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Com^m_eon People

**Physical health, lifestyle and quality of life in persons with
psychosis and their striving to be like everybody else**

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In memory of Torbjörn Lindström, my supervisor

Till Frida, Carl och Johan

*Den som växer och blir
stor, vet exakt var
värken bor. Om hon
nån gång tittat in,
innanför sitt skinn. Det
är du som väljer så var
noga med ditt val. Det
är ändå du som väljer
vem du är.*

*Om du lärt dig nåt om
livet, om du har valt
slitstarka skor. Så vet
du vad lyckan beror på,
men den chansen är
sällan så stor. Det är du
som väljer så var noga
med ditt val. Det är
ändå du som väljer vem
du är.*

Olle Ljungström

PREFACE

Perhaps the seed that would lead to this thesis was planted that day when I, as part of a school project during my training to become a mental health nurse, was to carry out an activity outside the psychiatry walls. The people accompanying me were young and were all affected by a psychotic disorder. My idea was to do something that would dispel their thoughts from psychiatric everyday life, and what could be better than to go fishing? Seeing these people in this environment was an awakening, how they with great difficulty moved in the boats or in the hilly terrain. The day was very successful, but the remaining memory is still of all these young people entering adulthood with completely different prerequisites than the average person. A great responsibility rests on the health care system to address this, in part, iatrogenic condition.

Throughout my professional career as a nurse and later as a mental health nurse, I have always worked in psychiatric care. My work experience includes both inpatient and outpatient care, and has mostly involved the acute events of illness. In my clinical work, I have experience of working with persons with the diagnoses that occur in this thesis. Although many of those I met were affected by physical ill health as a result of metabolic syndrome or an inactive lifestyle, I did nothing or very little to make a difference. Any ideas that included physical activity for inpatients had no influence on activities organised by staff because of a fear of hospitalisation. The idea was that inpatients should feel somewhat bored as the goal was that they should long for their ordinary life. In that culture, there was a clear distinction between physical and mental health. Today I know better.

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ABSTRACT

Background: As psychosis is often a lifelong disorder, improved health-related quality of life (HRQoL) can be a relevant treatment goal. Persons with psychosis have significantly reduced physical health. Research has demonstrated a great excess of mortality due to cardiovascular diseases, as psychosis may lead to an inactive lifestyle and difficulties making healthy lifestyle choices. Metabolic side effects of second-generation antipsychotics are also common. Many are therefore affected by the metabolic syndrome. The overall situation calls for action by developing health promotion interventions suitable for this group. In recent years, there has been an increased interest in the physical health of persons with psychosis. However, efforts have not been optimally tailored to the needs of this group, and health care services have not done enough, despite being aware of the problem.

Aim: The general aim of this thesis was to study HRQoL, and metabolic risk factors in persons with psychosis, and by a health promotion intervention and through the participants' own perspective contribute to an improvement in lifestyle interventions.

Methods: Study I had a cross-sectional cohort study design that was carried out in specialised psychiatric outpatient departments in Sweden. The patients (n=903) were diagnosed with a psychotic disorder and invited consecutively to participate. A prospective population-based study of public health in the south-east of Sweden (n=7238) served as reference group. Patients were assessed using psychiatric questionnaires, including the Global Assessment of Functioning (GAF). Health-related quality of life was assessed using the EQ5D, both for patients and the population. Several other health status outcomes relevant to the metabolic syndrome were measured, together with lifestyle habits and clinical characteristics. Study II, III and IV were based on a lifestyle intervention for persons with psychosis. Study II was a longitudinal intervention study with a matched reference sample. The purpose of the lifestyle intervention was to promote a healthier lifestyle by combining theoretical education with physical activities. The intervention group consisted of 42 participants. A matching procedure was made in which two individuals per participant were matched (n=84) into a reference group. The reference sample was matched for sex, BMI class, and being of as similar an

age as possible. Socio-demographics were collected and metabolic risk factors relevant to the metabolic syndrome were measured. Symptom severity was measured using Clinical Global Impression (CGI), and HRQoL was assessed using EQ5D. Measurements were made at baseline and at a one-year follow-up. In study III, a qualitative exploratory study was conducted in order to explore prerequisites for a healthy lifestyle. Data were collected through individual interviews (n=40), using a semi-structured interview guide with participants who had undergone the lifestyle intervention. Data were collected 6–7 months after the intervention had been completed. Conventional content analysis was used. Study IV was also based on these 40 interviews and aimed to describe how persons with psychosis perceive participation in a lifestyle intervention. A phenomenographic analysis approach was used.

Results/conclusions: Persons with psychosis are at great additional risk of physical comorbidity. Almost half of the patients met the criteria for metabolic syndrome. In addition, persons with psychosis had significantly lower HRQoL in all dimensions in the EQ5D, except for the pain/discomfort dimension. The only risk factor included in the metabolic syndrome that was associated with lower HRQoL was elevated blood pressure. Raised LDL-cholesterol was also related to lower HRQoL, together with low GAF, older age, high BMI, and female gender. The intervention study demonstrated that HRQoL was significantly improved in the intervention group when comparing EQ-VAS at baseline and at the one-year follow-up. It can be concluded that our intervention was not powerful enough to influence the metabolic factors to any greater extent. The key prerequisite for a healthy lifestyle seemed to be a wish to take part in the society and a longing to live like everybody else. However, many became stuck in a constant state of planning instead of taking action towards achieving a healthy lifestyle. Support by health care professionals is therefore also a prerequisite for a healthy lifestyle. This support should target the transition from thought to action and facilitate the participants' ability to mirror themselves against healthy people in society by introducing activities they perceive that "common people" do. The challenge for health care professionals is to find a moderate intervention level that does not underestimate or overestimate the person's capacity. This can facilitate continued participation, and participants can thereby find new social contacts and achieve health benefits.

Key words: Health promotion, HRQoL, Lifestyle, Metabolic syndrome, Phenomenography, Physical health, Psychosis, Qualitative content analysis, Self-care, Stigma.

LIST OF PAPERS

This thesis is based on the following studies, which will be referred to in the text by their roman numerals:

- I Foldemo, A., Wärdig, R., Bachrach-Lindström, M., Edman, G., Holmberg, T., Lindström, T., Valter, L., Ösby, U. (2014). Health-related quality of life and metabolic risk in patients with psychosis. *Schizophrenia Research*, 152, 295-299.
- II Wärdig, R., Foldemo, A., Hulstjöö, S., Lindström, T., Bachrach-Lindström, M. An intervention with physical activity and lifestyle counseling improves health-related quality of life and show small improvements in metabolic risk factors in persons with psychosis. Accepted for publication in *Issues in Mental Health Nursing*, 2015-09-06.
- III Wärdig, R., Bachrach-Lindström, M., Foldemo, A., Lindstrom, T., Hulstjöö, S. (2013). Prerequisites for a healthy lifestyle- Experiences of persons with psychosis. *Issues in Mental Health Nursing*, 34, 602-610.
- IV Wärdig, R., Bachrach-Lindström, M., Hulstjöö, S., Lindström, T., Foldemo, A. (2015). Persons with psychosis perceptions of participating in a lifestyle intervention. *Journal of Clinical Nursing*, 24, 1815-1824.

ABBREVIATIONS

ANOVA	Analysis of variance
BMI	Body Mass Index
CGI	Clinical Global Impression severity, the clinician's opinion of the severity of the patient's disease state in comparison with other patients within the specific disease category
CVD	Cardiovascular disease
EQ5D	EuroQoL 5-dimensions, a standardised instrument for measuring health status
GAF	Global Assessment of functioning, social, occupational, and psychological functioning level
HCs	Health coordinators (the group leaders in the intervention)
HDL	High-density lipoprotein
HPM	The Health Promotion Model
HRQOL	Health-related quality of life
IDF	International Diabetes Federation
LDL	Low-density lipoprotein
QOL	Quality of life
RCT	Randomised controlled trial
SGA	Second generation antipsychotics
SMI	Severe mental illness
TTM	The Transtheoretical Model
WHO	The World Health Organisation

INTRODUCTION

It is well known that persons with psychosis face serious challenges regarding their psychiatric health (American Psychiatric Association 2013). In recent years, there has also been an increased interest in physical health and lifestyle among persons with psychosis, resulting in guidelines for screening and monitoring cardiovascular risks (De Hert et al. 2011b, Gothevors et al. 2010). One reason for this growing interest is due to the fact that persons with psychosis lives are considerably shorter than those of the general population. Life expectancy for persons diagnosed with schizophrenia is about 25 years less than a healthy person (Colton & Manderscheid 2006), even if the life expectancy gap in the Nordic countries has become somewhat diminished during the era of deinstitutionalisation (Wahlbeck et al. 2011). Still, a major part of this group is affected by the metabolic syndrome, many even before the age of 30 (Meyer & Stahl 2009). Cardiovascular risk factors, such as obesity, tobacco use, diabetes, and dyslipidemia occur frequently (McEvoy et al. 2005), and together they contribute to a great risk of somatic illness and metabolic syndrome.

A number of factors should be understood to interact in the development of physical ill health. Persons with psychosis often have cognitive impairments (American Psychiatric Association 2013), which hamper the possibilities to meet general human needs and make informed decisions about nutrition, sleep, activity, and the balance between loneliness and social life. Feelings of alienation and stigma are aggravating factors for participation in society, affecting the person's self-esteem (Mestdagh & Hansen 2014). The first treatment option of psychotic disorders is medication with second-generation antipsychotics, which are necessary to keep the psychotic symptoms under control. However, these medicines themselves increase the risk of weight gain and hyperglycemia (Deng 2013), thus increasing self-care requirements and creating multifaceted problems that contribute to a greater risk of developing the metabolic syndrome.

In addition to a direct connection with mortality rates, physical health problems have also been associated with lower quality of life (QoL) in psychosis (von Hausswolff-Juhlin et al. 2009). Health-related quality of life (HRQoL) has become an increasingly relevant outcome measure in health care.

In psychiatry and the context of psychotic disorders it can be viewed as an alternative treatment goal as a total cure often is impossible (Baker & Intagliata 1982). As HRQoL is similar to the concept of health, it can be viewed as an aspect that can be influenced by health care activities (Saarni et al. 2010).

