work). We found that apathy predicted the number of hours worked during the study, with participants with higher levels of apathy working fewer hours a week. However, apathy did not predict employment status or work behavior at post treatment.

In Paper III we examined the development in apathy from baseline to post treatment, and whether baseline apathy or change in apathy predicted employment status at follow-up. There

was a small but statistically significant improvement in apathy from baseline to post treatment. Baseline apathy did not predict employment status or work behavior, but predicted social functioning at follow-up. Change in apathy did not predict vocational or social functioning at follow-up.

The association between apathy and vocational functioning was not as strong as expected, and many participants were able to work in spite high levels of apathy.

These findings indicate that the impact of apathy on vocational functioning may be attenuated by the JUMP interventions. The JUMP study provided a complex intervention enabling people with schizophrenia to work irrespective of the level of apathy. However, we found some association, as level of apathy predicted hours worked per week.

Our findings underline the need for future studies to investigate the relative importance of various aspects of vocational rehabilitation interventions, so we can best tailor our services to enable people with schizophrenia to work.

1. Introduction

As an occupational therapist (OT) working in the field of mental health, the lack of motivation, passivity and lack of engagement seen in many patients on the ward was disturbing. At the same time the engagement and enthusiasm often seen in the workshops and activities provided in the OT department called into question the apathy seen on the ward. Different activities engaged different people. For many patients their main motivator was to be of use. Years of these experiences provided me with a slightly optimistic view on the nature of apathy. It seemed to have a relational and a situational dimension, and that our challenge as therapists was not to give up in the face of so little encouragement. Our focus then was on providing meaningful activities, as work was not considered a natural choice for people with severe mental illness in Norway in the 1980's and 1990's. This approach is being challenged by a large body of research, attitudes are slowly changing and work is becoming a possibility also for people with severe mental illness again.

Engaging in vocational activities has however been an important aspect of the recovery from mental illness since the advent of moral treatment in the 18th century (Killackey, 2015). Before the late 18th century, conditions for the mentally ill were severe, including incarceration under dreadful conditions. In a time with limited knowledge of mental illness and limited resources, the mentally ill were not considered entirely human and were often subject to ridicule, neglect or even pain. The Moral treatment that gained popularity and momentum in Europe and the USA in the 19th century took an enlightened view of mental illness, believing that the mentally ill should be treated as moral subjects. This involved providing decent living conditions in modern asylums, and meeting the mentally ill with 'normal' expectations. At that time it meant working and taking part in religious services. It also meant being spoken to, listened to, and treated as a valued member of society.

From early records of the asylums, including our place of work, previously Gaustad asylum, there are descriptions of how men worked on the farm and women did the knitting, weaving and cooking necessary to run the asylum. Many recovered and went back to fill a role in society. With the subsequent overcrowding of the asylums and the emergence of a more medical approach to mental illness, the functional recovery perspective went into decline, and work was no longer considered important to recovery (Killackey, 2015).

Over the last decades employment rates for people with schizophrenia have been consistently low. International reviews have found employment rates between 6 % and 39 % depending on the definition of work and on the population examined (Davidson et al., 2015; Jonsdottir & Waghorn, 2015; Marwaha et al., 2007; Tandberg et al., 2011), with the current rate in Norway being approximately 10 % . The high unemployment rates generate a significant burden both for the individual and for society at large.

Furthermore unemployment has a detrimental effect on mental health with increased levels of depression, anxiety and reduced subjective well-being and self-esteem (Paul & Moser, 2009). Youth unemployment is particularly damaging to future mental health (Strandh, Winefield, Nilsson, & Hammarström, 2014).

When asked, the majority of people with schizophrenia state that they wish to work (Davis & Rinaldi, 2004; Marwaha & Johnson, 2004, 2005; Mueser, Salyers, & Mueser, 2001). They emphasize that working is the normal thing to do, allowing them to take responsibility, use their resources and contribute to society (Auerbach & Richardson, 2005). Working provides income, improving economic security and social status, and is described as an antidote to chaos and boredom, providing structure and content to daily life (Auerbach & Richardson, 2005). Moreover work has a positive effect on self-esteem, quality of life and social functioning (Burns et al., 2009; Nordt, Müller, Rössler, & Lauber, 2007; Ruesch, Graf, Meyer, Rossler, & Hell, 2004; Üçok, Gorwood, & Karadayı, 2012). Work has for many years been considered an effective means of integration in society (WHO, 2000), and promotes health and well-being (Schultz & Gatchel, 2016).

Both societal and individual factors contribute to the high unemployment rates. Traditionally, treatment has focused on reducing the positive symptoms of schizophrenia: hallucinations and delusions, believing that if these symptoms were relieved, function would return. Both research and clinical experience have informed us that this is not always the case (Erickson, Jaafari, & Lysaker, 2011; Harvey, Velligan, & Bellack, 2007; Marwaha & Johnson, 2004). Furthermore the belief that work is too challenging for people with schizophrenia has led to protective attitudes among health and social services employees, again resulting in exclusion (Lloyd & Waghorn, 2007; Rinaldi, Killackey, et al., 2010). Among the individual factors, symptoms and cognition are both important predictors of functioning, with the relative importance of each varying between studies. Symptoms such as reduced expression and

motivation have proved to be a challenge for people who wish to work, as they have a negative impact on vocational functioning (Erickson et al., 2011; Fervaha, Foussias, Agid, & Remington, 2014a; Hunter & Barry, 2012; Tsang, Leung, Chung, Bell, & Cheung, 2010). The same is found for cognitive impairment (Fervaha, Foussias, Agid, & Remington, 2014b; Shamsi et al., 2011).

The discrepancy between the number of patients who wish to work and the low employment rates needs to be addressed, as work holds many benefits, from which people with schizophrenia may also profit. Over the past decades efforts have been made to improve employment rates for people with schizophrenia through various vocational rehabilitation approaches (Crowther, Marshall, Bond, & Huxley, 2001; Kinoshita et al., 2013; Marshall et al., 2014). In spite of improved employment rates in the course of the studies, many participants still did not gain or maintain work, and there is need for further improvements (Campbell, Bond, & Drake, 2011; Cook & Razzano, 2000; Marshall et al., 2014).

1.1 Psychosis and Schizophrenia spectrum disorders

The understanding and conceptualization of mental illness is an ongoing process. During the 19th century the term psychosis was a common term for all forms of mental illness, with no distinction between what we now term psychosis and neurosis (Bürgy, 2008). In the 20th century the concept of psychosis as a distinct category was explored, and we owe much of our present day understanding of psychosis and schizophrenia to the German physician Emile Kraepelin, the Swiss psychiatrist Eugen Bleuler and the German psychiatrist Kurt Schneider.

Kraepelin was one of the first to classify the mental disorders into different categories. He used the term "dementia praecox" for individuals who had symptoms that we now associate with schizophrenia, and was the first to make a distinction between what he called dementia praecox and manic depression. According to Kraepelin dementia praecox was recognized by its early onset, chronic and deteriorating course, and poor functional outcome (Tandon, Nasrallah, & Keshavan, 2009). Bleuler changed the name dementia praecox to schizophrenia. It was obvious that dementia praecox was a misleading name. It was not a dementia as the illness did not always lead to mental deterioration, and was not praecox as it could occur late as well as early in life. Bleuler believed that the core characteristic of schizophrenia was the

disintegration of various psychic functions, leading to blunt or incongruous *affect*, *ambivalence*, and *autism*, now considered as negative symptoms, and to loosening of thought *association*, (Tandon et al., 2009) (known as Bleuler's four A's). Bleuler was also the first to describe the symptoms as "positive" or "negative", considering the positive symptoms to be secondary to the negative symptoms.

Schneider rejected both Kraepelin's reliance on the course of illness for diagnosis, and Bleuler's idea that disturbance of thinking could define schizophrenia. He chose instead a pragmatic approach, where he defined some core symptoms that to his mind distinguished schizophrenia from the other psychoses (Cutting, 2015). Schneider called these the first rank symptoms. They include auditory hallucinations (hearing thoughts spoken aloud, hearing voices referring to oneself, made in the third person, hearing a running commentary), thought withdrawal, insertion and interruption, thought broadcasting, somatic hallucinations, delusional perception and feelings or actions experienced as made or influenced by external agents. Schneider's definition has heavily influenced the diagnosis of schizophrenia to the present day, placing strong emphasis on positive symptoms, while negative symptoms were not mentioned.

Onset and course

Schizophrenia is regarded as the most serious of the psychotic disorders and remains one of the top ten leading causes of disability worldwide in young adults (Velligan & Gonzalez, 2007; WHO, 2000). Onset is usually in late adolescence or early adulthood, with cognitive and negative symptoms often preceding the positive symptoms (Tandon et al., 2009), and often enduring after the positive symptoms have been successfully treated. Schizophrenia is defined by the presence of a combination of symptoms, either positive or negative or a combination of both, and presentation and course will vary according to symptoms. Men tend more often than women to have early onset and poorer functional outcome and symptoms characterized by lack of motivation and social withdrawal, while women tend more often to have later onset and a more benign course, with hallucinations and delusion being the characteristic symptoms (van Os & Kapur, 2009).

Schizophrenia is considered to be a disabling disorder with poor outcome, but there may be reason to moderate this view. Services have changed, and the majority of people with

schizophrenia now live outside hospital with varying levels of support. Focus is gradually shifting to a recovery point of view (van Os & Kapur, 2009), where coping with symptoms in everyday life is the goal rather than curing the illness. A summary of prospective outcome studies in schizophrenia found that less than 50 % had poor outcome and less than 50 % had good outcome defined as complete remission, no readmissions or symptomatic recovery with no social or intellectual deficit throughout follow-up (van Os & Kapur, 2009). This shift in focus from curing the illness to living a good life is more in keeping with the management of other chronic disorders, and opens up the possibility of education and work.

Etiology and prevalence

Despite decades of research, the etiology of schizophrenia remains uncertain. Hereditary factors, such as having a parent or a sibling with schizophrenia, constitute the highest risk (Torrey, Bartko, & Yolken, 2012). The prevalence of schizophrenia is higher among people with a history of migration, especially when migrating to an area with low density of own ethnic group, and among those living in or having been brought up in an urban environment (Tandon, Keshavan, & Nasrallah, 2008; Torrey et al., 2012). Other risk factors include high paternal age, obstetric complications and cannabis use. Some prenatal infections may also increase the risk of developing schizophrenia (Tandon et al., 2008; Torrey et al., 2012).

Estimates of lifetime prevalence vary between studies, ranging from approximately 0.2 % to 0.9 % (Tandon et al., 2008). Analyses of Norwegian data suggest a lifetime prevalence of 0.28 %, with a twelve-month prevalence of 0.17 % for the entire population (Evensen et al., 2015). The incidence of schizophrenia is fairly consistent world-wide, with pockets of higher and lower incidence.