Research has shown that lifestyle interventions that include physical activity and lifestyle counselling can make a difference towards a healthier lifestyle (Happel et al. 2012). According to the WHO (1998), a healthy lifestyle is a way of living, based on identifiable patterns of behaviour that are determined by the interplay between the individual's personal characteristics, social interactions, and socioeconomic and environmental living conditions. Still, there are reasons to believe that interventions and approaches in clinical psychiatry need to be developed to suit the specific needs of this group (Lowe & Lubos 2008). This is where this thesis intends to contribute. If interventions that take into account the perceptions of persons with psychosis are identified, a more individualised care can be developed. The ambition was to provide approaches that can decrease metabolic risk factors, increase HRQoL, and contribute to better self-care capacity and perhaps, as a result, reduce the need for care.

BACKGROUND

This thesis is based on a positivistic as well as a naturalistic epistemology. The various methods used should be recognised as originating from different epistemological traditions which, when combined, can add new perspectives to the phenomenon under study. The different types of knowledge should be viewed as equally valid and necessary in order to obtain a richer and more comprehensive picture of the investigated issue (Foss & Ellefsen 2002). The background has two main focuses; partly to offer an understanding of persons with psychosis, their problems and specific challenges related to the research area, and also to describe the knowledge of what health care services, or others who are working closely to the group can do to meet these challenges and needs, primarily from a nursing perspective.

The characteristics of symptoms in psychotic disorders

As this thesis does not focus on any specific psychosis diagnosis, key features that define psychotic disorders are presented below. The presentation of symptoms is not comprehensive, but serves to create an understanding of the main symptoms that the persons in this thesis may exhibit. It can also facilitate an understanding of the prerequisites for the studies in this thesis. It is, however, important to bear in mind that there is a great heterogeneity of symptoms in psychosis (Flaum et al. 1995). Two generally accepted systems for classifying psychotic disorders are in use worldwide, the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (2015), and the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-V) (2013). Although the DSM-V is not officially recognised in Sweden, it offers extensive clinical value and provides rich symptom descriptions. This is why the characteristics of symptoms in psychotic disorders are described with DSM-V below. In DSM-V, psychotic disorders are gathered under the heading schizophrenia spectrum and other psychotic disorders. Together, these are defined by abnormalities in one or more of the following five domains: delusions, hallucinations, disorganised thinking or

speech, grossly disorganised or abnormal motor behaviour (including catatonia), and negative symptoms (American Psychiatric Association 2013). A symptom picture for each domain is presented below.

Delusions: Delusions refer to fixed beliefs that do not change, despite conflicting evidence. Persecutory delusions are the most common ones, which may be about being injured or harassed by a specific individual or organisation. There is also a distinction between non-bizarre and bizarre delusions. Bizarre delusions are impossible to understand on the basis of the individual's cultural context and cannot be attributed to ordinary life experiences (American Psychiatric Association 2013).

Hallucinations: Hallucinations are perceptions that occur without any external stimuli. Auditory hallucinations are the most common ones, and they are often perceived as voices, either familiar or unfamiliar, yet clearly separated from the person's own thoughts (American Psychiatric Association 2013).

Disorganised thinking (Speech): This domain is characterised by the person switching topics in communications. Answers to questions may be less related or completely unrelated. To be valid, the symptom must be severe enough to substantially impair effective communication (American Psychiatric Association 2013).

Grossly disorganised or abnormal motor behaviour (including catatonia): These symptoms can occur in a variety of ways. The problems can be highly manifest in different aspects when performing activities of daily living. Catatonic behaviour ranges from resistance to instructions, to a complete lack of verbal and motor responses (American Psychiatric Association 2013).

Negative symptoms: These symptoms are common in schizophrenia but less frequent in other psychotic disorders. Negative symptoms can be manifested through diminished emotional expression and avolition. Diminished emotional expression is made visible when a person's face does not express emotions, or the person has difficulty maintaining eye contact. Another example of avolition is when a person remains sitting for a long while, showing little interest in participating in work or social activities (American Psychiatric Association 2013).

The framework for Swedish psychosis care

Different pieces of legislation form the basis for the care offered to the patient. In specialised psychiatric care, the Health and Medical Services Act, the Patient Act, and the Compulsory Mental Health Act, are central laws that regulate the work. In accordance with the Social Services Act and the Act concerning Support and Service for Persons with Certain Functional Impairments, (Ministry of Health and Social Affairs (Socialdepartementet) 2015), patients also receive care from social services, focusing on coping with daily life and having meaningful activities. The National Board of Health and Welfare (Socialstyrelsen) is a Swedish national administrative authority for activities related to health care. It monitors and analyses the development of health care, and conveys knowledge to professionals who meet the patients. They also have a supervisory role of health and social care.

The Swedish National Board of Health and Welfare (2011b) has developed national guidelines for psychosocial interventions associated with schizophrenia or similar psychoses. The guidelines cover mainly health care and social services, and aim to emphasise evidence-based measures so that people with schizophrenia have access to high quality health care and social care. The recommendations that are expected to have the greatest impact are coordinating measures, psychological treatment, vocational rehabilitation, and family interventions. Through increased collaboration between health care providers and social workers, the goal is to reduce the number of people who need inpatient hospital care and instead enhance stability in their own homes. The recommendations for psychological treatment propose to increase the use of cognitive behavioral therapy (CBT), which has proven effective for dealing with the individual's central problem.

As a complement to the guidelines relating to psychosocial interventions, the National Board of Health and Welfare (2014) have also published national guidelines for antipsychotic drug treatment. Considering that all persons with psychosis need antipsychotic drugs in order to live as normal a life as possible, they have published guidelines indicating what drug is to be preferred in a particular situation. The choice of antipsychotic drug should be based on severity of the disease and the risks that are associated with the patient's condition, such as suicidality, or metabolic risks. Regardless of treatment regimen, the treatment should be based on shared decision-making, where

great emphasis is placed on the patient's perspective about what contributes to their quality of life (QoL).

The psychosis outpatient care context

In the outpatient psychiatric care department at the psychiatric clinic, all patients have a contact person, who is one of the team members. These contact persons represent different professions available in the clinics, such as psychologists, nurses, physiotherapists, occupational therapists, or assistant nurses. The meetings with the contact person are held when necessary and may be intensified when the patient is feeling worse. During these periods, meetings on a weekly basis or inpatient care are not uncommon.

When the patient is feeling better, the meetings are less frequent, approximately a few times a year. Most of the meetings consist of supportive conversations. Patients meet their doctor less often, usually one or two times a year. At deterioration, however, meetings are more frequent. All patients have an individual care plan. The care given is based on this plan, which also describes how the patient should respond to any health deterioration. Monitoring of the current medication, therapy calls, or investigations of various kinds is determined by the team at the treatment conference. The treatment conference is an opportunity for the contact person to raise questions about the patient and receive suggestions about the person's future care. Whenever possible, the aim is also to include relatives in the patient's care.

The metabolic syndrome

The metabolic syndrome is a growing problem worldwide. It constitutes a major clinical challenge, leading to severe consequences for public health. It has been considered the global epidemic of the 21st century and the primary health problem in the modern world (Reaven et al. 2001). Increasing obesity and sedentary lifestyles are the main reasons for its increase. The concept of metabolic syndrome holds interrelated risk factors for cardiovascular disease. These risk factors comprise elevated blood pressure, dysglycaemia, obesity, elevated triglyceride levels, and low high-density lipoprotein cholesterol. The

metabolic syndrome therefore contains a cluster of factors that often occur simultaneously (Alberti et al. 2009).

The underlying causes for developing the metabolic syndrome can be summarised by insulin resistance and central obesity, together with physical inactivity, genetics and ageing. When cells in the body become less sensitive and finally resistant to insulin, they are unable to absorb glucose. The body therefore tries to compensate for this by producing more insulin in an attempt to process the glucose. When the beta-cells in the pancreas are no longer capable of producing enough insulin, the person becomes hyperglycaemic and thereby diagnosed with type 2 diabetes (International Diabetes Federation 2006). Since human beings are provided with a highly varying reserve capacity regarding beta-cells, elevated blood glucose is seen at different times in the development of the metabolic syndrome (Nyström & Nilsson 2012).

The damage to the body occurs even before the diabetes diagnosis, as a build-up of triglycerides further impairs insulin sensitivity. Obesity is also associated with insulin resistance and leads to risk factors such as hypertension, high serum cholesterol, low HDL-cholesterol, and hyperglycaemia. These risk factors are independently associated with higher risk of cardiovascular diseases (CVD) (International Diabetes Federation 2006).

Metabolic syndrome is not something new. The Swedish physician Kylin provided an early description of its roots in the 1920s. He showed a correlation between hypertension, hyperglycemia, and gout (Kylin 1923). Even though the metabolic syndrome has a long history, it is only in recent years that its significance and definition have been debated (Kahn et al. 2005). The main criticism has been directed at its role and value in clinical practice as the syndrome tends not to predict cardiovascular disease any better than the risks mentioned above combined (Wannamethee et al. 2005). Several attempts have been made to define the metabolic syndrome since the WHO created the first formal definition in 1988. Different actors and organisations have then adjusted and made their mark on the syndrome. In this thesis, the frequently used definition by the International Diabetes Federation is applied (IDF 2006). This definition describes five criteria that form the metabolic syndrome, where three must be present in order to diagnose a person with the metabolic syndrome;

1. Elevated waist circumference, with consideration given to population and country-specific definitions.

2. Elevated triglycerides, above 1.7 mmol/L, or drug treatment for elevated triglycerides.
3. Reduced HDL-cholesterol, below 1.0 mmol/L in men and below 1.3 mmol/L in women. Drug treatment for reduced HDL-cholesterol is an alternative indicator.
4. Elevated blood pressure, systolic pressure above 130 mm Hg and/or diastolic pressure above 85 mm Hg. Antihypertensive drug treatment in patients with a history of hypertension is an alternative indicator.
5. Elevated fasting glucose, above 5.6 mmol/L, or drug treatment for elevated glucose as an alternative indicator.

The health risks associated with the metabolic syndrome are very extensive. A meta-analysis of 87 studies by Mottillo et al. (2010) showed that patients with the metabolic syndrome had a 2-fold increased risk of CVD, stroke, and CVD mortality. The risk of all-cause mortality showed a 1.5-fold increase. The metabolic syndrome was still associated with a high risk of CVD, even among patients who had not developed type 2 diabetes.

Research has identified an upward trend in abdominal obesity in the entire US population (Beltrán-Sánchez et al. 2013). European data also show this trend, indicating that more than half of the EU population is overweight or obese (European Commission Eurostat 2011). Comparing prevalence of metabolic syndrome in worldwide populations has been difficult due to the lack of consensus on the definition. This becomes evident when the prevalence of metabolic syndrome in Sweden almost doubles when one definition is compared to another (Cameron et al. 2004). However, it can be concluded that at least a quarter of all adults in the US, Europe and India suffer from the metabolic syndrome (Grundy 2008).

Somatic consequences, as well as health-economic effects and suffering on an individual level, have led to the scientific community reaching consensus about the need for vigorous action. The main treatment involves lifestyle interventions, and any remaining risks should be managed with adequate medical treatment (Eckel et al. 2010), or bariatric surgery (Ochner et al. 2015). Weight loss together with a minimum of 30 minutes of daily physical activity, increased intake of fruit, vegetables, and wholegrain products can make a difference. Nutritional recommendations should also prescribe a reduced intake of refined sugar and high glycemic index food, together with a lower intake of saturated fat and total fat (Kaur 2014). Recent research has shown

that the classic advice to “eat less” and “do more exercise” is not enough. If obesity is already established, it will hamper any efforts to lose weight due to biological adaptations designed to prevent starvation. These biological processes can probably explain the often poor long-term success rates of lifestyle modifications (Ochner et al. 2015).

The metabolic syndrome and other threats to physical health in persons with psychosis

Health in persons with psychosis and the general population differs substantially (Saha et al. 2007). According to a meta-analysis by Mitchell et al. (2013), one third of patients with schizophrenia suffer from the metabolic syndrome, half are overweight, and a fifth appear to have significant hyperglycaemia. Life expectancy among persons with schizophrenia is reduced by approximately 15-25 years (Ringen et al. 2014, Colton & Manderscheid 2006). In addition, they have not experienced the same improvement in life expectancy over the past few decades as the general population (Laursen et al 2012). Many will develop the metabolic syndrome before the age of 30. (Meyer & Stahl 2009). The high mortality rate is mainly explained by cardiovascular disease and not by suicide, despite higher suicide rates (Ösby et al. 2000). Metabolic syndrome, cardiovascular disease and diabetes are not the only threats to physical health in persons with psychosis. Viral diseases, respiratory tract diseases, musculoskeletal diseases, urogenital diseases, and pregnancy complications together with stomatognathic diseases are other groups of diseases that persons with severe mental illness (SMI) frequently suffer from (De Hert et al. 2011a). Research has also revealed that psychotic disorders per se are a major independent risk factor for increased waist circumference and increased fasting glucose, two important cardiovascular risk factors (Ösby et al. 2014).

Lifestyle habits in persons with psychosis

The over-representation of physical ill health in persons with psychosis can be partly explained by their psychiatric symptomatology. Cognitive functional impairments can cause problems learning and adopting new behaviours, and

making informed choices about health and lifestyle issues (Mueser & McGurk 2004). Symptom burden may lead to persons with schizophrenia failing to recognise early signs of physical ill health (Connolly & Kelly 2005). The situation may therefore be linked to the psychosis itself, where negative symptoms, such as apathy or comorbid states such as depression, restrict opportunities for physical activity (von Hausswolff-Juhlin et al. 2009). Research has revealed that persons with severe mental illness, such as psychosis, have less knowledge about the health benefits of diets and exercise (Osborn et al. 2007). For persons with psychosis, health is mainly a matter of psychological well-being as they have difficulties identifying physical aspects of health (Hultsjö & Syren 2013). Mental health is considered more important than physical health (Hultsjö & Brenner Blomqvist 2013). When trying to verbalise physical health, being free from pain and being agile are described. There is also a lack of awareness of physical health risks, which makes it hard to perform lifestyle changes (Hultsjö & Syren 2013, Brunero & Lamont 2010).

Several frequently found lifestyle factors can aggravate physical health. Poor dietary habits, e.g., low consumption of fibre and fruit (Dipasquale et al. 2013) and a higher consumption of saturated fat, together with a lack of motivation to take physical activity are some explanatory factors (Osborn et al. 2007). There is also a large number of smokers among persons with psychosis, approximately 2.5-fold more than in the general population. When persons with schizophrenia start to smoke, they tend to smoke more frequently and inhale deeper, which makes them more affected by the consequences (Connolly & Kelly 2005). Drug abuse and poor adherence to medical treatment are other causes of a variety of somatic issues beside the metabolic syndrome (Sebastian & Beer 2007).

Stigma and discrimination in psychosis

A further threat to physical health and decreased HRQoL can be derived from discrimination and stigma. Persons with psychosis fear exclusion and discrimination due to their diagnosis. It is not certain that social withdrawal should be considered a negative symptom, but may instead be a way to hide the diagnosis by avoiding contact (Mestdagh & Hansen 2014). A separation between “us” and “them” is central to the concept of stigma. It creates negative emotional reactions that result in discrimination and devaluation of

the person (Schomerus et al. 2013). In the same way that an outsider can be created by those who consider themselves to be normal, it also happens that people who cannot maintain a certain identity choose to exclude themselves from social interaction (Goffman 2014). Regardless of cause, stigma is a negative experience for the individual. It is associated with rejection and being regarded as abnormal by the surrounding community. This affects the person's attitude to themselves and has adverse effects on the possibilities to recover (Watson et al. 2007), although it is common that the stigmatised person is making great efforts to be socially accepted (Goffman 2014). Stigma as a consequence of limited financial opportunities may also contribute to physical activity not being realised (Thornicroft et al. 2009, Hudson 2005). Mestdagh and Hansen (2014) argued that health care professionals can facilitate and actively contribute to decreased perceptions of stigma. Research has also shown that health care professionals can be the cause of the problem. Medical staff, influenced by negative stereotypes, tend to treat persons with mental illness less thoroughly and less effectively (Thornicroft 2011), and often neglect to refer the patient for further care, despite medical needs (Sebastian & Beer 2007). This could result in persons falling through the cracks and that they therefore do not receive the somatic care they need. Chaudry et al. (2010) considered that health care professionals who do not work in psychiatry are afraid of their mentally ill patients, which is why actions to overcome this must be taken.

The added challenge of antipsychotics

Antipsychotic treatment can be crucial for a person's ability to live as normal a life as possible (Leucht et al. 2009). However, side effects of antipsychotic medication play a significant role in the poor physical health among persons with psychosis (Deng 2013, Mitchell et al. 2013), leading to consequences for the person's quality of life (von Hausswolff-Juhlin et al. 2009). One of the most debilitating adverse effects is weight gain (Das et al. 2012, Tschoner et al. 2007), although weight problems and a higher frequency of diabetes in persons with psychosis were reported even before the introduction of first and second-generation antipsychotics and before the term metabolic syndrome had been coined (Bushe & Holt 2004). Besides weight gain and diabetes, second generation antipsychotics have other adverse effects, such as atherogenic lipid profile and increased appetite. This causes problems with

regard to adherence to treatment. However, the added risk of cardiovascular diseases and premature death is even more alarming (Tschoner et al. 2007).

Managing physical health in psychosis

Managing physical health in psychosis requires multiple strategies to promote healthier lifestyle habits together with good preventive care through regular monitoring of metabolic parameters (Meyer & Stahl 2009, Mitchell et al. 2013). Papanastasiou (2012) argued that these physical check-ups must be an essential part of the clinical routine. Guidelines for good quality screening and monitoring practice are available (De Hert et al. 2011b, Gothefors et al. 2010). These different guidelines are very similar, and the differences lie primarily in the time interval between the measurement points (De Hert et al. 2011b). Unfortunately, research has found that they are not used to the desired extent. Most patients do not undergo adequate testing (Mitchell et al. 2012). De Hert et al. (2011b) recommended baseline measuring and annual checks as a minimum, provided that baseline values are normal. When starting antipsychotic treatment, follow-up monitoring after 6 and 12 weeks is also proposed. On these occasions, body weight, waist circumference, body mass index (BMI), blood pressure, fasting glucose, and fasting lipids should be checked, and advice on lifestyle should be given. Another clinical approach has been described by Tschoner et al. (2007). Clarifying to the patient that a drug may cause weight gain and creating an individualised plan for each patient, with measures if weight gain occurs, is to be recommended. Based on a European perspective, it appears that management of physical health in persons with schizophrenia receives much less attention in the community setting than in the hospital setting (Chaudhry et al. 2010).

Meyer and Stahl (2009) have also pointed out the need to develop expertise in switching antipsychotic treatments for metabolic reasons, thereby increasing the use of drugs with less metabolic side effects. Regardless of the choice of drug, the objective is to provide as low an effective dose as possible (Tschoner et al. 2007). As drugs have different side effect profiles, the choice of antipsychotic treatment can be based on the person's risk profile for developing different problems (Rummel-Kluge et al. 2010). Persons with psychosis represent a heterogeneous group, and therefore, everyone does not have the potential to work actively with their health and lifestyle. These persons may

instead benefit from medical treatment for various risk factors (Das et al. 2012, Meyer & Stahl 2009, Orchard et al. 2005).

Previous interventions and their outcomes

In previous interventions designed for persons with psychosis, different concepts regarding design and content have emerged, which can make it difficult to interpret what has been implemented in the context of different interventions. Sometimes the concepts seem to be used synonymously or share certain parts. Papanastasiou (2012) has explained the most common concepts for behavioural interventions:

- 1) *Wellbeing programs*, a holistic approach which, for instance, incorporates physical health and exercise, together with physical check-ups and dietary advice. Sometimes, a specific condition is targeted, such as smoking or obesity. However, the aim is also to improve overall quality of life, particularly mental health. The programs are declared to be “tailor-made” to patients’ needs and vary in duration from a few weeks to several months.
- 2) *Cognitive behavioural treatment* (CBT), a psychosocial module that primarily aims to modify erroneous beliefs and behaviours. The methodology can have different application areas, for example in smoking cessation.
- 3) *Nutritional education*, usually focuses on a healthy diet and calorie restriction.
- 4) *Weight management*, a concept used to explain a combination of strategies that target obesity or overweight, such as physical activity and modification of dietary habits.
- 5) *Psycho-education*, usually describes the information offered to the patient regarding their illness and medication in a manner that can enhance medication adherence and promote relapse prevention.