Cognitive impairment

Cognitive impairment is prevalent in schizophrenia, but varies in degree (Lewis, 2004). There may be general cognitive impairment, or impairment on specific areas such as processing speed, attention, verbal learning, executive functions and working memory (Lewis, 2004; Lystad et al., 2014; Tandon et al., 2009). Cognitive impairment often precedes the presentation of positive symptoms (Tandon et al., 2009), and may endure after the positive symptoms have been successfully treated (Lewis, 2004). Cognitive impairment is an important predictor of vocational and social dysfunction (Fervaha et al., 2014b; Lystad et al., 2016; Shamsi et al., 2011).

Positive and negative symptoms

From the early descriptions by Emil Kraeplin and Eugene Bleuler to the present day, hallucinations and delusions, affective flattening, lack of motivation, cognitive impairment, deviant/odd behavior and social withdrawal have been identified as core symptoms of schizophrenia.

Where there is an excess, too much of something, the symptoms have been defined as positive, while symptoms that represent the lack of something that is normally present have been defined as negative symptoms. According to the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV), the positive symptoms include delusions, hallucinations and disorganized thought, speech and behavior, and involve an element of reality distortion (APA, 1994). Definitions of negative symptoms have varied over time, and may include impairments in affective experience and expressions, abulia (loss of motivation), alogia (poverty of speech), anhedonia (inability to experience pleasure), avolition (lack of initiative), asociality (social withdrawal), apathy (lack of interest) and reduced social drive (Crow, 1980; Tandon et al., 2009).

The distinction between positive and negative symptoms and the disabling effect of negative symptoms is well recognized. In 1980 Crow proposed two types of schizophrenia. Type I was characterized by hallucinations, delusions and thought disorder (positive symptoms). The onset was acute; it responded to antipsychotic medication and was considered reversible. Type II was characterized by affect flattening, poverty of speech, loss of drive (negative symptoms), with poor response to antipsychotics, and poorer prognosis. Intellectual impairment was sometimes present and the condition was believed to be irreversible. This was called chronic schizophrenia (Crow, 1980). The distinction between two types of schizophrenia is still relevant today, with Crows Type II schizophrenia having much in common with the deficit syndrome which is characterized by insidious onset and persistent negative symptoms, entailing important functional impairment (Carpenter, Heinrichs, & Wagman, 1988).

Functional outcome

Schizophrenia is generally associated with poor functional outcome, as social or occupational dysfunction is an integral part of the diagnostic criteria. Over time the negative symptoms

have emerged as an important predictor of poor outcome, while positive symptoms rarely predict functional outcome in these studies.

Reviewing the evidence, negative symptoms were found to be consistently linked to poor functional outcome, including poor vocational functioning, household integration, social functioning, participation in leisure activities and quality of life (Foussias, Agid, Fervaha, & Remington, 2014), emphasizing the severe impact negative symptoms potentially have on all aspects of daily living. A multicenter study with 1493 participants found that higher levels of negative symptoms were associated with impairment in all aspects of daily living, such as interpersonal relations, role functioning and the participation in common activities (Fervaha et al., 2014a). Negative symptoms also reduce job seeking and impair the ability to continue to work and study (Üçok et al., 2012). In people with persistent negative symptoms the lack of interest and initiative (avolition), social withdrawal (asociality) and low expectations of future enjoyment (prospective anhedonia) interfere with daily living and work (Beck, Grant, Huh, Perivoliotis, & Chang, 2013; Kirkpatrick, Fenton, Carpenter, & Marder, 2006). Importantly, negative symptoms are considered to be fairly stable and treatment resistant (Kirkpatrick et al., 2006). They may be present early in the prodromal phase of the illness, and may persist after positive symptoms have been successfully treated. Their impact on functioning may therefore endure after positive symptoms are successfully treated.

1.2 Diagnostic categories.

The Diagnostic and Statistical Manual of Mental disorders, DSM-IV (APA, 1994) subcategorizes “Schizophrenia and Other Psychotic Disorders” into subgroups based on varying criteria (APA, 1994). For all groups psychotic symptoms are the common denominator. The diagnosis of schizophrenia and other psychoses is complex, has varied over time and is still under discussion. The diagnoses included in this thesis are the DSM-IV diagnoses of Schizophrenia, Schizoaffective Disorder, Delusional Disorder and Psychotic Disorders Not Otherwise Specified (APA, 1994).

1.2.1 Schizophrenia

The present thesis applied the diagnostic criteria of the DSM-IV. According to this system, the diagnosis of schizophrenia requires that three criteria are met: The *first* criterion (A) is to have at least two of the following five symptoms: 1) delusions, 2) hallucinations, 3) disorganized speech, 4) grossly disorganized or catatonic behavior and 5) negative symptoms such as affective flattening (poverty of nonverbal expression), alogia (poverty of speech) or avolition (lack of motivation).

The *second* criterion (B) is social or occupational dysfunction. One or more areas of functioning (work, social relations and self-care) must be markedly below earlier or expected levels of functioning for a significant period of the time since onset.

The *third* criterion (C) is that the symptoms must be present for at least one month (unless treated), and continuous signs of the disturbance must persist for at least six months. There is a wide range of possible combinations of symptoms, allowing for a diverse population meeting the diagnostic criteria for schizophrenia.

1.2.2 Schizoaffective Disorder

Schizoaffective disorder is characterized by the same symptoms as schizophrenia (criterion A) with the presence of affective symptoms for a significant period of the total duration of illness. During the period of illness, delusions or hallucinations have to be present for at least 2 weeks without prominent affective symptoms.

1.2.3 Delusional Disorder

Delusional disorder is defined by the presence of one or more non-bizarre delusions (situations that may actually occur in real life) that continue for at least 1 month. Other symptoms of schizophrenia (criterion A) must never have been met. Function is not markedly impaired.

1.2.4 Psychotic Disorder Not Otherwise Specified (Psychosis NOS)

Psychosis NOS is a diagnostic category that also includes non-organic psychotic syndromes that do not meet the criteria for any of the psychotic disorders, or psychotic presentations where there is insufficient or contradictory information, making conclusive diagnosis difficult.

1.2.5. Schizophrenia spectrum disorders

The diagnostic categories described above: schizophrenia, schizoaffective disorder, delusional disorder and psychotic disorder not otherwise specified, are included in the broad definition of schizophrenia spectrum disorders applied in the JUMP study.

1.3 Apathy

1.3.1 Disorder of the will

The term apathy has roots back to Greek philosophers of the Stoic school. The literal meaning of apathy was to be free of passion or emotion, a state which was considered the only road to a virtuous and happy life, as emotions would cloud rational judgement (Starkstein & Leentjens, 2008). The contemporary equivalent may be mindfulness. Over time the understanding of apathy has changed, and the concept now holds a negative value, describing a lack of response or emotion or thought. In the modern understanding of the concept, apathy might be a state does interfere with rational judgement.

Apathy is a symptom of a number of mental and neurological disorders, such as Alzheimer's disease, Parkinson's disease, multiple sclerosis, vascular and frontotemporal dementia. It may be present in depression, after stroke or head injury, and it is one of the negative symptoms in schizophrenia.

Even though apathy is a common symptom, there is no general consensus on the definition of the phenomenon (Clarke et al., 2011; Weiser & Garibaldi, 2015), and it is not described under the negative symptoms in the DSM-IV (APA, 1994).

One broadly accepted definition is that of Marin, who describes apathy as reduced motivation leading to reduced goal directed behavior not attributed to diminished level of consciousness, cognitive impairment or emotional distress (Marin, Biedrzycki, & Firinciogullari, 1991)

Marin argues that for apathy to be present there must be a lack of goal-directedness in overt behavior, thought content and emotional responsivity simultaneously. The behavior may range from mild apathy described as the lack of efficiency, to severe impairment requiring prompting in order to perform basic activities of daily living. The cognitive element of apathy entails the lack of 'goal-directed thought content' ranging from having no plans to having no interest in doing anything. The emotional element entails flat affect, emotional indifference and restricted responses to important life events (Marin, 1991, 1996).

The aim of this definition is to distinguish apathy from other symptoms, in particular cognitive impairment and depression. Cognitive impairment may be due to Alzheimer's disease, other dementias or brain injury, and identifying and treating the underlying disorder may be crucial. Similarly apathy may be drug-induced, or a side effect of medication (Marin, 1990).

Loss of motivation is a core symptom in both depression and apathy, making it difficult to distinguish the two. While depression may be similar to apathy in the loss of interest and change in activity causing impaired social, occupational or educational function (APA, 2000), it differs from apathy by the characteristic presence of despair and emotional distress. By defining apathy as the loss of motivation without co-occurring emotional distress, Marin has attempted to provide a differentiation between apathy and depression (Marin, 1990)

In this thesis apathy is understood mainly as a motivational disorder. In the literature the terms avolition, amotivation and apathy represent overlapping concepts that are not easily distinguished from each other. They will henceforth be termed apathy in this text.

1.3.2 Apathy - a negative symptom in schizophrenia

The term negative symptoms encompasses several symptoms including the reduction or lack of motivation and expression, and social withdrawal. The individual negative symptoms have often been grouped together and reported as one symptom. Due to this tradition there is a wealth of studies on negative symptoms in general, while there are fewer and smaller studies on the individual negative symptoms, such as apathy. While avolition and not apathy is mentioned in the DSM-IV, apathy is considered one of the negative symptoms of

schizophrenia according to the National Institute of Mental Health (NIHM) consensus statement on negative symptoms (Kirkpatrick et al., 2006).

With the NIHM consensus there has been an increased interest in the independent contribution of each negative symptom, and research on the separate symptoms has been encouraged (Kirkpatrick et al., 2006). In order to provide a broad research base for this thesis we have chosen to refer to studies on both negative symptoms in general and on apathy in particular.

1.3.3 Diminished expression and diminished motivation in negative symptoms

One way to disentangle the negative symptoms into useful categories has been to factor analyze the negative symptom scales. Factor analyses have fairly consistently shown two underlying subdomains of negative symptoms in schizophrenia (Foussias et al., 2014; Messinger et al., 2011). One is the diminished expression subdomain with diminished verbal and nonverbal expression (alogia, flat affect), and in some cases motor retardation and lack of spontaneity. The other is the motivational deficit subdomain, with diminished motivation (avolition, apathy, amotivation, anhedonia) and social withdrawal (Foussias et al., 2014; Foussias & Remington, 2010; Messinger et al., 2011; Strauss et al., 2012). While most studies report two factors, analyses of the Scale for Assessment of Negative Symptoms have found alogia and inattention to be an additional subscale, albeit highly correlated with the blunted affect subscale (Malla & Payne, 2005; Mueser, Sayers, Schooler, Mance, & Haas, 1994).

The two factor structure has been found within the subgroup with persistent negative symptoms (Kimhy, Yale, Goetz, McFarr, & Malaspina, 2006; Nakaya & Ohmori, 2008), in first-episode non-affective psychosis (Malla & Payne, 2005), and irrespective of whether participants were taking antipsychotics or not (Kelley, van Kammen, & Allen, 1999), demonstrating remarkable stability.

Apathy thus constitutes a separate area of interest for research.