Another review study has also demonstrated this large heterogeneity, both in terms of study design, intervention content, and measured outcomes. Interventions have been conducted individually, in groups, with or without control groups, and for different durations (Bonfioli et al. 2012). Likewise, target groups have varied, for instance, persons with psychosis (Bonfioli et al. 2012), schizophrenia, or mental illness (Happell et al. 2012a). Lowe and Lubos (2008)

have called for more research with standardised outcome measures. The absence of a golden standard in study designs make comparisons between studies problematic (Pearsall et al. 2014b) and can affect credibility in review studies (Holley et al. 2010). A comprehensive explanation of the intervention design is therefore needed (Rosenbaum et al. 2014). Other criticism has concerned the absence of follow-up beyond six months in most intervention studies (Bradshaw et al. 2005, Faulkner et al. 2003). In order to identify long-term effects, participants should be assessed after the intervention (Krogh et al. 2014). Furthermore, it has been found that evaluations of more holistic healthy living programs are lacking, and that “treatment as usual” control groups have not been used to a desirable extent (Bradshaw et al. 2005, Faulkner et al. 2003).

Lifestyle interventions have had varying results. The findings in the review by Happel et al. (2012a), involving health behaviour interventions for persons with a mental illness, have provided great promise in changes of health behaviours. The majority of the studies had a group-based approach. All included studies used a combination of psychosocial education and behaviour change instructions, such as exercise programs or dietary advice. Interventions targeting weight management were the most common ones, and the vast majority of the studies were able to demonstrate a significant weight loss. The programs reported mainly positive changes in all health behaviours targeted; smoking cessation, physical activity, nutrition, and alcohol abuse. The review study of randomised controlled trials (RCT) by Pearsall et al. (2014b), comparing the effects of exercise interventions on persons with serious mental illness, found that exercise programs could improve exercise activity, but had no effect on mental health or body weight.

Green et al. (2014), Bonfioli, et al. (2012), and Verheeghe et al. (2011) have stated that persons with psychosis lose body weight during intervention programs compared to usual care, but still remain classified as overweight or obese (Verheeghe et al. 2011). Although some intervention studies have demonstrated a significant improvement in comparison with the control group, this does not necessarily mean that the intervention group makes changes. Comparisons between the groups may instead demonstrate that the control group continues to gain weight, while the intervention group remains at a status quo (Attux et al. 2013). Research has also emphasised alternative outcomes of lifestyle interventions. Besides mental health (Gorczynski & Faulkner 2010, Scheewe et al. 2013), QoL and CGI have been found to improve

through interventions (Verhaeghe et al. 2011). Health-related quality of life has been found to be positively influenced by regular physical activity (Schmitz et al. 2004). Likewise, physical activities have been shown to have a beneficial effect on psychological well-being (Holley et al. 2011).

Previous research targeting weight loss has also compared outcomes of lifestyle or behavioural interventions with pharmacological interventions. One study concluded that both behavioural and pharmacological interventions resulted in moderate weight loss. Behavioural treatment may be effective in a controlled environment, but has a more questionable effect in outpatient follow-up. The most effective pharmacological treatment for weight loss in combination with second generation antipsychotics (SGA) is Metformin. Switching SGA to a drug with fewer metabolic side effects is commonly practiced and demonstrates a modest weight loss in the short term. Taking into account the moderate weight loss achieved regardless of method used, bariatric surgery in patients who do not respond to either behavioural or pharmacological treatment is a possibility. Further studies to assess long-term outcomes of bariatric surgery in psychiatric patients are needed before any definite conclusions can be drawn (Das et al. 2012).

Previous qualitative perspectives of lifestyle interventions for persons with psychosis

Only a few studies have adopted a qualitative perspective on participation in lifestyle interventions among persons with psychosis (Pearsall et al. 2014a, Roberts & Bailey 2013, Forsberg et al. 2010, Tetlie et al. 2009, McDevitt et al. 2006, Fogarty & Happell 2005). In Fogarty and Happell's study (2005), both patients and health care professionals participated and were asked to describe their experiences of the intervention program. The findings highlighted that the program was tailored to the participants' individual needs. The patients described improved physical capacity and fitness, as did the staff, who also noticed a positive change in the participants' attitude to exercise. Furthermore, the benefits of having someone to exercise together with were emphasised. Support and encouragement were also important elements, which is also evident in Roberts and Bailey's study (2013) about the incentives and barriers to lifestyle interventions for persons with SMI. Weight loss, social interaction and the possibility to gain knowledge could act as incentives. Being overweight,

unwilling to meet new people and unaware of the potential benefits of a healthy lifestyle could on the other hand act as barriers.

The study by Forsberg et al. (2010) investigated the meaning of participation in a lifestyle program through persons with different psychiatric disabilities. The intervention consisted of a combination of theoretical education and physical activity, where staff members participated under similar conditions to promote the intervention as part of the daily routine. The findings showed that participating in a lifestyle intervention increased the possibility of a healthier lifestyle, even if there were obstacles to overcome. Poor fitness and coordination, tiredness owing to medication, and social phobia counted among some of the obstacles. However, participation was experienced as becoming an important part of life and something to be proud of. By participating, new skills were gained and there was an opportunity to try new activities or new, healthy eating habits. The fact that staff also participated in the intervention was mainly experienced as positive, which was also described in the study by Tetlie et al. (2009), and created feelings of closeness and equality. In the study by Forsberg et al. (2010) there was also an awareness of the patients' vulnerable life situation. Expressions of a longing for a meaningful life situation and a hope for change can be understood as awareness creating pathways for changes. However, awareness can also reinforce a sense of hopelessness and create concerns about one's own health.

The study by Pearsall et al. (2014a) had a different focus and instead examined the attitudes and experiences of the persons with psychosis who had declined to participate in a healthy living program. According to the findings, nearly half of the informants stated that they could not remember receiving an invitation by mail. Other explanations for choosing not to participate could be that informants felt that their physical health was under control, or that they simply were not concerned about their physical health. Their physical or mental health could also make it impossible to participate. As for awareness of the risks of an unhealthy lifestyle, the findings described that many informants seemed to understand the concept unhealthy behaviour, but appeared to lack an awareness of the potential consequences. The findings also described severe difficulties changing habits, and the link between the habit and the potential risk seemed unclear. The informants identified a number of reasons for not changing their lifestyle. Their comfortable and habitual behaviours were perceived as too difficult to abandon.

Physical health in psychosis- an area for mental health nurses

As nurses have four essential responsibilities; promoting health, preventing illness, restoring health, and alleviating suffering (ICN 2012), health promotion interventions could be one way to meet this responsibility. A holistic approach to patients that takes into account both physical and mental health needs is assumed. Mental health nurses can orientate practice away from an illness perspective and instead focus on wellness and recovery. A health service culture that focuses on problems, illness, and psychiatric disorders contributes to a sense of hopelessness and reinforces the dependence on mental health services (Wand 2013). The term positive health instead recognises the relationship between physical and mental health. A mental illness can, but does not necessarily limit opportunities. There are opportunities for positive emotion, engagement, purpose, positive relationships, and positive accomplishments, even in the context of a psychiatric disorder. Thus, the mindset is viewed as a reasonable choice for mental health nursing (Seligman 2008). Traditionally, mental health care has been based on the opinion that mental illness should be treated with different therapies or programs. Very little attention has been paid to asking the recipients about what helped them recover. Helping relationships in mental health services are based on recovery-oriented professionals. These professionals have the courage to deal with the complexities and individuality of the process of change. Through an approach that goes beyond of what is considered the professional role and being available when needed, together with an openness as to what helps people recover, health care professionals can work from individual preferences towards recovery (Borg & Kristiansen 2004).

Mental health nurses are often trusted by their patients and can therefore play an important role in health promotion interventions. The lifestyle education provided by mental health nurses should be practical and adapted to the individual, focusing on a healthy diet, exercise habits, and changing smoking habits (Hultsjö & Hjelm 2012). Nurses may also be helpful for facilitating understanding and verbalising potential health risks, together with finding out what motivates the patients to adopt health behaviours (Hultsjö & Syren 2013). However, it is not certain that mental health nurses are prepared to make the efforts required. They are often ambivalent about their role in the person's physical health, which is based on them considering themselves to

lack adequate training. If health inequalities for persons with psychosis are to be addressed, mental health nurses must accept that they have an important role to play and be prepared to take responsibility (Bradshaw & Pedley 2012).

THEORETICAL AND CONCEPTUAL FRAMEWORK

The theoretical and conceptual framework in this thesis consists of the specific challenges that persons with psychosis face in relation to the theories described below. These theories are explained both in general terms as well as being specifically applied on persons with psychosis. The theoretical framework is grounded in health promotion as the project should be regarded as a possibility to increase control over and improve health (WHO 1986). Health promotion interventions can promote self-care ability and thereby lead to increased quality of life. Quality of life and health-related quality of life combined with self-care can therefore be viewed as goals or tools in these efforts.

Health promotion

According to the WHO (1986), health promotion is a process that enables people to increase control over and improve their health. Health promotion moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions. Health promotion methods may include activities as diverse as information campaigns, provision of health information, lobbying for change, advice-giving, community development, or professional training. The different components are often seen in combination in multifactorial interventions (Speller et al. 1997). Health promotion activities have in recent years gained increasing influence in diverse areas of health care. It ranges across physical and mental health and has long been considered as central in nursing (Delaney 1994). Nurses therefore have a key role in promoting public health on the basis of multi-disciplinary knowledge and experience of health promotion in nursing practice (Kemppainen et al. 2012). In their study, Thornicroft et al. (2009) described that persons with psychosis are exposed to a structural discrimination by the somatic care, and may not always receive the care they need. The psychiatric and somatic care must change their approach from merely trying to prevent or cure mental disorders towards including promotion of physical health. Taking into consideration an overall picture of mental and somatic health is of utmost importance, as they

cannot be separated and affect each other. Against this background, lifestyle interventions, such as in this thesis, have occurred in research and clinical practice.

The Health Promotion Model (HPM) by Pender first appeared in 1996. The model attempts to portray the multidimensional nature of persons interacting with their interpersonal and physical environment as they pursue health. The HPM integrates constructs from expectancy-value theory and social cognitive theory within a nursing perspective of holistic human functioning. The model proposes a framework for integrating nursing and behavioural science perspectives, with factors influencing health behaviours. Thereby, it offers a guide to exploring the complex processes that motivate individuals to engage in behaviours directed towards enhancing health (Pender et al. 2015).