1.3.4 Apathy and functioning

Negative symptoms predict impaired vocational and social functioning (Foussias et al., 2014), and of the negative symptoms those of the motivational deficit subdomain interfere with daily living and work in people with persistent negative symptoms (Beck et al., 2013; Kirkpatrick et al., 2006). An important reason to examine apathy and functioning is the independent adverse impact apathy has on vocational and social functioning.

In cross-sectional studies, apathy is associated with poorer living skills (Kiang, Christensen, Remington, & Kapur, 2003), psychosocial functioning (Konstantakopoulos et al., 2011) functional status and quality of life (Foussias, Mann, Zakzanis, van Reekum, & Remington, 2009), and with poorer GAF scores in a first-episode study (Faerden et al., 2009).

In longitudinal studies, apathy has consistently predicted poorer functioning, both in a ten year follow-up study (Evensen et al., 2012), a first-episode study (Faerden et al., 2013) and in schizophrenia in general (Fervaha, Foussias, Agid, & Remington, 2015; Foussias et al., 2011). When applying the diminished expression and diminished motivation dimensions in analysis of negative symptoms and function, the main finding is that poor vocational and social functioning is more strongly associated with diminished motivation than with diminished expression (Rocca et al., 2014; Strauss et al., 2013).

Considering the impact apathy has on vocational functioning and the wealth of vocational rehabilitation studies for schizophrenia, there is a scarcity of studies examining the impact of apathy on vocational functioning within the context of vocational rehabilitation.

Hoffman et al found that negative symptoms had an adverse impact on vocational functioning, while cognitive deficits were more important to the acquisition of competitive work (Hoffmann, Kupper, Zbinden, & Hirsbrunner, 2003). In the few vocational rehabilitation studies we have found specifically examining the effect of apathy on work *behavior*, apathy has not consistently predicted work behavior at a later time (Erickson et al., 2011; Evans et al., 2004; Saperstein, Fiszdon, & Bell, 2011), indicating that the relationship between apathy and work behavior is complex and needs more research.

There is still limited knowledge about the relationship between apathy and functioning from longitudinal studies, in particular in the context of vocational rehabilitation, and more

knowledge is needed in order to improve treatment (Foussias et al., 2014; Kirkpatrick et al., 2006).

1.3.5 Stable or fluctuating symptom?

The negative symptoms of schizophrenia, their enduring nature and disabling consequences have been recognized since the early descriptions of schizophrenia by Kraepelin and Bleuler (Buchanan, 2007). Negative symptoms are perceived as stable and enduring. While first generation antipsychotics were effective in the treatment of positive symptoms, they had little effect on negative symptoms or on cognition. Both cognitive impairment and negative symptoms were recognized as important challenges in daily functioning, and as unresponsive to first generation antipsychotics. With the introduction of second generation antipsychotics there was some hope that the new medication would have a positive effect on cognitive impairment and negative symptoms, thereby improving daily functioning and recovery for people with schizophrenia. Sadly, this was not the case, and the search for effective treatment of negative symptoms continues.

Contrary to the current view that negative symptoms are stable in the non-acute phase of schizophrenia, a recent meta-analysis found that negative symptoms improved over time in outpatients with schizophrenia (Savill, Banks, Khanom, & Priebe, 2015). This was true for a wide range of studies, with improvement varying a little according to the rating scale used. There is some evidence that apathy also may improve over time. For instance, Faerden et al (2009) showed that apathy decreased from 51% at baseline to 40% at one year follow-up in a study of patients with first episode psychosis, whereas Evensen et al (2012) found that 30% had apathy at ten year follow-up in an early intervention study. Evensen et al did not measure apathy at baseline directly, but the development in a proxy score for apathy (PANSS items N2 and N4) indicated a considerable drop from baseline.

The use of different rating scales and samples reminds us to be cautious when interpreting results. The reduction in apathy rates in these studies may be inflated compared to those in an outpatient population. Firstly, patients were assessed in an acute phase of symptom exacerbation, leaving more room for improvement. Secondly, the studies recruited participants early in the course of illness. Not all participants developed schizophrenia,

resulting in a lower rate of schizophrenia at the ten year follow-up than at baseline (Evensen et al., 2012). However, we interpret the findings to indicate that there may be improvement in apathy during the course of schizophrenia.

Primary and secondary apathy

In schizophrenia the terms primary and secondary were first applied to negative symptoms, where primary symptoms were considered to be intrinsic to schizophrenia, and secondary to be a response to positive or affective symptoms, medication side effects or to environmental deprivation (Carpenter, Heinrichs, & Alphs, 1985). The same terms were applied to apathy by Marin. Conceptually, primary apathy is considered inherent to schizophrenia, while secondary apathy is a response to environmental challenges such as hospitalization, loss of work or friends (Marin, 1990) or to environmental deprivation (Möller, 2007). Secondary symptoms may improve with improvements in treatment or in the environment (Marin, 1990; Möller, 2007).

1.3.6 Anticipatory anhedonia, effort and reward

In a comprehensive review of negative symptoms, Foussias et al (2014) distinguished between anticipatory hedonism (the pleasure of looking forward to a future pleasure) and consummatory hedonism (the pleasure of enjoying something now), finding that most studies on schizophrenia reported intact ability to experience pleasant or unpleasant emotions in the moment, but reduced belief in future pleasure (Foussias et al., 2014). So people with schizophrenia experience the same amount of pleasure from pleasurable experiences as healthy controls in the moment, but seem to have a bias in memory, reporting less pleasure from a pleasurable experience in the past than healthy controls, and less anticipation of future pleasure (Strauss & Gold, 2012).

This distinction may be of importance in vocational rehabilitation, especially in understanding the role of apathy. Notably the diminished ability to anticipate pleasure may contribute to lack of goal directed behavior, as the anticipation of future pleasure motivates us to act in order to achieve a goal (Buck & Lysaker, 2013).

As consummatory hedonism is intact, it is important to ascertain whether the rewards offered are perceived as rewarding also to people with schizophrenia. Money is a common reward,

and in a study examining the value of money, participants with schizophrenia were found to allocate the same value to monetary rewards as healthy controls (Fervaha et al., 2013), indicating that money may be an appropriate reward in studies. Furthermore, money was found to be motivating for people with schizophrenia in a work setting decades ago, where under otherwise identical conditions, people receiving wages worked more hours (Bell, Lysaker, & Milstein, 1996).

However, money is not the only source of reward. Experiencing pleasure was also perceived as rewarding to participants with schizophrenia (Wang et al., 2015). When offered a pleasure experience task, patients with high levels of negative symptoms were less likely to choose hard tasks than healthy controls, and did not increase the number of hard tasks with increased rewards (Wang et al., 2015). In keeping with the findings of Foussias et al (2014), participants with negative symptoms experienced the hedonistic pleasure of the reward, but showed deficits in both reward motivation and anticipatory pleasure experience or anticipatory hedonism (Wang et al., 2015).

Similarly, in a summary of studies where participants were given the choice between exerting little effort for a small reward, or a larger effort for a larger reward, people with schizophrenia would more readily discount larger rewards, choosing hard tasks less frequently than controls, even with high rewards (Green, Horan, Barch, & Gold, 2015). In five out of eight studies reduced willingness to exert effort was associated with negative symptoms, and in particular with apathy (Green et al., 2015). Rewards are often provided in an experimental setting. Cognitive remediation studies indicate that the delivery of tangible rewards in a supportive context may improve functional outcomes, and that extrinsic motivation therefore should not be neglected as an important determinant of behavior (Silverstein, 2010).

Defeatist beliefs about own performance or low expectancies of success are both common in schizophrenia (Foussias et al., 2014). Believing one will not succeed makes future reward irrelevant, and making an effort will therefore seem useless. Expectations of success are largely related to perceptions of one's ability, self-efficacy, and of the difficulty of the task. For example, successful past performance may influence a positive expectation for future success, but a task with vague, remote, or unpredictable goal properties may lower expectations of reward (success) (Medalia & Brekke, 2010).

Bandura sums this up nicely:

"Unless people believe they can produce desired effects by their actions, they have little incentive to undertake activities or to persevere in the face of difficulties" (Bandura, 2010).

The desired effect involves rewards, the belief that you can achieve the rewards, self-efficacy, and the anticipation of pleasure. Any impairment in self-efficacy or the ability to perceive, enjoy or anticipate rewards may lead to reduced willingness to exert an effort to reach a variety of goals.

1.3.7 Assessment of apathy

A variety of assessment tools are in use in both clinical work and research. Some are specific to apathy, while others are part of broader assessment tools. The lack of a gold standard assessment tool or a gold standard definition of apathy is clearly a challenge in the assessment of apathy (Clarke et al., 2011; Weiser & Garibaldi, 2015).

In the current study we used the Apathy Evaluation Scale (AES) (Marin et al., 1991). Being a general assessment of apathy, the AES has been applied to a broad range of clinical conditions. The scale has been revised and altered for use according to the most pertinent expressions of apathy in the relevant group. To mention some, there is a 10 item scale developed for demented nursing home residents (Lueken et al., 2007), a 7 item version assessing motivation in the elderly (Resnick, Zimmerman, Magaziner, & Adelman, 1998), a 5 plus 2 item scale for Parkinson's (Sockeel et al., 2006), and a 12 item scale for first episode psychosis (Faerden et al., 2008). In the current study the full 18 item scale was used.

1.4 Barriers to work

Impaired vocational functioning is one of the diagnostic criteria for schizophrenia. However, the illness fluctuates, and with medication and adequate psychosocial treatment, both symptoms and functioning may improve over time. Vocational functioning is influenced by symptoms and other illness-related factors, often defined as internal barriers, and various structural, organizational, and sociocultural factors, defined as external barriers.

The aim of the JUMP study was to address both internal and external barriers.

1.4.1 Internal barriers

Positive symptoms

Treatment focus in schizophrenia has traditionally been on the positive symptoms. These respond better to medication than negative symptoms, and are often adequately treated. Clinicians and researchers have held the belief that remission of positive symptoms would lead to improved daily or vocational functioning. This has however turned out not always to be the case (Erickson et al., 2011; Harvey et al., 2007; Marwaha & Johnson, 2004).

In studies of predictors of vocational functioning, positive symptoms generally do not contribute significantly to the results (Marwaha & Johnson, 2004; McGurk & Mueser, 2004; Rabinowitz et al., 2012), indicating that the level of positive symptoms has little influence on vocational outcome. This finding does not seem intuitive, as positive symptoms may affect concentration and take attention away from practical tasks, and may lead to behaviour that appears disturbing or frightening at the work place. However, in qualitative studies participants describe how working may distract them from their positive symptoms, allowing them to work undisturbed (Auerbach & Richardson, 2005; Borg & Kristiansen, 2008), thereby lending some support to the findings of the quantitative studies.

Negative symptoms

Negative symptoms are present early in the course of illness. They are a well-established predictor of poor vocational functioning for individuals with schizophrenia (Fervaha et al., 2014a; Foussias et al., 2014; Üçok et al., 2012), and are associated with social withdrawal (Strauss et al., 2013). While positive symptoms tend to fluctuate, negative symptoms tend to be more stable over time, being core symptoms in Crows Type II, or chronic schizophrenia (Crow, 1980). Negative symptoms may be misinterpreted as laziness or lack of interest. As the negative symptoms include reduced expression, reduced initiative and drive along with social withdrawal, the impact on daily functioning may be severe.