The HPM model consists of three parts, starting from individual characteristics and experiences, based on the idea that the best predictor of behaviours is who the person is and what behaviours they used to have in the past. The next part is Behavioral-Specific Cognitions and Affect. These behavioural-specific variables are considered to have a major motivational significance that can be modified during an intervention. These variables include factors such as perceived benefits, perceived self-efficacy, and perceived barriers. Believing in a positive outcome has proved important for engaging in a specific health behaviour. If the barriers are instead high, action is unlikely to occur. The last part in the model is the behavioural outcome, in other words, the health-promoting behaviour or action. Health-promoting behaviours integrated into a healthy lifestyle result in improved health, quality of life, and functional ability (Pender et al. 2015), which can be achieved by lifestyle interventions for persons with psychosis.

Health promotion in vulnerable populations is an important area as the likelihood of them developing health problems is much greater and their preparedness to deal with the consequences considerably lower. Vulnerable populations therefore require additional attention from clinicians, researchers and policy makers, and may include a plurality of different groups. This vulnerable group includes persons with mental illness and those who experience stigma and discrimination. In their professional role, nurses have opportunities to design and implement health-promotion programs tailored to suit different groups and their specific challenges by getting to know the group and their prerequisites well. Specific potential barriers must be taken

into account when planning these interventions for a healthy lifestyle (Pender et al. 2015).

Nurses have a well-known reputation for caring for the whole person and taking into account physical, psychosocial and spiritual needs. The work with health promotion should therefore also include mental health, so called mental health promotion (Calloway 2007). Mental health promotion aims to promote individual resources and competencies, and psychological strengths. It further seeks to strengthen community assets to prevent mental disorder and increase the well-being and QoL for people and communities (Jané-Llopis et al. 2005). Through mental health promotion, people across various socio-demographic subgroups and community settings can receive the attention they previously had not (Kobau et al. 2011), and thereby reduce the burden and stress induced by the mental illness (Kalra et al. 2012). Alongside psychiatric health, persons with psychosis are often not capable of managing the challenges of coping with chronic illnesses and the negative health effects that often follow on their own. The psychiatric symptomatology creates difficult challenges and contributes to a lack of access to health promotion facilities. Mental health nurses must therefore provide health promotion, education, and appropriate referrals to optimise the patients' QoL (Humphrey Beebe 2008), and be at the forefront by implementing mental health promotion whenever possible within nursing practice, nursing education and research (Calloway 2007).

Quality of life and Health-related quality of life

Questions about what the good life involves have concerned mankind through all ages (Kajandi 2006). Several attempts to define the concept have been made by various researchers and organisations. Lehman (1996) described QoL as patients' perspective on what they have, how they are doing and feel about their life circumstances. The World Health Organization Quality of Life group has made a frequently used proposal (1995), where QoL is explained as the individual's perceptions of their position in life in the context of the culture and value system in which they live, and in relation to personal goals, expectations, standards and concerns.

There is a difference between objective and subjective QoL and both parts are contained in the concept. The objective part includes factors such as somatic

status, occupation, and residential and family situation. The subjective part includes both own perceptions of the objective parts and the person's general mood (Nordenfelt 2004). When the concept made its entry in psychiatry there were several reasons for considering QoL as a relevant outcome measure. A general trend towards a holistic perspective, where the patient should be seen as a customer, together with the fact that a cure is not always possible has resulted in QoL being considered an alternative treatment goal (Baker & Intagliata 1982).

Health-related quality of life is a concept that has been increasingly used in the medical scientific literature. Although a very large number of studies claim to have measured HRQoL, it is not always explained what the term represents. Often, authors refer to the measurement methodology used, or use the term without explaining its meaning. The term HRQoL is a combination of the concepts health and quality of life (Nilsson 2012). According to the World Health Organization (1946), health is a state of complete physical, mental, and social well-being and not merely the absence of infirmity or disease. There is no consensus on the definition of HRQoL. In this thesis, HRQoL refers to physical, social, and mental well-being and functioning. Nilsson (2012) used this definition in her thesis by arguing that HRQoL can be considered to be the patient-reported part of the WHO definition of health. Health-related quality of life is the part of the quality of life concept that can possibly be influenced by health and health care activities (Saarni et al. 2010). The person's assessment of their subjective health status can be measured using either generic or disease-specific instruments. The outcome can then be used as a supplement to morbidity or mortality data (Dempster & Donnelly 2000), or provide guidance for continued treatment (Calvert & Freemantle 2003).

Health-related quality of life in persons with psychosis has been examined in several studies. Various lifestyle factors and typical symptoms of the disease, such as comorbid symptoms of depression (Dan et al. 2011), together contribute to lower HRQoL in persons with psychosis. Chou et al. (2014) found that psychosocial factors, such as self-efficacy, self-esteem, and social stigma were determinants of lower HRQoL in patients with schizophrenia. Research has also demonstrated a link between the presence of various risk factors for metabolic syndrome and lower HRQoL (Roohafza et al. 2012). Other contributing factors that can be linked to lower HRQoL are side effects of second generation antipsychotics (Bebbington et al. 2009), social isolation (Sibitz et al. 2010), and a high BMI and waist circumference (Faulkner et al. 2007).

Together, these factors cover large parts of this patient group. Research has also shown that a lack of physical activity during leisure time contributes to impaired HRQoL in persons with schizophrenia, which further supports the importance of arranging activities that include physical activity in psychiatric clinical practice (Vancampfort et al. 2011).

Self-care

The ability to self-care can be regarded as an important part of health promotion, which in turn can promote QoL. The World Health Organization (WHO 1983) describes self-care as an action that individuals perform in order to improve health, prevent disease, reduce disease, and restore health. These actions are derived from knowledge and skills gained from personal experience or through professional advice, and may be performed either by the individual or in cooperation with professionals. Riegel et al. (2012) have described self-care maintenance, monitoring, and management. These can be carried out by listening to the body's signals, monitor signs of change and be prepared to take action when needed, with or without professional support. According to Swedish regulations, health care professionals shall determine whether care can be performed as self-care. This assessment should be based on the patient's physical and mental health and be made in consultation with the patient (National board of Health and Welfare 2009). According to Orem (2001), self-care is explained as a human regulatory function with activities that the individual must perform on their own or through someone else to maintain health. Self-care deficiency occurs when the self-care capacity is less than the self-care demands and care is required to maintain self-care needs. Partly or completely compensated self-care can therefore be needed (Orem 2001).

Orem has described different components that are necessary for a patient to perform self-care. This may involve taking the initiative to maintain self-care activities, which demonstrates the patient's involvement and willingness to improve the situation. Another component is the ability to become aware of external factors that can influence self-care, such as social relationships with family and friends. An additional component is the motivation that makes it easier to perform good self-care. The ability to understand, use, and maintain

gained knowledge about self-care is also central in order to actively apply and develop self-care skills (Orem 2001).

According to the Swedish National Board of Health and Welfare (2003), self-care in psychosis is about managing continuous psychotic symptoms in order to be able to live an everyday life and avoid stressful events that may trigger a psychotic relapse. Previous research has illustrated that the concept of self-care has been used only to a limited extent in connection with mental health (El Mallakh 2006). Rather, the focus has been on the patients' medical problems or diseases. Care that instead focuses on recovery and self-care emphasises the individual in a holistic way (Lucock et al. 2011). Research has shown that patients with psychiatric problems require insight into their illness, which promotes the ability to perform self-care (Shanley & Jubb-Shanley 2007). Psychiatric symptoms constitute barriers to self-care (El-mallakh 2006), and, therefore, an understanding of and insight into the diagnosis is of great importance. Patients with psychiatric problems and poorer self-care ability are at a higher risk of relapse and thus of inpatient care (Cutler 2003).

Cutler (2003) described two areas in psychiatric self-care, compliance to the prescribed medication and how patients manage the symptoms that arise. Self-care is hampered if medication is not adhered to, and common causes for lack of compliance may be tangible side effects, forgetfulness, and a lack of understanding as to why the medication is needed. For patients in psychiatric care self-care is necessary to maintain health, which makes it possible for the patient to participate in the society. Nurses in psychiatric care should therefore strive towards the patient being able to independently carry out self-care, ranging from basic activities such as sleep and nutrition, to more complex dealings involving medication and management of symptoms. Nurses should be aware that self-care should not only be viewed from the caregiver's perspective. It also has to involve the patient's perceptions of their own ability to perform self-care. By taking advantage of the patient's own abilities and promoting independence, nurses contribute to professional nursing (Cutler 2003).

RATIONALE FOR THIS THESIS

Health-related quality of life has become an increasingly important outcome factor in health care. As a psychotic disorder usually involves a lifelong condition, HRQoL can constitute an important treatment goal. The fact that poor physical health is overrepresented among persons with psychotic disorders has been known for a long time and may contribute to lower HRQoL as well as cardiovascular diseases, often as a consequence of the metabolic syndrome. Despite this knowledge, it is only in the last few decades that research and clinical practice have shown interest in addressing the problem. Previous research has demonstrated a wide variety in content and design in lifestyle interventions, but a golden standard for interventions seems to be missing, making it difficult to compare outcomes. Furthermore, previous research has demonstrated problems with participants not completing the interventions and certain interventions not having been adapted to the prerequisites of this group. A central assumption in this thesis is that the prerequisites and limitations that occur as consequences of a psychotic disorder are best understood through the eyes of those with personal experience, which is why qualitative studies are useful for providing insights and descriptions. Research has shown how difficult it is to change lifestyles and maintain these changes, even in a non-disease context. Living with a psychotic disorder causes a range of symptoms that create aggravating prerequisites for a healthy life and maintenance of these habits over time. It is therefore important to develop interventions and clinical approaches that are based on the needs of this group. Previous research has also criticised interventions that have been carried out. This criticism has concerned the lack of follow-up or short-term follow-up, and the fact that the interventions have focused too much on a single lifestyle phenomenon. With this in mind, it is relevant to study the effects of a lifestyle intervention developed for this group on HRQoL and metabolic risk factors. The intervention attempted to take a multifaceted grasp of lifestyle, meaning physical activities and education on lifestyle and nutrition habits, with a follow-up measurement at one year. There is limited knowledge in research about persons with psychosis experiences of participating in a lifestyle intervention and their prerequisites for living a healthy life. There is therefore a need for knowledge on how lifestyle interventions or clinical approaches can be arranged, based on needs and prerequisites as experienced by persons with psychosis.

AIMS

General aim

The general aim of this thesis was to study HRQoL and metabolic risk factors in persons with psychosis, and by a health promotion intervention and through the participants' own perspective contribute to an improvement in lifestyle interventions.

Specific aims

- To compare HRQoL in patients with psychosis, especially schizophrenia, with a reference sample and to analyze the relationship between HRQoL and metabolic risk factors in these patients.
- To study the effects of a lifestyle intervention on HRQoL and metabolic risk factors in persons with psychosis.
- To explore prerequisites for a healthy lifestyle as described by individuals diagnosed with psychosis.
- To describe how persons with psychosis perceive participation in a lifestyle intervention and use these perceptions to present factors to be considered in future interventions.

METHODS

Design

This thesis is based on four studies as showed in Table 1. Within the framework of the project, various methods were used to attempt to answer the general aim. The two qualitative studies are derived from a naturalistic paradigm, while the two quantitative studies belong to a positivistic paradigm (Polit & Beck 2004). Together, these two paradigms allow a presentation of both objective data, derived from measurements of different variables, and subjective data based on the person's descriptions and perceptions of the investigated phenomena.

Table 1. *A comprehensive view of study designs, data collection methods, and analysis*

	Study design	Sample size	Inclusion criteria	Data Collection	Data collection (years)	Analysis
Study I	A cross-sectional cohort study with a population-based reference group	903	Age over 18 diagnosed with schizophrenia or other long-term psychotic disorders (ICD 10)	Questionaries; Demographic and clinical characteristics, level of functioning, patient severity, somatic health, health-related quality of life Physical examinations; blood samples, blood pressure, body weight, body height	2005-2012	Descriptive statistics, Pearson chi-square, ANOVA, logistic regression analysis
Study II	A longitudinal intervention study with a matched reference sample	42	Psychotic disorder according to ICD 10, established metabolic syndrome or at risk of developing metabolic syndrome (IDF 2006)	Questionaries; Demographic and clinical characteristics, patient severity, health-related quality of life Physical examinations; blood samples, blood pressure, body weight, body height, waist circumference	2011	Descriptive statistics, student's paired and unpaired t-test, Wilcoxon and Mann-Whitney U test, Pearson chi-square, Fisher's
Study III	A qualitative exploratory study	40	The same inclusion criteria as Study II	Individual interviews, semi-structured interview guide	2011-2012	Qualitative content analysis
Study IV	A qualitative phenomenographic study	40	The same inclusion criteria as Study II	Individual interviews, semi-structured interview guide	2011-2012	Phenomenographic analysis

Study I was a cross-sectional cohort study that took place at a number of sites in Sweden and compared HRQoL in the patient cohort with a large population-based reference group. Metabolic risk factors relevant for the metabolic syndrome were measured in patients. The natural continuation was

to implement a lifestyle intervention. The next three studies therefore focused on evaluating a lifestyle intervention for persons with psychosis and their prerequisites for a healthy lifestyle. This was done through one quantitative study (II) and two qualitative studies (III and IV). Study II consisted of a longitudinal intervention study with a matched reference group. The third study had a qualitative exploratory design. Conventional content analysis was used. In study IV a qualitative, phenomenographic approach was selected. Semi-structured interviews were used for data collection in both study III and IV. The variation of approaches enabled a deep and great understanding of persons with psychosis and their prerequisites for living a healthy life, and of how lifestyle interventions and clinical approaches towards physical health should be arranged.

Participants

The participants in the studies in this thesis were primarily recruited from the prospective study "Metabolic risks in psychosis" at Karolinska Institutet, Stockholm, Sweden. It is a data collection on patients with schizophrenia or other long-term psychoses (ICD 10). A sample of 903 persons from the original study above was consecutively invited to participate in study I when visiting specialised psychiatric outpatient departments for patients with long-term psychotic disorders in seven different locations in Sweden. The inclusion criteria were; aged over 18 and diagnosed with schizophrenia or other long-term psychotic disorders (ICD 10). Data were collected between 2005 and 2012. Out of the 903 persons in study I, those who fulfilled the inclusion criteria and lived in a particular geographic region were offered to participate in an intervention (n=26). To allow for a larger number of participants, another region also conducted the intervention. These persons (n=18) are therefore not part of study I. A purposeful sample (Patton 2002) of 44 participants conducted the lifestyle intervention (II), of whom two were excluded when the data were analysed. In one of the cases, the participant underwent a gastric by-pass, and in the second case the participant was unwilling to cooperate regarding the intervention content.

The inclusion criteria were; having a psychotic disorder according to ICD 10 (2010) and established metabolic syndrome in agreement with IDF (2006), or at risk of developing the metabolic syndrome. Exclusion criteria were; being in

an acute psychotic state according to a clinical assessment by the regular case managers, having a personality disorder or anorexia nervosa as primary diagnosis, and being addicted to alcohol and narcotics according to ICD 10 (2010). Persons over the age of 65 were excluded (II, III, IV). In addition, the HCs (health coordinators) made a subjective assessment, based on their knowledge of the patient, of whether the person had the cognitive ability to assimilate the intervention. In most cases, this meant a GAF-value (American psychiatric association 1994) above 40. Data were collected at baseline and at the one-year follow-up.

In study III and IV, everyone who had undergone the intervention was invited to participate in an interview. Forty people agreed to participate. Both qualitative studies are based on the same interviews, and as everyone participated in the intervention the inclusion criteria were the same as in study II. The interviews were conducted 6-7 months after the intervention was finished. Below is a flowchart of the participant and reference sample inclusion.

Figure 1. Flowchart of the participant and reference sample inclusion

Reference group

In study I, a population-based survey sample served as reference group. This survey was conducted in 2006 and consisted of individuals from the general population aged 18 to 84 years. The survey was stratified regarding age, gender and community, with a total sample size of 13,440 people. The reference group was assessed with a self-administrated questionnaire, which included questions about somatic health as well as smoking and alcohol habits. The questionnaire also included self-reported body weight and height together with an EQ5D assessment. The response rate was 54% (n = 7,238).

In study II, the reference group of 776 people was recruited from the Swedish national cohort database “Metabolic risks in psychosis”, described above as the original study, which also formed the basis for participation in study I. All participants were diagnosed with a psychotic disorder and received care in accordance with standard treatment. In order to create a more homogeneous comparison group, two individuals per participant were matched against the intervention participants from the 776 reference persons (n=84). These people were matched for sex and BMI class (below 25, 25-29,99 and 30-40). The reference sample was also selected so that their age would correspond as closely as possible to the participant they were matched against.

The intervention

The second, third and fourth study are to some extent based on the intervention presented below. The intervention was conducted during 2010 and 2011. The purpose of the lifestyle intervention was to promote a healthier lifestyle and followed the program “Solutions for Wellness” (Porsdal et al. 2010), a concept developed for persons who suffer from psychiatric disorders, use psychotropic medication, and have weight problems. The program combines a theoretical part about knowledge of one's own body, healthy eating, and physical activities. One of the ideas behind the intervention concept is that thinking and acting healthily should not be isolated to the group sessions. Therefore, everyday physical activity is also focused upon. This does not always involve physical exercise in the sense of going to a gym or swimming pool. It is emphasised that all activity counts and there is a call for changes in everyday life, such as choosing the stairs rather than the lift, or to clean the

house because it also involves physical activity. As the method goes beyond group meetings, it is flexible and at least 30 minutes of physical activity daily is recommended. We know from previous research that a large proportion of persons with psychosis are smokers. Furthermore, consumers of large amounts of alcohol are overrepresented. With this in mind, our intervention also dealt with reducing smoking and alcohol consumption in order to attain a healthier lifestyle.

Before the intervention, the participants' case managers, home aid, and ordinary caregivers were invited to open meetings. There, they were informed about the design and implementation of the intervention by two members of the research team (RW and AF). The intervention consisted of group sessions with six to eight participants under the guidance of health coordinators (HCs) (n=9). To be able to recruit a larger number of participants, the intervention was conducted in two county council areas. The intervention took place in three different outpatient psychosis departments and consisted of either 9 or 20 sessions, (9 sessions = n 18, 20 sessions= n 26). The sessions were held on a weekly basis, but with a break for the Christmas and summer holidays, depending on when the group had started. During the intervention, the research team had regular meetings with the HCs, in order to synchronise the intervention to the standardised study protocol, and thereby ensure that the adopted program was followed.

The HCs were mental health nurses (n=3), physiotherapists (n=3), assistant nurses (n=2), and one occupational therapist (n=1). They were educated in Motivational interviewing (MI) and had extensive experience of working with persons with psychosis from their ordinary work within outpatient psychosis care. All HCs had experience of working with lifestyle issues from previous physical group activities for persons with psychosis.

The intervention began with an individual meeting between each participant and one of the HCs. In these conversations, current as well as previous lifestyle habits and personal goals were identified, and in addition to the written information, participants were given a more comprehensive presentation of the intervention and its approach. Initially, the participants each received a pedometer and a food diary, which were later subjects of discussion in the group sessions. Each group session included a theoretical part and a physical activity part, with a break in the middle during which different fruits were tested. The physical activities were based on exercise to music and occasional

walks, and were increased gradually both in time and intensity from 30 minutes up to one hour. Although each group session had an original plan, the HCs were free to find forms of physical activity that captured the participants' interest on the day, or activities that were in line with their previously identified individual goals. A basic requirement for the physical activity was that it should be of such a nature that everyone could manage it, albeit with different intensity based on individual capacity. In order to demonstrate any progress and increase the participants' motivation to make further efforts, body weight and waist circumference were measured on several occasions during the intervention.