As described earlier, apathy is an independent predictor of impaired functioning (Rocca et al., 2014; Strauss et al., 2013), being associated with poorer living skills (Kiang et al., 2003),

psychosocial functioning (Konstantakopoulos et al., 2011) functional status and quality of life (Foussias et al., 2009).

Together with neurocognitive impairment, negative symptoms are recognized as a core feature of schizophrenia affecting many areas of daily life (Green, Kern, Braff, & Mintz, 2000; Leifker, Bowie, & Harvey, 2009) including vocational functioning (Lystad et al., 2016; Strassnig et al., 2015; Tsang et al., 2010).

As the negative symptoms are often present before the onset of psychotic symptoms, they may have a detrimental effect on functioning before the diagnosis of schizophrenia. The consequences may be unmet educational and vocational milestones, resulting in incomplete education and little work experience when trying to enter the job market. Lack of formal education reduces the chances of success when competing for work.

1.4.2 External barriers

Stigma

In a survey of perceptions of schizophrenia, the most common stereotype was that people with schizophrenia were unpredictable and incompetent , an understanding associated with 'a desire for social distance' (Angermeyer & Matschinger, 2004). In addition people with schizophrenia were often seen as dangerous.

Severe mental illness still holds stigma for the public and for health professionals (Lauber, Nordt, Braunschweig, & Rossler, 2006) resulting in low expectations to people with severe mental illness (Lloyd & Waghorn, 2007; Rinaldi, Killackey, et al., 2010). Public stigma refers to this type of commonly held beliefs, and may lead to self-stigma: an internalizing of the negative attitudes and low expectations held by others (Rinaldi, Perkins, McNeil, Hickman, & Singh, 2010).

People with schizophrenia may experience stigma and exclusion in several areas of life, such as housing, education and employment (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). Stigma constitutes an important barrier to vocational services and to employment, and may contribute more to poor self-efficacy and coping than positive, negative or general symptoms (Kleim et al., 2008).

Protective attitudes

Work relates to mental health in complex ways. While there is worry that the stress of work will exacerbate positive symptoms, the detrimental effect of unemployment on mental health seems to be underestimated in the treatment of people with schizophrenia. Unemployment has a well-documented negative effect on mental health. It leads to increased anxiety and depression and reduced subjective well-being and self-esteem. Moreover unemployment leads to diminished social network, poorer economy and quality of life (Paul & Moser, 2009; Strandh et al., 2014; Zhang & Bhavsar, 2013). Notably, youth unemployment is found to have a long-term scarring effect on mental health, with poorer mental health at 21, 30 and 42 years of age (Strandh et al., 2014). An increase in anxiety and depression following unemployment may exacerbate symptoms of psychosis.

The documented stress of unemployment is not taken into account by family and therapists when people with schizophrenia are protected from the stress of work. Furthermore, if the therapists believe that work is too challenging for people with schizophrenia and adopt a protective attitude, clients and their families tend to internalize the low expectations (Rinaldi, Perkins, et al., 2010), leading to a vicious cycle of low expectations.

A qualitative study by Gowdy et al (2004) exemplified the importance of staff attitude and actions for vocational outcome. Where health- and vocational service providers held positive and high expectations of work (expecting clients to work, introducing work as a natural topic with clients) more people gained competitive work, while at sites where service providers had low expectations and believed work was stressful and detrimental (did not mention work, or expect clients to work) fewer people gained or maintained work (Gowdy, Carlson, & Rapp, 2003, 2004). The stress of work needs to be balanced with the benefits of employment (Broom et al., 2006) and the effect of unemployment (Paul & Moser, 2009; Strandh et al., 2014; Zhang & Bhavsar, 2013).

Welfare systems

Employment rates vary according to the general unemployment levels in an area, but also according to the provision of services. Benefits in Europe are considered to be generous compared to those in the USA (Burns et al., 2007), and furthermore benefits in the Nordic countries are considered generous compared to the rest of Europe. Such generous systems

create a benefit trap, where the fear of losing benefits may constitute financial disincentives to returning to work (Burns et al., 2007).

In Norway there has been financial incentive to apply for a particularly generous Young Disabled benefit. A diagnosis of schizophrenia usually grants eligibility, and with the promise of economic security this has been the preferred benefit for young people with schizophrenia. Sadly, being on disability benefit generally disqualified the person from accessing vocational services, including vocational rehabilitation, leading young people with severe mental illness fairly directly into unemployment, with the challenges that entails.

Although unemployment rates are relatively low in Norway, the rate of mentally ill among the unemployed is 'strikingly high' compared to other countries, with more than every other unemployed in Norway having a mental illness (OECD., 2013). The extensive use of sick leave and disability benefits for mental illness is fairly unique to Norway. Once disability benefits have been granted, individuals rarely transfer into employment (OECD., 2013). This indicates that the benefit trap is strong in Norway and is particularly so for people with mental illness.

1.5 Vocational rehabilitation

Vocational rehabilitation is a common term for approaches aimed at enabling people to gain and maintain employment. There are two main approaches.

Vocational rehabilitation: Train then place

The traditional vocational rehabilitation (VR) model is based on the belief that people with reduced capacity for work should first participate in a training or qualification program in a segregated environment before applying for ordinary work (Spjelkavik, 2012). The model advocates a step-by-step approach to work, starting with low intensity and low complexity tasks, moving gradually on to more challenging tasks as skills improve, with competitive employment as the long-term goal. Emphasis is placed on assessment of the individuals "readiness for work". It is coined the "train-then-place" model, and assumes that the possibilities for success increase if basic skills are practiced before entering a demanding job. The vocational outcome of VR for people with schizophrenia has been modest. A comprehensive review found that between 24% and 34 % of participants gained competitive

employment with the VR model (Marshall et al., 2014). In a Swedish study 11% gained work with the VR model (Bejerholm, Areberg, Hofgren, Sandlund, & Rinaldi, 2015).

There seems to be a challenge crossing the threshold from sheltered to competitive employment, resulting in an involuntary lock-in effect where people who presumably are capable of holding competitive work remain in sheltered employment. The poor results have generated a need to improve vocational outcome, and new models have been developed.

Supported Employment/Individual Placement and Support: Place then train

The other main approach is Individual Placement and Support (IPS). It is a manualized version of Supported Employment (SE) specially developed for people with psychotic disorders. The model includes no prevocational training or sheltered work. Emphasis is on the clients' preferences and the process of finding and applying for a job, focusing on tasks such as writing a job application and practicing for an interview. Once the job is secured, the model advocates ongoing, time-unlimited support, and is coined the "place-then-train" model. There are eight defined core elements in the IPS approach: competitive employment, eligibility based on client choice, integration of rehabilitation and mental health services, attention to client preferences, personalized benefits counselling, rapid job search, systematic job development and time-unlimited and individualized support. A fidelity scale has been developed to assess the level of adherence to the eight principles (Bond, Becker, & Drake, 2011).

Over the last decades the SE/IPS model has shown improved vocational outcome for people with schizophrenia compared to VR (Bond, Drake, & Becker, 2012; Bond, Drake, & Becker, 2008; Burns et al., 2007; Burns et al., 2009; Nygren, Markström, Svensson, Hansson, & Sandlund, 2011). Participants in IPS programs were more likely to obtain competitive employment, work more hours and earn higher wages than participants in VR programs or sheltered work, with between 52% and 60% gaining competitive employment (Marshall et al., 2014). These findings were replicated in a Swedish study with 46% gaining employment with IPS (Bejerholm et al., 2015).

However, in a randomized trial of supported employment in 2054 subjects, average employment rates in the intervention group were 28.3% but only 3% earned enough income to support themselves without social security benefits (Drake et al., 2013), thus even in the best

models to date, gaining competitive, paid employment remains a challenge. Job tenure and early termination of work remain as issues that need to be addressed (Campbell et al., 2011; Catty et al., 2008; Cook & Razzano, 2000).

1.6 Assessment of vocational functioning

Comparison of vocational functioning across studies is challenging, as there is no gold standard on how to define vocational outcome, or on the choice of validated assessment tools. When planning the current study, it was important to have a validated tool for the assessment of vocational functioning. We approached the Norwegian Labor and Welfare Service and several vocational service providers, but found a general lack of validated tools in Norwegian, and a complete lack of tools assessing the functional problems associated with schizophrenia. This was a challenge, as accurate assessment of functional impairment is a prerequisite for precise evaluation of outcome in vocational rehabilitation programs (Harvey et al., 2007).

The Work Behavior Inventory (WBI) is an on-site assessment of work behavior, developed specifically for people with severe mental illness. The instrument was developed in the USA, and is well-validated for assessing areas of vocational functioning particularly relevant to people with severe mental illness (Bryson, Bell, Grieg, & Kaplan, 1999). The original version of this instrument has demonstrated good psychometric properties. In a study comparing 12 measures of vocational functioning for individuals with psychotic disorders, the WBI was judged to be practical, reliable, well-validated and quite comprehensive (Peer & Tenhula, 2010). One possible disadvantage associated with the WBI was the relative disclosure involved in the on-site assessment. People in competitive jobs often choose not to disclose their illness or the challenges they may have at work to their employer or supervisor, thereby precluding an assessment with the WBI (Peer & Tenhula, 2010).

As there was no validated instrument in Norwegian language available, we chose to translate the WBI. However, assessment instruments are sensitive both to cultural differences and to nuances in translation. It was therefore necessary not only to translate the WBI, but also to test the psychometric properties of the translated version.

1.7 The Job Management Program (JUMP)

This study is part of the Job Management Program (JUMP), a multi-site vocational rehabilitation program run in six counties in Norway, providing vocational rehabilitation enhanced by either cognitive remediation or cognitive behavior therapy techniques.

The overall aim of JUMP study was to improve vocational outcome for persons with schizophrenia spectrum disorders by targeting both internal and external barriers to employment.

The JUMP study involved extensive collaboration between vocational- and mental health service providers. There was one designated coordinator from the vocational services and one from the mental health services in each county. The coordinators promoted the study and performed the preliminary screening of participants. They were responsible for establishing collaboration between individual case workers in the vocational services and the participant's general practitioner or therapist within the health/mental health services.

The interventions were tailored to address work-related issues, and are more closely described under *3.3 Interventions*.

While competitive employment is the goal in IPS, vocational rehabilitation services in Norway have routinely offered sheltered work in a train and place tradition (Hagen et al., 2011). The JUMP study was undertaken within the established vocational rehabilitation services, thus all types of employment were considered a success. Although employment specialists were based in sheltered workshops, they were encouraged to select competitive employment whenever possible, as this was an important goal for many.