The theoretical part included issues regarding healthy eating based on Nordic nutrition recommendations (Alexander et al. 2004). In brief, these recommendations propose a fat intake of approximately 10% of the total energy intake, carbohydrates should provide 50-60 %, and protein 10-20% of the total energy intake. The theoretical part also dealt with anatomy, muscles and ligaments, together with how to achieve well-being and health. The latter could be about balancing activity and rest, or practical help with how to find appropriate food in the supermarket. The theoretical part was also flexible in order to manage issues that arose. The intervention had a proactive approach, meaning that absence from sessions was followed-up in a special way. The HCs called missing participants and in some cases sent postcards asking why they had not attended. Through the phone calls and postcards they also investigated whether they could do anything to facilitate attendance to forthcoming sessions, which could result in staff or next of kin giving them a lift to the next session. Towards the end of the intervention, the HCs tried to find further opportunities for physical activity in the community, based on the participants' individual preferences.

Theoretical standpoints for the intervention

As previously described, the intervention had a health promotion approach where self-care and HRQoL were important elements. The theoretical foundation for the intervention concept originates from MI and a cognitive approach. Motivational interviewing is a method dating from the 1980s. It aims to increase the individual's motivation to change problem behaviours. Motivational interviewing emerged in contrast to the prevailing paradigm at

the time, where a tougher attitude and descriptions of the negative effects of a person's current lifestyle were to create change through fear of future consequences (Miller 1983). The MI approach is instead characterised by client-centred thinking, where the individual's ambivalence is explored to possibly later be dissolved (Rollnick & Miller 1995). Motivational interviewing is explained as a contrast to traditional advice-giving, and seeks to identify the individual's ability and willingness to create changes (Rollnick et al. 1992).

Motivational interviewing has become an increasingly frequently used method in the health care work to support people to implement lifestyle changes. It can be used as a freestanding intervention, but is often combined with other approaches, such as cognitive behavioural therapies (Lindhe-Söderlund 2010). Motivational interviewing methodology assumes a collaborative partnership and a shared decision-making process. The counsellor should honor the client's autonomy and evoke their own arguments and reasons for change (Rollnick et al. 2008).

Cognitive behavioural treatment (CBT) is one tool for initiating change in patients. The effect of CBT has been widely documented for many different conditions in both psychiatric and somatic illnesses (Beck & Dozois 2011). Initially, this therapy was applied in cases of depression, but in recent years there has been increasing evidence for practice also in psychotic disorders (Beck et al. 2009).

Data collection

Data was collected by instruments, physical examinations and interviews.

Instruments

EQ5D

In study I and II, the generic instrument EQ5D-3L (hereafter referred to as EQ5D) was used for measuring HRQoL in persons with psychosis and in the reference sample (Brooks 1996, Dolan 1997). The EQ5D is a standardised instrument for measuring health status (Dolan 1997). The instrument consists

of two parts. The first part is the EQ5D questionnaire that includes five items related to mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Responses in each dimension are divided into three ordinal scales: 1) no problems, 2) moderate problems, and 3) extreme problems. The EQ5D scores can then be converted into a single summary EQ5D index, which quantifies health status (Brooks 1996). The index has a range of -0.594 , (lowest HRQoL), to 1.000 , (highest HRQoL) and 243 possible health outcomes (Dolan 1997). The outcome of the EQ5D may be presented by using the index value or by presenting the five dimensions directly. The advantage of presenting the dimensions is that it demonstrates in which dimensions problems occur. Using the mean value alone may hide important information in the material (Devlin et al. 2010). The second part is the EQ visual analog scale (EQ -VAS), a vertical scale that reflects the current health status, ranging from 0 (worst imaginable health state), to 100 (best imaginable health state) (Brooks 1996). The EQ5D has been found to be reliable and valid (Coons et al. 2000), and has also been proven valid within the context of psychotic disorders (König et al. 2007).

Clinical Global Impression

In study I and II, patient symptom severity was assessed with the Clinical Global Impression-severity (CGI-s) scale. The CGI-S is a single-item clinician rating of the severity of the patient's symptoms in relation to the clinician's total experience of previous patients with the same diagnosis. Severity is rated on a seven-point Likert-type scale ranging from 1 (Normal, not ill at all), to 7 (among the most extremely ill patients) (Guy 2000). The CGI-s asks the clinician one question: considering your total clinical experience of this particular population, how mentally ill is the patient at this time (Busner & Targum 2007)? The CGI-s has proved to be valid (Busner et al. 2009), suitable for routine use in various psychiatric diagnoses, and reliable in the hands of skilled clinicians (Berk et al. 2008).

Global Assessment of Functioning

In study I, the patients' level of functioning was assessed, using the Global Assessment of Functioning (GAF) (American Psychiatric Association, 1994). Global Assessment of Functioning assesses overall social, occupational, and psychological functioning level on a scale from 1 to 100, where 1 is the lowest and 100 the highest functional level. It constitutes one of the axes in DSM-IV

and has proven to be valid and reliable for assessing the level of function in psychiatric disorders (American Psychiatric Association 1994, Schennach-Wolff et al. 2009, Startup et al. 2002).

Somatic questionnaire

In study I, somatic health was assessed with a questionnaire about cardiovascular disease, diabetes and hypertension, developed by the research team. Data on the patients' current medication for these conditions were collected. The questionnaire also included questions on smoking habits and alcohol consumption.

Physical examinations

Blood samples

In study I and II, blood samples included in the metabolic syndrome (Alberti et al. 2009) and LDL-cholesterol were drawn with the subjects fasting, and were subsequently analysed using routine methods at Swedish Hospital laboratories. The laboratories were accredited according to a quality assurance system (Good Laboratory Practice; GLP).

Anthropometric measurements

In study I and II, body weight was measured with the participant wearing indoor clothing on a calibrated weight scale. Height as well as waist circumference were measured to the nearest centimetre, and BMI (kg/m^2) was calculated in both studies.

Blood pressure

In study I and II, systolic and diastolic blood pressure was measured in the supine position after a resting period of five minutes. The blood pressure manometers were calibrated according to the usual routine at Swedish hospitals.

Interviews

In order to explore the prerequisites for a healthy lifestyle (III) and describe how persons with psychosis perceive participation in a lifestyle intervention (IV), individual interviews were performed. A semi-structured interview guide was developed in collaboration with the research team. This guide was tested in four pilot interviews with persons diagnosed with psychosis who had undergone a similar lifestyle intervention in the outpatient psychiatric organisation approximately one year before. A few minor changes were made to the interview guide and these interviews were not used in the analysis. The interviews were conducted during 2011 and 2012.

At the beginning of the interviews there was time to make the participants feel as comfortable as possible. The interviews began with a broad question about their perception of the intervention. Open-ended questions were asked, such as “what do you think about your lifestyle and your prerequisites for a healthy life”, or “can you tell me what you would change or develop in the intervention concept?” The questions were used together with probing questions (Patton 2002), such as “can you tell me more” or questions based on their previous statements. All interviews ended by asking the participants if there was anything else they wished to add.

The majority of the interviews took place in outpatient psychiatry facilities, but as the participants decided where the interview would take place, some of the interviews were held in their homes. One of the participants did not want to be audio-recorded. Therefore, field notes were taken instead. No quotes were used from that interview. All interviews ended with social small talk. If required, further contact with the regular psychiatric services as a result of the interviews could be organised.

The interviews were conducted six to seven months after the intervention was finished. They lasted for 15-60 minutes and were transcribed verbatim using a transcription guide (McLellan et al. 2003). The transcripts were validated against the audio-recordings. The data for both qualitative studies were derived from the same interview series (n=40). The interviews generated a rich body of data, which made it possible to analyse the material with two different methods and aims.

Data analysis

Statistical analysis

The statistical analyses were performed using SPSS 20.0 (I) and SPSS 22.0 (II) (SPSS Inc, Chicago, IL, USA). In study I, the variables were summarised with standard descriptive statistics, e.g., mean and frequency. Differences between the patients and the reference sample regarding gender and smoking were analysed with Pearson's χ^2 -test. Differences in age, alcohol consumption, and EQ5D index were analysed with two-way (group * gender) analysis of variance (ANOVA), as there was a significant difference in the gender distribution. The relationship between HRQoL and BMI was analysed in a three-way ANOVA (group * gender * BMI-group), with age as a covariate, in which the relationship between the separate factors (group, gender, and BMI-group) and the EQ5D index appeared as main effects. The relationship between HRQoL, according to the EQ5D index, and the metabolic risk factors was analysed with a logistic regression analysis. In the analysis, the index was dichotomised according to the median and used as the dependent outcome variable. All variables constituting the metabolic syndrome (Alberti et al. 2009), including the metabolic syndrome per se, were entered as independent variables together with gender, age, smoking, high LDL-cholesterol and GAF.

In study II, the level for statistical significance was set to $p < 0.05$. Descriptive statistics were computed for all study variables. Mean and SD were presented. Parametric and non-parametric analyses were conducted in relation to data level. Comparisons between and within the groups were performed with student's paired and unpaired t-test. The EQ5D questionnaire was calculated with Wilcoxon and Mann-Whitney tests to make comparisons within and between the groups. Independent sample t-test was used when comparing changes over time between groups, using delta values.

Qualitative analysis

Qualitative content analysis (III) and phenomenographic analysis (IV) were used to analyse data from the interviews. In this thesis (III), a text-oriented

approach to content analysis was chosen. Krippendorff (2004) explained the methodology as being descriptive by nature, which is advantageous as there is only a small risk of impact on the data because the analysis is close to the text. Conventional content analysis as described by Hsieh and Shannon (2005) was used. This design is suitable when existing research on a specific phenomenon is limited. No preconceived categories were used, a procedure known as inductive category development. The categories and their names were derived from data (Kondracki & Wellman 2002). The approach was considered appropriate as there is very limited research on persons with psychosis experiences of their prerequisites for a healthy lifestyle.

The interviews (III & IV) were transcribed verbatim in line with the recommendations in the transcription guide by McLellan et al. (2003). As a first step of the analysis, the transcripts were read repeatedly. The repeated reading created a sense of the whole and enabled the researcher to become familiar with the interviews conducted by the other interviewing author. The transcripts were then read word-by-word in order to find and highlight exact words in the text that captured key thoughts or concepts that were related to the aim. Codes were labelled as closely to the original text as possible, taking into account the chosen approach. The codes were categorised based on how they were related and linked, and the larger number of subcategories was subsumed within categories. A hierarchical structure in the form of codes, subcategories and categories emerged. Definitions for the categories and subcategories were developed and relevant quotations were identified from data (Hsieh & Shannon 2005).