Institutionalized barriers, such as problems accessing vocational services, were addressed in the JUMP study design, where vocational services were made available to people on disability benefits, not only to those on other, less permanent benefits. Low expectations and fear of exacerbations within the staff were addressed by educating employees in vocational services and in vocational rehabilitation agencies on the benefits of work and the possibilities of success. Further, barriers to work were addressed by providing easy access to supervision and consultation by skilled mental health professionals, supporting both employment specialists and employers when coping with the challenges that arose at the workplace. A recent study supported the principle that close collaboration and ongoing, adequate support was important

to employers when hiring people with severe mental illness (Lexén, Emmelin, & Bejerholm, 2016). The internalized low expectations and fears were met through the direct collaboration with the employment specialist, partly through the cognitive approaches, and partly through encouragement and support in all situations related to work.

A crucial question is to what extent this might have contributed to help overcome the barrier of apathy.

2. Aims of the present thesis

2.1 Overall aims

The overall aim of this thesis was to examine the impact of apathy on vocational functioning in the context of the Job Management Program.

2.2 Specific aims

Paper I

The aim of Paper I was to provide a validated tool for assessment of work function. We validated the Work Behavior Inventory for use in Norway by examining the psychometric properties of a Norwegian version of the instrument,

Paper II

The aim of Paper II was to examine the impact of baseline apathy on vocational functioning at post treatment in a vocational rehabilitation study. The vocational outcome measures were the average number of hours worked from baseline to post treatment, and employment status at post treatment. We also investigated whether the two specific interventions of the JUMP study (cognitive remediation and cognitive behavior therapy) had an impact on vocational outcome.

Paper III

The aim of Paper III was to examine the impact of apathy on vocational functioning at two-year follow-up in a vocational rehabilitation study. We first examined whether apathy changed from baseline to post treatment and from post treatment to follow-up. We then examined the impact of baseline apathy and change in apathy on vocational outcome. To examine whether the vocational rehabilitation program had an impact beyond vocational functioning, we examined the impact of baseline apathy and change in apathy on social functioning.

3. Material and methods

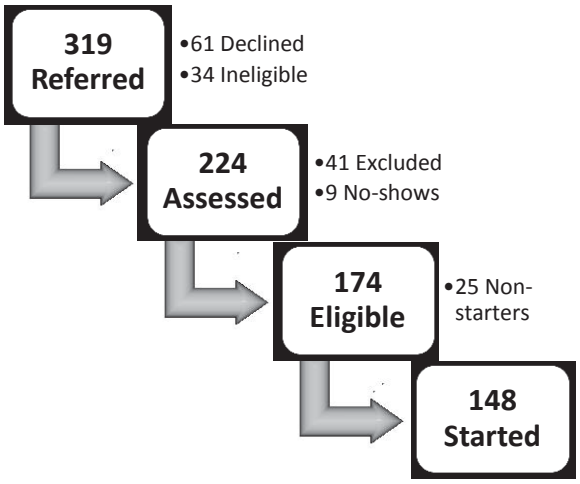
3.1 Subjects

The inclusion criteria for the JUMP study were age between 18 and 68 years, IQ of 70 or above and meeting the DSM-IV criteria for schizophrenia spectrum disorders, in this study defined as schizophrenia, schizoaffective disorder, delusional disorder and psychosis NOS. Further inclusion criteria were a motivation for work, being willing to take part in a research project, ability to tolerate the assessments and to provide written, informed consent. The participants had to understand and speak a Scandinavian language. Exclusion criteria were severe head injury with loss of consciousness for more than 10 minutes or requiring medical treatment, neurological disorder, or unstable medical condition interfering with brain function. Severe alcohol or drug dependence, violent behavior, or active suicidality assessed as a score of 3 or more on items 1, 2 and 3 on the Health of the Nation Outcome Scale (HoNOS) also lead to exclusion (Wing, Curtis, & Beevor, 1996).

Participants were referred from mental health services, social-and vocational services, GPs or from hospitals. Self-referral was also possible.

A total of 319 persons were referred to the JUMP study. Thirty-four were excluded after the initial assessments as they were not eligible, 61 declined before assessment, mainly due to lack of motivation, but also due to other obligations, such as therapy commitments or reluctance to participate in research. Of the 224 who started the assessments, 41 were excluded as not eligible, nine did not complete the assessments, and 25 completed the

assessments without entering the study. The remaining 148 persons were included in the study. Participants were assessed at baseline, post treatment, and at follow-up.



The majority of the participants (87 %) had a diagnosis of schizophrenia, 7 % schizoaffective disorder, 2% psychosis not otherwise specified (NOS), and 2 % delusional disorder.

3.2 Design

Vocational rehabilitation services in all 19 counties in Norway were invited to participate in the study, and of the 11 counties that volunteered, six were randomly selected to take part. From the six counties, three were randomly selected to provide cognitive remediation, and three to provide a cognitive behavior therapy based intervention. Participants were assessed at baseline, at post treatment (approximately 10 months after baseline) and at two-year follow-up.

The study involved collaboration between vocational and mental health services at several levels of organization. Each county had one designated coordinator for the JUMP study from the vocational services and one from the mental health services. These were experienced practitioners within each field, and collaborated closely. At an individual level the employment specialist collaborated with the local vocational and mental health services, according to need. The county coordinator for vocational services assisted in the formal demands and applications. The county coordinator from the mental health services provided weekly or bi-weekly supervision for the employment specialists on mental health issues and

on the use of the specific interventions. They were also available to employers for consultation on how to handle situations that arose at work.

3.3 Interventions

The JUMP study offered vocational rehabilitation within the established vocational rehabilitation services. The services were augmented with three elements: (1) close collaboration and support, (2) psychoeducation and (3) either cognitive remediation or cognitive behavior techniques addressing work-related issues.

3.3.1 Collaboration, psychoeducation and support

The designated county coordinators from the mental health services were responsible for establishing close collaboration between all involved parties, such as participants, general practitioners, mental health workers, employers, family and social and vocational services.

Employment specialists provided continuous support for the participants during the intervention period. This included weekly meetings to provide the cognitive interventions.

The county coordinators offered education on characteristics, risk factors, course and prognosis of psychotic disorders to the employment specialists and to employees in the vocational services. In addition knowledge about schizophrenia was provided to the participants and could be provided for employers or co-workers at the participants' discretion.

3.3.2 Cognitive interventions

Another aspect of the JUMP study was to provide psychological treatment in the vocational rehabilitation setting, using recognized methods to address specific work related challenges. Cognitive behavior therapy (CBT) and cognitive remediation (CR) address different aspects of the illness. Cognitive behavior therapy addresses thought *content*. It was originally developed to treat anxiety and depression, but has since been adapted to treat positive, and more recently, negative symptoms of schizophrenia. Cognitive remediation addresses thought *process*, and is mainly used to alleviate the cognitive impairments associated with

schizophrenia. Both symptoms and cognition are central to vocational functioning in schizophrenia. CR and CBT are well established in the treatment of schizophrenia, and augmenting vocational rehabilitation with either CR or CBT have been shown to improve outcome in vocational rehabilitation (Lysaker P, Bond, Davis LW, Bryson GJ, & M., 2005; McGurk & Mueser, 2004).

The employment specialists were trained to provide these interventions. They received an eight hour introductory course covering elements common to the two interventions, such as a general understanding of schizophrenia, and a 40 hour course on the specific CBT and CR interventions. Furthermore they were supervised by a skilled mental health practitioner throughout the study.

3.3.2.1 Cognitive behavior therapy

CBT has increasingly been applied in the treatment of schizophrenia (Brabban, Tai, & Turkington, 2009; Turkington, Dudley, Warman, & Beck, 2006). When this study was starting up, a rigorous meta-analysis found favorable results for CBT for psychosis, compared with treatment as usual and other psychological treatments (Wykes, Steel, Everitt, & Tarrier, 2008).

The employment specialists in the CBT intervention were taught the frequently encountered problems in vocational rehabilitation for persons with psychotic disorders, for instance social withdrawal, lack of initiative and motivation, delusions and hallucinations that interfere with work ability. They were also taught the basic principles of CBT, and various techniques including Socratic dialogue, problem solving, cognitive restructuring, behavioral experiments, and the use of homework. A translated version of "Cognitive Therapy of Schizophrenia" (Kingdon & Turkington, 2005; Kingdon, Turkington, Kjær, Kravik, & Persons, 2007) provided the theoretical basis for the CBT intervention. In addition a manual provided step-by-step instructions, work sheets and examples of some central techniques. The boundaries between the role of the employment specialist applying CBT for work related issues, and the role of the participants' therapist were discussed and clarified as and when such issues arose. The employment specialist endeavored to employ the CBT techniques to help the participant address work-related problems only, referring other issues to the therapist.

3.3.2.2 Cognitive remediation

In a thorough meta-analysis CR showed positive effects on cognition and functioning among patients with schizophrenia, but not on symptoms. The best effects were achieved when CR was combined with psychosocial rehabilitation (McGurk , Twamley, Sitzer, McHugo, & Mueser, 2007; Wykes, Huddy, Cellard, McGurk, & Czobor, 2011). In the JUMP study, the CR intervention employed a computer-based approach, based on the principle of errorless learning, where the supervisor adapted the program to suit the participant's skills. The employment specialists in the CR intervention group were educated on neurocognitive impairment in psychotic disorders; characteristics, prevalence and stability, interaction with other symptoms, and consequences for functioning in general and vocational functioning in particular. They were also taught the basic principles of cognitive remediation, use of the computer software and strategies to transfer knowledge and skills acquired through training to the work setting. The CR program included the following elements: Feedback from the neurocognitive assessment, negotiation of personal aims for the training, psychoeducation about cognitive impairment, and two weekly training sessions of computer based training. The training was made relevant to everyday tasks and to challenges faced in the work situation.

3.4 Measures

3.4.1 Clinical assessments

Diagnosis

The diagnostic evaluation was carried out by trained and calibrated clinicians using the MINI-International Neuropsychiatric Interview (Parts A, C, D, K, L and M), a structured clinical interview providing DSM-IV diagnoses (Sheehan et al., 1998). The Longitudinal, Expert, All Data (LEAD) procedure (Kranzler, Kadden, Babor, & Rounsaville, 1994) was applied when necessary, with additional data collected from mental health professionals and other central providers of care.

Cognitive ability

IQ was assessed with The Wechsler Abbreviated Scale of Intelligence (WASI), using the two subtests form including Matrix reasoning and Vocabulary (Wechsler, 2007).

Psychotic symptoms

The current level of positive, negative and general symptoms were rated using the Structural Clinical Interview of the Positive and Negative Syndrome Scale (SCI-PANSS) (Kay, Fiszbein, & Opler, 1987).

Apathy

Apathy was measured with the Apathy Evaluation Scale (AES) developed by Marin to assess apathy in both neurological and mental disorders (Marin et al., 1991). The AES consist of 18 items scored on a 1-4 Likert scale (1= Not at all characteristic, 2= Slightly characteristic, 3= Somewhat characteristic, 4= A Lot characteristic), yielding a sum score range of 18-72. The time frame is the last four weeks. Questions cover goal-directed behavior, cognition and emotion, and are mainly positively worded ("I get things done during the day", "I'm interested in learning new things" and "When something good happens, I get excited"). Positively worded items were reversed for analysis in the JUMP study. High scores indicate more apathy. Items 10 and 11 are negatively worded, and were not reversed. There are three versions of the AES: self-reported, clinician rated, and informant rated. Marin (1991) found the clinician-rated and self-rated versions of the AES to be moderately correlated (r=.72). Further AES was found to discriminate well between patients and controls and between apathy and depression in several diagnostic groups, including psychosis (Faerden et al., 2009; Kiang et al., 2003; Marin et al., 1991).

In the current study the 18-item self-rated version was used (Cronbach's alpha =.89).

Depression

Depression was measured with the Calgary Depression Scale for Schizophrenia (CDSS) (Addington, Addington J, Maticka-Tyndale E, & Joyce J, 1992), a nine item clinician rated scale with item scores ranging from 0 to 3 (0=Absent, 1=Mild, 2=Moderate and 3=Severe) yielding a sum score range of 0-27 (Cronbach's alpha in the present study = .82). The time frame is the last two weeks.

Differentiating between depression and negative symptoms is a challenge. Some overlap is due to similarities in symptoms, some to comorbidity, and the amount of overlap varies with the type of measures used. In view of these challenges, the CDSS has been found to differentiate well between depression and negative symptoms (Addington et al., 1992; Kim et

al., 2006). Cut off for major depression was set at six (Addington, Addington, & E., 1993), a cut off that detects major depression with good sensitivity and specificity (Sonmez et al., 2016). As expected, the depression scores were skewed, thus we dichotomized the scores and applied this cut off level for the CDSS.

Duration of illness

Duration of illness was retrieved from hospital records and was defined as the time from the first contact with the mental health services for psychotic symptoms to the participant's entry into the JUMP study.

3.4.2 Functional assessments

There is no clear consensus in the literature on how to define vocational outcome. In the current study we have applied the average number of hours worked per week during the study, employment status at post treatment and at follow-up, and work behavior at post treatment. Hours worked were registered weekly during the intervention, as well as at post treatment and at follow-up. Employment status was registered at post treatment and at follow-up, while work behavior was assessed at post treatment, but not at follow-up.

Work Behavior Inventory

Work behavior was assessed with the Work Behavior Inventory (WBI) (Bryson, Bell, Lysaker, & Zito, 1997), an on-site assessment tool developed particularly to assess work behavior relevant for people with severe mental illness. The assessment is based on a brief observation of the person at work, and an interview with their immediate supervisor. The WBI has 36 items comprising five sub-scales with seven items each and one global rating of the general vocational functioning. The five subscale sum scores add up to a WBI total score. The five scales (example items in parentheses) are A: Social skills (Seems comfortable when approached by co-workers), B: Cooperativeness (Listens attentively to instructions), C: Work quality (Work is done accurately), D: Work habits (Begins work tasks promptly) and E: Personal presentation (Refrains from inappropriate joking and profanity). Each item is scored on a five-point scale (1 =Consistently an area needing improvement , 2 = Occasionally an area needing improvement , 3 = Adequate performance , 4 =Occasionally an area of superior performance, and 5 =Consistently an area of superior performance) yielding a sum score

range of 7-35. The rater's guide provides detailed descriptions of behavior for the scoring of each item. In the current study, work behavior was rated by employment specialists who had received training in the use of the WBI.

The WBI was translated into Norwegian by a bilingual psychologist and a master of neuroscience, and back-translated by a native English speaker. The translation has been approved by the American developers as the official Norwegian version. To ensure content validity of the Norwegian version of the WBI, the individual items and the description in the rater's guide were discussed in an expert panel including the JUMP study research team. The panel decided to replace the term "performance" in the scoring key with "functioning" in the Norwegian version, and to adjust the content of item E5 slightly (Comes to work appropriately dressed). The American version specifies pressed clothes and polished or well-kept shoes. This specification has been removed, as the dress code in Norway rarely includes this level of finish. Further, the content validity of B4 (Follows directions without resistance) and B5 (Listens without interrupting when given instructions) were discussed, as the Scandinavian work culture normally tolerates and sometimes even encourages critical questions and attempts to solve tasks in new ways. In the same way item C4 (Takes breaks only when scheduled) was discussed, as employees in many Norwegian firms are expected to take reasonable breaks, while the length and frequency are often not specified, leaving the judgment to the employees. Even if these three items might have uncertain content validity, the panel chose to include them without modification in a principal component analysis. With this small change on one item, and an awareness of possible cultural issues, all items were included.

Ideally, work behavior should be measured at both post treatment and follow-up. However, the WBI requires a degree of disclosure as it involves an interview with an immediate superior at work. At follow-up participants were not necessarily in close contact with the employment specialist, and might be working in settings where they did not wish to disclose. Completing the assessments would also require more resources, and for these reasons WBI was not assessed at follow-up.

Work and education

Number of hours worked were registered weekly throughout the study by the employment specialists. The average number of hours worked per week during the intervention was used as a measure of vocational functioning. Employment status was registered by mental health clinicians at post treatment and at follow-up.

Type of employment included the following categories: competitive work, work placement, sheltered work and no work. By work placement we mean a time-limited placement in a regular workplace where the person works for benefits without receiving wages.

Information on education and work history was obtained by interviews performed by experienced mental health clinicians. The highest completed education was recorded as number of years at school. Work history comprised the total number of months worked with part time or full time employment, irrespective of whether the participant received wages or worked for benefits.

Social functioning

The Social Functioning Scale (SFS) (Birchwood, Smith, Cochrane, Wetton, & Copestake, 1990), is a measure of daily life and community social functioning. It was developed to measure different areas of functioning that are crucial to the community living for individuals with schizophrenia, and to synthesize this detailed reporting into coherent, reliable scores. The SFS is based on self-report, and the original scale has been demonstrated to be reliable, valid and sensitive to change for patients with schizophrenia (Birchwood et al., 1990).

The SFS consists of 76 items on seven subscales, addressing the following aspects of community living: 1) Withdrawal (time spent alone, initiation of conversation, social avoidance), 2) Interpersonal behavior (number of friends/having a romantic partner, quality of communication), 3) Pro-social activities (engagement in a range of common social activities) 4) Recreation (engagement in a range of common hobbies or interests) 5) Independence-competence (the ability to perform skills necessary for independent living) 6) Independence-performance (frequency of performance of those same skills). The seventh scale, Employment (employment or engagement in a structured program of daily activity) was not applied in the JUMP study, as we had other measures of employment. The items indicate how often a set of activities were undertaken within the last three months, with one exception; the Independence

competence scale assesses the person's evaluation of their ability to undertake an activity if necessary.

Each subscale was standardized and normalized to a scales score with a mean of 100 and a standard deviation of 15, based on a sample of 334 unemployed individuals with schizophrenia. The SFS total mean score was computed by summing the scaled scores of all subscales. The Norwegian version has been validated for people with schizophrenia and bipolar disorder (Hellvin et al., 2010).

Participants were given both oral and written instructions on how to fill out the forms, with time to ask questions if they were in doubt about the meaning of specific items. The SFS was scored at all three time points.

3.5 Statistics

Analyses were performed using IBM SPSS 20 and 22 (IBM, 2011). All tests were two-tailed. The significance level was set at p=.05. Mean differences between groups were examined with independent or paired samples t-tests. Chi^2 tests were used for categorical variables.

To identify the dimensional structure of the Norwegian version of the WBI we conducted principal component analyses (PCA) with varimax rotation. The internal consistency of each subscale was assessed using Cronbach's alpha. To examine validity, we calculated the correlation between the WBI subscale and global scores, and the SFS total score and age, work history and education.

To compare baseline demographic variables and outcome between the two cognitive interventions, Chi-square tests were used for dichotomous variables, and student t-tests for continuous variables. In order to determine the influence of baseline apathy on vocational outcome both logistic and linear regressions were performed. Multiple logistic regressions were performed for dichotomous outcome variables and multiple hierarchical linear regressions for the continuous outcome variables, entering potential predictors of functioning as covariates: age, gender, education, work history, duration of illness, depression and apathy (Fervaha et al., 2014b, 2015; Tsang et al., 2010; Üçok et al., 2012), correcting for PANSS positive. For the change in apathy over time a linear mixed model analysis was performed.

3.6 Ethical considerations

The study was approved by the Regional Committee for Medical Research Ethics and The Norwegian Data Protection Authority. ClinicalTrials.gov Identifier: NCT01139502.

All participants provided informed consent to participate. They were given a thorough description of the study both verbally and in writing, with information on the purpose of the study, the procedures, data collection and provision of both vocational rehabilitation and either CR or CBT.

The test battery was comprehensive, and being able to tolerate the tests was a prerequisite to be included in the study. Great effort was made to provide a supportive environment for the tests, breaks were provided, and tests were taken over several days in order to make them tolerable for the individual.

Disclosure at work is an important issue, with the fear of stigma and discrimination. There are various levels of disclosure, and there are choices to be made about the context and content of disclosure. These issues were discussed with participants. Disclosure was at the participants' discretion, and therefore varied from full disclosure of diagnosis and individual challenges to supervisors all co-workers, through disclosure of some challenges to the immediate supervisor and closest co-worker, to no disclosure at all.

4. Results

In this thesis we examined the impact of apathy on vocational and social functioning within the context of a vocational rehabilitation study. We followed 148 participants over two years, and examined apathy and aspects of vocational and social functioning at baseline, post treatment and at follow-up. Assessing vocational functioning for people with schizophrenia has been challenging, partly due to the lack of validated assessment tools, and in this thesis we validated the WBI.

Paper I: Validation of the Work Behavior Inventory

- The principal component analysis produced three substantial and reasonably clean factors, with corresponding subscales providing a good representation of the data (Cronbach's alpha ranging from .77 to .93).
- The three subscales were termed Social skills revised, Work quality revised and Compliance with work norms.
- This change in factor structure from five to three factors may in part be due to differences in sample characteristics or in workplace culture in the USA and Norway. The WBI remained sensitive to known predictors, differentiating vocational functioning according to age, education and work history.

Paper II: Vocational functioning in schizophrenia-spectrum disorders – does apathy matter?

- Apathy score at baseline predicted the mean number of hours worked per week during the study
- Apathy score at baseline did not predict employment status or work behavior post treatment.
- There was no significant difference in apathy scores at baseline, post treatment or at follow-up between the employed and unemployed.

Paper III: The impact of apathy on vocational and social functioning in persons with schizophrenia spectrum disorders – a two-year follow-up

- There was a modest improvement in apathy from baseline to follow-up, with the main improvement occurring between baseline and post treatment.
- Baseline apathy score did not predict vocational functioning at follow-up.
- Baseline apathy score predicted social functioning at follow-up.
- Change in apathy score did not predict vocational or social functioning.

5. Discussion

5.1 Summary of main findings

- A principal component analysis of the Norwegian translation of the WBI produced three factors with corresponding subscales (Social skills revised, Work quality revised and Compliance with work norms). These subscales provided a good representation of the data.
- The main finding of this thesis was that apathy was not a strong predictor of vocational outcome in the context of the JUMP study. Apathy predicted the number of hours worked during the study, but not work behavior at post treatment or employment status at post-treatment or follow-up. There was no significant difference in apathy between the employed and the unemployed, and the results did not differ across interventions.
- Apathy predicted social functioning.

5.1.1 A three dimensional structure of the Norwegian version of the WBI

There are inherent challenges to translating a tool from one language and culture to another. Subtle changes in understanding due to linguistic nuances or cultural differences may influence how the instrument performs. While the USA and Norway are both Western countries with many similarities, there are some important differences between them in the social structures in the work-place. For instance, maintaining a good relationship with coworkers seems to be more important in working life in Norway, while production appears to be more valued in the USA (Ennova, 2013; Sjøvold & Park, 2007). A survey of leadership styles in 28 countries found that US leadership style was primarily characterised by focus on production, clear expectations and feedback on performance, while the Scandinavian leadership style was primarily characterised by its focus on building good relationships and maintaining trust and security at work, and by a lack of individual performance goals and direct feedback (Ennova, 2013). According to this study employees in Norway would deviate from their production goals in order to maintain good relationships at work, while the US employees would tend to maintain their focus on production goals (Sjøvold & Park, 2007).

The difference might conceivably influence the rating of the WBI, which is a performance based measure. If the Norwegian raters were more focused on relationships than on production, we might expect higher WBI scores for the work quality items in the JUMP study than in comparable studies in the USA. However, the mean subscale scores of the WBI in the JUMP study fell between those in two US vocational rehabilitation studies for people with similar diagnoses (Bell, Lysaker, & Bryson, 2003; Bryson et al., 1997). Thus it seems that the possible differences in the work-place priorities did not lead to clear differences in ratings, and the Norwegian raters seemed to apply the rating scale as it was intended.

There is one exception. When comparing scores on the original scales, the JUMP participants were rated slightly higher than participants in the two US studies on the items of the personal presentation subscale. When translating the WBI, we discussed the items of this subscale and adjusted the raters' guide, as the dress code in Norway is more casual than in the USA, probably making it easier to gain a high score on dress code items. The remaining items of the personal presentation subscale address inappropriate behavior. These were also discussed, but found to be in accordance with our understanding of inappropriate behavior at work. The higher scores in the JUMP study possibly reflect selection bias. As this was the first study in Norway providing vocational rehabilitation for people with schizophrenia, therapists and others who referred participants to the study may have selected those most likely to succeed, and it is possible that they would be somewhat reluctant to refer people with higher levels of inappropriate behavior to the study.

The significant correlations between work history and work quality, compliance with work norms and WBI global score support the criterion validity of the WBI. In conclusion the three subscales in the Norwegian version of the WBI displayed good psychometric properties, and may be used to reliably assess work behavior for people with schizophrenia.

5.1.2 Apathy was moderately reduced during the intervention

There was a significant, but small reduction in apathy during the intervention period between baseline and post-treatment. This reduction was followed by a slight, non-significant increase in apathy from post treatment to follow-up. In all there was a moderate but significant

reduction in apathy from baseline to follow-up. This finding indicates that vocational rehabilitation according to the JUMP model did not alleviate apathy to any important degree.

Does the moderate change demonstrate the stability of apathy, or does it indicate general slow improvement in apathy even in a stable phase?

Apathy may be characterized as primary, that is to say persistent and inherent to schizophrenia. It may also be characterized as secondary to the condition, as a normal response to environmental factors. This secondary apathy is commonly found among people experiencing adverse life events such as illness or hospitalization (Marin, 1990; Möller, 2007). Being diagnosed with schizophrenia may in itself be an adverse life event for many, due to public stigma, self-stigmatization and functional impairments (Fervaha et al., 2015; Lauber et al., 2006; Lloyd & Waghorn, 2007). The symptoms of schizophrenia may lead to periods of hospitalization, adverse effects on educational, vocational and social functioning and social isolation, circumstances that might evoke secondary apathy (Möller, 2007). In Norway this situation may be exacerbated by the high level of unemployment and poor access to vocational services for people with mental illness (OECD., 2013). Taking part in a vocational rehabilitation study, gaining access to scarce vocational services and being met with hope and expectations of success may counteract some of the self-stigmatization and isolation associated with schizophrenia.

Following this train of thought, the modest improvement in apathy could be due to the alleviation of secondary apathy.

This argument assumes that participants with higher levels of apathy lived in an impoverished environment before entering the JUMP study, and that the provision of the JUMP intervention would enrich their environment. The JUMP intervention provided frequent contact between participants and employment specialists, the opportunity to work, and weekly sessions of CBT or CR to cope with work-related issues. Employment specialists offered hope, encouragement and support. Each of these actions could constitute an enrichment of the environment by breaking social isolation, filling a role as a worker and experiencing rewards, and might arguably provide an enriched environment conducive to the alleviation of secondary apathy.

Persistent negative symptoms are well described in schizophrenia (Kirkpatrick et al., 2006), and negative symptoms are seen as highly stable in the non-acute phase of illness (Möller, 2007). Recent research does however question the stability of negative symptoms (Savill et al., 2015). While the improvement in negative symptoms was modest in many studies, these findings moderate our understanding of negative symptoms, indicating that they are less resistant to change than we believed.

The participants in the JUMP study were mainly in a non-acute phase when they entered the study. The modest improvement in apathy during the study may thus be an expression of a general trend towards improvement over time, and not a response to the enriched environment provided by the JUMP intervention.

The improvement in apathy was so modest that it is of questionable clinical importance, and might indicate that even with comprehensive interventions, improvements in apathy are slow.

5.1.3 Apathy predicted hours worked per week

Baseline apathy was associated with the average number of hours worked per week during the study, with higher levels of apathy predicting fewer hours worked per week. Thus apathy had a negative impact, not on whether people worked or not, but on the number of hours worked.

Apathy is associated with a reduced willingness to exert effort to achieve rewards (Green et al., 2015; Hartmann et al., 2015). This lack of effort is one aspect of the reduced goal directed behavior characteristic of apathy (Buck & Lysaker, 2013; Foussias et al., 2014). Applying these findings to the work setting, we may assume that working demands effort, and that for people with higher levels of apathy this effort may be perceived as too demanding in relation to the potential future rewards.

The distinction between consummatory and anticipatory hedonism (Foussias et al., 2014) may be of importance here. In addition to monetary rewards, the anticipation of future pleasure motivates us to act in order to achieve a goal (Buck & Lysaker, 2013). Intact consummatory hedonism allows participants to enjoy work while they are working. Anticipatory anhedonia means that they do not anticipate having the same pleasure from working tomorrow or next

week, and so are deprived of looking forward to work, or the lunch break, or meeting co-workers, whichever aspect of work they enjoy when in the moment.

Working more hours a week requires more effort in the present in order to gain a future reward, such as higher wages or more interesting tasks. If the ability to anticipate pleasure is impaired, we are asking people to exert effort without being able to offer them a reward they perceive as rewarding.

Thus our results indicate that irrespective of apathy, people with schizophrenia can work although they may work fewer hours a week.

5.1.4 Apathy did not predict employment status

We found no significant difference in the level of apathy between the employed and the unemployed at baseline, post treatment or at follow-up. Moreover, neither baseline apathy nor change in apathy predicted employment status at post treatment or follow-up. This is in contrast to the general understanding of apathy as a robust predictor of concurrent and future vocational functioning (Fervaha et al., 2015; Galderisi et al., 2013; Strauss et al., 2013). As apathy did not improve importantly during the study, the change in employment status cannot be explained by improvement in apathy, but rather by some aspects of the intervention compensating for the impact of apathy on vocational outcome.

Considering the comprehensive evidence on the impact of apathy on functioning, it was somewhat surprising that apathy had little impact on vocational functioning in the current study. In a comprehensive review McGurk and Mueser compared outcome in general schizophrenia populations with outcome for people with schizophrenia receiving vocational services. While negative symptoms predicted vocational outcomes in the general schizophrenia population, they did not consistently predict vocational outcomes for people receiving vocational services, suggesting that vocational services might attenuate the impact of negative symptoms on work outcomes (McGurk & Mueser, 2004).

Which aspects of work and of the JUMP study might contribute to this attenuation?

Anticipating and recollecting pleasure is found to be impaired in people with schizophrenia, while enjoying the pleasure of the moment remains intact (Foussias et al., 2014). Interestingly

consummatory hedonism is independent of impaired emotional expression, thus the lack of expression of pleasure does not necessarily indicate lack of experienced pleasure. Impaired expression of pleasure together with lack of initiative may conceivably lead service providers to believe that work was unimportant, while the importance of work for people with schizophrenia is well documented (Auerbach & Richardson, 2005; Davis & Rinaldi, 2004; Marwaha & Johnson, 2004, 2005; Mueser et al., 2001).

Assessing motivation and potential for work in a person with apathy may be particularly challenging, as apathy often entails a lack of plans, lack of emotional expression and poverty of goal directed behavior (Marin, 1996). Service providers are thus given few clues as to the person's interest or ability to work. In a client-centered approach, this lack of expressed interest and goals may hinder access to work or vocational services. Barriers to work may be classified as internal or external, but exist in close interplay. Poverty of initiative and drive constitutes an internal barrier, while scant provision of vocational rehabilitation and work constitutes an external barrier, both potentially contributing to low employment rates.

In the JUMP study all participants were offered work, either sheltered or competitive, therefore obtaining work did not depend on the individual's ability to express interest or motivation for work. Equal employment rates regardless of apathy indicate that this barrier was overcome in the JUMP study, probably through the provision of work for everyone enrolled in the study. One clinical implication is not to wait for people with schizophrenia to express motivation to work before offering work or vocational services. Assuming that there has been a good job match providing some pleasure at work, participants in the current study would in general enjoy work as much as healthy controls, albeit with diminished capacity to anticipate enjoying work again tomorrow. The clinical implication of anticipatory anhedonia may be the need for continued support.

In the current study, there was no significant difference in employment rates according to level of apathy, thus people with apathy were making the necessary effort to go to work over a period of time.

What constitutes a success (or a desired effect) may vary, but in the JUMP study success could be coping with work demands such as arriving on time, completing tasks or having a conversation at lunch.

Expectation of success is an important aspect of motivation, with people exerting more effort if they believe they may succeed. Defeatist beliefs, low expectations of success and reduced willingness to exert effort are however more prevalent in schizophrenia than in healthy controls (Foussias et al., 2014; Green et al., 2015). Understanding how we may improve belief in success is important for vocational functioning, as it is necessary in order to 'persevere in the face of difficulty'.

Expectation of success is linked to self-efficacy, to believing in one's personal capacity or ability. Interestingly, the expectation of success may be influenced by the environment, and provision of rewards within a supportive environment may improve the expectation of success (Medalia & Brekke, 2010). With higher expectation of success people are willing to exert more effort to reach a goal, and succeeding at a task further increases the motivation to try again (Medalia & Brekke, 2010). The old proverb "Nothing succeeds like success" may be important in vocational rehabilitation. Changing the expectation for success is therefore important. In a recent study, providing four months of a CBT-based approach addressing defeatist beliefs and motivation to work, participants improved their defeatist beliefs and motivation to work, but more importantly showed stronger adherence to SE after the intervention was ended (Mervis et al., 2016). The authors argue that the metacognitive approach may provide participants with skills to maintain their motivation for work.

People with schizophrenia have trouble assessing the complexity of a task and the value of the potential reward, being biased towards seeing the task as insurmountable and the reward as unimportant. Having well defined, proximal goals that you are likely to reach, improves the will to exert effort (Medalia & Brekke, 2010). As success is so important, and proximal, attainable goals are central to success, starting with simple tasks might give hope for future success, thereby increasing self-efficacy and goal directed behavior. In the JUMP study the type of work was registered weekly and categorized according to complexity. The majority of participants held jobs with tasks of low complexity (Lystad et al., 2016). While such simple tasks might be under stimulating for some of the participants, they may increase the perceived chance of success for others, giving hope for future success. Employment specialists may have compensated for lack of initiative and drive by providing job opportunities and offering support. Through their expectations and general interest employment specialists probably activated the person repeatedly throughout the working day. The employment specialists'

support probably also increases the participants' belief in success, thereby increasing effort and counteracting the effect of apathy.

5.1.5 Apathy did not predict work behavior assessed with the WBI

The negative effect of apathy on work behavior measured with the WBI has varied between studies(Erickson et al., 2011; Evans et al., 2004; Saperstein et al., 2011), suggesting that the relationship between apathy, vocational rehabilitation and outcome is complex, and that VR does not consistently moderate the negative impact of apathy on vocational functioning.

Due to the association between apathy and social withdrawal (Strauss et al., 2013) we expected participants with higher levels of apathy to be more withdrawn, and to show less initiative to engage in social interactions at work. The cognitive and emotional aspects of apathy, such as having no interest in doing anything or displaying emotional indifference (Marin, 1991) may affect social interactions. Items from the Social skills subscale assess social initiative, such as joining groups, appearing interested in others or seeming comfortable with others, aspects of social functioning that would be impaired by emotional indifference.

The lack of association between apathy and the social skills subscale may be due to the structured activity of the JUMP interventions. Working provides opportunities to interact with others and to practice and improve social skills (Burns et al., 2009; Lehman et al., 2002; Ruesch et al., 2004). Participating in scheduled weekly CBT or CR sessions and working entail social interaction and provide opportunity to practice social skills.

According to Marin, lack of goal-directed behavior is one of the key elements in apathy, with behavioral impairment ranging from lack of efficiency to severe passivity requiring prompting in order to perform basic tasks (Marin, 1991, 1996). Items on the Work quality subscale assess whether work is done efficiently, whether there is need for prompting, the ability to adhere to a time frame or taking initiative. These are work behaviors that correspond closely to Marin's description of the behavioral expression of apathy. We expected apathy to predict work quality, as work quality entails making an effort, paying attention to detail and maintaining that effort over time, aspects that may be challenging for people with higher levels of apathy (Green et al., 2015). Sustained support was an important element in the

current study and providing frequent prompting, adaptations or compensatory strategies at work may have compensated for the lack of initiative and drive inherent to apathy.

The Complying with work norms subscale addresses issues such as appearance and dress, which demand some mastery of basic tasks. However, this subscale also addresses impulse control through items such as refraining from interrupting or refraining from saying unsuitable things. Refraining from action should conceptually be less challenging than being active for people with apathy.

5.1.6 Apathy predicted general social functioning

Apathy predicted social functioning on all the subscales in Birchwood's social functioning scale but one. These associations were in keeping with a body of literature demonstrating that apathy/negative symptoms predict vocational and social functioning in both cross-sectional and longitudinal non-intervention studies (Campbell et al., 2011; Faerden et al., 2013; Fervaha et al., 2015; Foussias et al., 2014; Hunter & Barry, 2012; Kiang et al., 2003).

We were interested in whether the benefits of taking part in the JUMP study might generalize to other areas of life. Taking part in the JUMP study involved some important changes to everyday life for many participants. It involved working (usually two or more days of part-time work a week), social interaction with an employment specialist and receiving a cognitive intervention. While the JUMP interventions did not target social functioning outside the workplace, we envisaged that working would provide an opportunity for practicing aspects of social functioning such as using public transport, spending less time alone and more time with others, or finding a new friend or interest.

We therefore examined whether the provision of opportunity and support would attenuate the association between apathy and social functioning outside the working arena. The impact of apathy on general social functioning was however maintained, demonstrating that the JUMP model compensated for the impact of apathy in the vocational context only.

The one scale not associated with apathy was Independence: Competence, the subjective assessment of one's own ability to perform daily living tasks. So while apathy had a negative

impact on performing social tasks, it did not predict the self-evaluation of the capacity to perform various tasks.

On the one hand this could be due to poor understanding of one's limitations due to impaired insight (Tandon et al., 2009). It may however also be an accurate assessment of own ability, where the opportunity and not the ability is missing. Interestingly, the current study has demonstrated that apathy did not prevent participants from performing work tasks. Thus they possessed the competence, and applied it, given adequate support.

5.1.7 Methodological issues

Representativity and generalizability

Participants in the JUMP study were recruited from six counties across the country, varying from urban and densely populated to more sparsely populated areas, representing the variety found in Norway. Participants were mainly referred by the person providing treatment or vocational services. Self-referral was also possible. In order to secure broad recruitment, a wide range of therapists, case workers and GP's were informed, and information leaflets were placed in waiting rooms where patients and families might find them. Furthermore, alcohol- and substance abuse, suicidality or violence was only an exclusion criterion where problems were severe, and there was no cut-off for psychotic symptom level at inclusion. One limitation was that participants had to tolerate the assessments.

There were however initial challenges with recruitment, as therapists and family at times expressed concern that the stress of work would lead to exacerbation of symptoms. This well-documented concern may have given a biased sample. People with more severe and ongoing symptoms may not have been informed about, or referred to the study. We therefore consider that they may be underrepresented in the study.

With these limitations the findings should be generalizable to a large, heterogeneous group of people with schizophrenia living in urban and more sparsely populated areas, who wish to work.

Assessments

The diagnostic and clinical assessments applied in this study are widely used instruments. To ensure reliable assessments, assessors at all sites were trained and calibrated, and received supervision during the study. In order to secure as unbiased assessments as possible, independent psychologists performed the diagnostic interviews and the assessments of cognition and symptoms. The mental health coordinator in each county collected sociodemographic data and self-report forms. The employment specialists assessed the WBI, but in order to keep bias to a minimum, they did not assess the participants they were directly involved with.

Self-report forms provide subjective evaluation of symptoms or functioning. There is however a risk of bias, as shame, lack of insight or trust may affect the information given. It may lead to both under- and over-reporting of symptoms or function. The challenge of bias is not exclusive to self-rating, as the same dynamics may play a part when clinicians do the rating. Two important scales for this study, the SFS and the AES have been found to provide reliable information in self-report forms (Hellvin et al., 2010; Marin, 1990). Effort was made to provide a secure and friendly atmosphere in order to build trust and hopefully reduce shame.

Duration of illness was assessed by accessing patient records, finding the first consultation describing symptoms of psychosis, and calculating the time to entry in the JUMP study. While this information is retrospective, recording psychotic symptoms on first presentation is important for diagnosis and for treatment, giving reasonably valid data. For work history we have relied on the participants' and therapists' memory, and sometimes on patient records, thus these numbers may be more open to bias.

5.1.8 Strengths and limitations

There are some strengths and limitations to this study that need to be considered.

The comprehensive screening and inclusion process ensured that participants were well informed of the study and their part in it. We sought to apply broad inclusion criteria, including participants with moderate substance- and alcohol use/abuse, suicidal ideation and aggression.

Providing two active interventions, CBT and CR in a vocational setting is clinically important as it may enable people with schizophrenia to cope with work. The study has a relatively large sample for a vocational rehabilitation study, and the two-year follow-period gives us opportunity to examine the effect of the JUMP study over time. There are however methodological issues.

Selection bias has been a concern in the study. Lack of initiative and goal directed behavior inherent in apathy might prevent people with high levels of apathy from entering the program. Furthermore, the comprehensive screening and assessment procedure may have excluded those with the highest levels of apathy from attending the program.

The study design originally included a control group receiving standard vocational rehabilitation. Sadly there were no participants with schizophrenia-spectrum disorders receiving vocational rehabilitation in any of three selected control counties during the two years of recruitment. This finding adds to the impression that people with schizophrenia and schizophrenia-spectrum disorders are rarely offered vocational rehabilitation and that there are severe barriers to their work for this group. It further implies that the JUMP study was providing a novel service within vocational rehabilitation in Norway at that time.

5.2 Implications for clinical practice and future research

With the validated Norwegian WBI we now have a tool for assessing work behavior in people with severe mental illness. The WBI assesses three areas: social skills, work quality and complying with work norms, providing information on strengths and on areas in need of improvement. The WBI can provide important information to guide vocational rehabilitation interventions.

Contrary to our expectations and to the existing evidence, participants in the JUMP study worked, irrespective of the level of apathy. An important clinical implication of the JUMP study is therefore not to wait for people with schizophrenia to express motivation to work before offering work or vocational services.

The JUMP interventions attenuated the relationship between apathy and vocational outcome. The specific elements are however difficult to disentangle. The close collaboration between

health and vocational services addressed societal barriers to employment, such as access to vocational services and stigma; therefore this collaboration may be a key to success.

Furthermore the CBT and CR interventions were delivered by a person with intimate knowledge of the challenges and possibilities at work, addressing the illness-related barriers to employment. In both intervention groups the employment specialists applied the techniques and encouraged the use of coping skills. We therefore think that providing the CBT and CR interventions in such close proximity to the real work environment may be a key to success.

Apathy maintained its negative impact on social functioning. Thus the positive results on vocational functioning did not generalize to social functioning, supporting the need for tailored interventions directed specifically at social functioning.

This thesis supports the increasing evidence that many people with schizophrenia are willing and able to work, given the appropriate support. Providing cognitively augmented vocational rehabilitation may contribute to the acquisition of work and the integration of people with schizophrenia in society, a step towards recovery and a way back to leading a productive and hopefully satisfying life.

6. Conclusion

This thesis examined the impact of apathy on vocational functioning in a vocational rehabilitation study. Apathy was fairly stable, demonstrating only a moderate improvement during the study. The modest change in apathy did not predict functional outcome. We found that apathy had no impact on employment rates or work behavior, while higher levels of apathy predicted fewer hours worked per week.

The results indicate that vocational rehabilitation augmented with either CR or CBT may largely compensate for the negative impact of apathy on vocational functioning, while some impairment remains in the form of hours worked. The results did not generalize to social functioning, supporting the need for targeted interventions to improve social functioning outside the workplace.

The use of these methods may enable more people with severe mental disorders to experience the gains of being part of the work force and contribute to society.

7. References

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Errata

Abbreviations

The abbreviation for National Institute of Mental Health NIHM is corrected to NIMH

Symptom is corrected to Syndrome in Positive and Negative Syndrome Scale and in Structured Clinical Interview for the Positive and Negative Syndrome Scale