In study IV, a phenomenographic analysis was conducted. Phenomenography is a suitable approach to describe varying perceptions of a phenomenon as experienced by a group of people (Sjöström & Dahlgren 2002). Phenomenography has its roots in educational research (Marton 1981), but can be used in a broader area. In nursing research, the aim can be to manage and emphasise the differences between how patients experience their states and needs. The findings can then be used by health care professionals in order to meet individual needs (Sjöström & Dahlgren 2002). In this thesis, this entails the things that health care professionals can do to enable a healthy lifestyle by taking the participants' perceptions into consideration.

The aim of this methodology is to understand the different ways phenomena are experienced in the surrounding world, and describe people's perceptions

of reality and the world in which they participate. A spectrum of human understanding of a particular phenomenon can be presented (Sjöström & Dahlgren 2002). Marton (1981) described a dividing line between how researchers could either choose a first-or second-order perspective. In phenomenography, the second-order perspective is the primary focus, i.e., how phenomena are perceived. The first-order perspective, i.e., how something really is, is therefore not central. The descriptions are based on the informant's point of view, not the researcher's.

The phenomenographic analysis followed Dahlgren and Fallsberg (1991). First, the transcripts were read repeatedly and carefully by RW and SH in order to become familiar with the data. The work continued by identifying each informant's most significant answers that were relevant to the research question. Long answers were shortened and condensed in order to find the central parts. Similar answers were grouped together in a preliminary classification. This was then used to make preliminary comparisons between categories to establish divisions between the categories and ensure that the categories were separated from each other. A description of the unique character of each category, as well as the varying perceptions within the category was made. Finally, a description of each category and how the categories are logically related to each other was made. This is presented in the outcome space, which is the main finding in phenomenography (Marton & Booth 1997). Neither of the chosen analyses (III, IV) should however be viewed as static. The analysis processes moved back and forth on several occasions.

Ethical considerations

All studies in the project were approved by the Regional Ethical Review Board in Stockholm (I and II) and the Regional Ethical Review Board in Linköping (III and IV), and conducted in agreement with the Declaration of Helsinki (2008). The fundamental starting point was that possible participants needed to understand the purpose and meaning of giving informed consent. This is particularly important when persons with mental illness are included in scientific studies, as privacy and autonomy are extremely important. The latest update of the Declaration of Helsinki (2013) further clarifies the importance of being cautious with vulnerable groups.

The group focused upon in this thesis comprises vulnerable persons, and it is important that research also provides a description of their prerequisites and health. This is an often overlooked group (Daumit et al. 2013), that has been frequently excluded by scientific studies for psychiatric reasons. Inclusion should obviously not be arbitrary, and necessary considerations must be taken, but it could be argued that caution should be taken not to habitually exclude such a large group where research can make a difference. Therefore, clear, well premeditated inclusion and exclusion criteria are a necessity. The reason why persons over the age of 65 were excluded from the intervention (II) and thereby also from the forthcoming qualitative studies (III and IV) was to avoid the health risks associated with physical exertion. Taking into account that 65 years of age may be considered a relatively high age in the context being studied, we were not prepared to take any unnecessary risks regarding physical activity and the associated risk of injury or illness.

Another consideration concerning which participants could participate in the project was related to disease severity, comorbidity and somatic status. This was viewed as a necessary distinction with regard to the intervention approach with group activities. There was also a readiness to deal with any feelings of failure in relation to the intervention. The risk of exposing people to further failures in case they experienced that they were unable to benefit from participation in the intervention is worth discussing. This is a decisive argument for keeping a moderate intervention level. Any required support by their regular outpatient staff had been prepared. Both interviewers in the qualitative studies are mental health nurses with experience of working with patients with psychosis. The interviewers also have experience in interviewing people with psychotic illness. Out of respect for individual statements, these were handled in a strictly scientific manner based on the chosen method of analysis. Obviously there was a risk of infringement of privacy in the context of the interviews. Still, it was not experienced that the interviews aroused feelings requiring further action by the health care services.

Being participant in a project that aims to change certain behaviours might conflict with the general human desire to belong “just as I am”. On a self-critical note it is plausible that a person with psychosis, after many years of contact with the psychiatric outpatient and inpatient care, will have been subject to a series of nursing interventions aiming to adjust behaviours and emotions towards normality. Even this thesis could be regarded as another one of those projects. On the surface, the intervention was a lifestyle

intervention, but on a deeper level it was still an expression of the desire to implement more socially acceptable behaviours. We wanted these people to internalise social norms and values regarding health and lifestyle in order to achieve or maintain their physical health. If the person succeeds there are positive consequences, but a sense of another failure can make future efforts more difficult and even more urgent.

Rigour

The two different scientific paradigms that contribute to this thesis have diametrically different ways for enhancing rigour. While quantitative research rests upon statistical analysis and its formulas and rules, qualitative analysis depends on the insights and conceptual capabilities of the researcher (Patton 2002). For this reason, the presentation of scientific rigour below is made on the basis of these different paradigms.

Validity and reliability in quantitative research

Strategies for enhancing the rigour of quantitative studies are necessary in order to judge how effectively threats to validity are minimised or considered in the interpretation of the findings. Validity is always relative and should not be considered as absolute (Polit & Beck 2012). Objectivity is a central concept dealing with the extent to which independent researchers arrive at similar judgements or conclusions, without being biased by personal values or beliefs.

Internal validity concerns the validity of inferences that it is the independent variable and not anything else that caused the outcome, given that an empirical relationship exists. The researchers have to develop strategies to rule out the possibility that anything other than the independent variable accounts for the observed relationship (Polit & Beck 2012). To ensure objectivity and internal validity in the studies, the authors had recurrent meetings where the data and how it should be handled were subject of discussion.

External validity, on the other hand, concerns whether inferences about observed relationships will hold over variations in persons, setting, time, or

measures of the outcome. This is about generalisability of causal inferences. Finally, reliability can be considered a key criterion for assessing the quality of quantitative instruments. The less variation an instrument produces in repeated measurements, the higher the reliability (Polit & Beck 2012). The instrument chosen for data collection in the studies (I and II) were valid and reliable and have all previously been used in the context of psychosis.

Trustworthiness in qualitative research

Trustworthiness in qualitative research is necessary in order to assess its worth. Trustworthiness can be achieved through establishing credibility, transferability, dependability, and confirmability. Credibility is about reliance in the “truth” of the findings. Transferability means that the findings are relevant in another context. Dependability means that the findings are consistent and can be repeated. Confirmability refers to a degree of neutrality, or to the extent to which the findings are based on the researcher's interest or coloured by their pre-understanding. There are several techniques to meet these criteria. Credibility can be achieved through spending sufficient time in the field and gain an understanding of the culture, social setting, and phenomenon of interest (Lincoln & Guba 1985). The qualitative studies (III and IV) included in this thesis involved 40 interviews, which made it possible to become familiar with both culture and context. In addition, both interviewing authors had extensive experience of working with persons with psychosis and thereby a good understanding of the area of interest. Another way to achieve credibility in a phenomenographic context is to provide quotations from the interviews, leaving the reader to judge if the categories are relevant (Sjöström & Dahlgren 2002). A large variety of quotes are represented in the qualitative studies.

Transferability is achieved through rich descriptions of the study procedures. By describing a phenomenon in detail, it is possible to determine whether the findings are transferable to other settings, situations, or people (Lincoln & Guba 1985). The qualitative studies (III and IV) have endeavoured to be transparent and give the reader a comprehensive insight into the study design and context. Dependability can be achieved by allowing external researchers to examine both the process and product of the research study. This creates opportunities to evaluate whether the findings, interpretations, and con-

clusions are supported in the data (Lincoln & Guba 1985). The studies included in this thesis have all been the subject of discussion and presentations during seminar series with researchers and PhD students. Based on phenomenography, it is, however, not necessary that other researchers working with the same material will form identical categories (Sjöström & Dahlgren 2002). It is rather a question of the degree to which the result is understood by other researchers. The outcome space and the description categories should therefore be presented in such a way that it is understood by other researchers (Marton 1994). Through close collaboration between the authors in the analysis process and by allowing the process to move back and forth, we pursued to make the result as clear as possible.

Confirmability can be achieved through transparent descriptions of the various research steps taken during the entire process (Lincoln & Guba 1985). These are carefully described in the studies (III and IV). The authors' own backgrounds as mental health nurses can be viewed as both a strength and a weakness. It implies an awareness that the outcome could be affected, even if efforts have been made to put preconceptions aside. Lincoln and Guba (1985) referred to this as reflexivity.

RESULTS

The findings of this thesis demonstrate that lifestyle changes are needed in persons with psychosis, based on the high frequency of metabolic risk factors and poorer HRQoL in this population. Based on their own descriptions and perceptions, lifestyle changes are possible to achieve. There are both internal and external obstacles and opportunities for persons with psychosis striving towards a healthy lifestyle, which is why health care professionals have an important role in helping them overcome these barriers and support the opportunities. Our findings show that individualised support can facilitate the transition from thought to action and help finding a moderate approach that is sustainable in the long run. The findings show that interventions or approaches towards a healthy lifestyle must therefore not underestimate or overestimate the person's capacity, and potential activities should mirror the type of activities that persons with psychosis think that "common people" do. There is a striking desire to live like everyone else.

This thesis also shows that an intervention that took a multifaceted grasp on lifestyle through physical activities, as well as education in lifestyle and nutrition habits, improved HRQoL but demonstrated only minor improvements in metabolic risk factors. Therefore, future interventions for persons with psychosis should take their own experiences of what works for them in relation to health and lifestyle into consideration.

The most important findings of each study are presented below. More detailed results are presented in the studies (I-IV). The two quantitative studies are presented first (I, II), while the qualitative perspectives that are derived from interviews with participants in a lifestyle intervention are presented last (III, IV).

Study I

The aim of study I was to compare HRQoL in patients with psychosis, especially schizophrenia, with a reference sample and to analyze the relationship between HRQoL and metabolic risk factors in these patients.

The distribution of diagnoses in the patient group (n=903) showed that the majority (62%) suffered from schizophrenia. The patient group had a higher proportion of men, and the reference sample was 4 years older in mean (n=7238). Among the patients there were more smokers and a larger proportion of teetotalers, as well as more high consumers of alcohol. Body mass index was higher among the patients. Demographic and clinical characteristics are presented in Table 2.

Table 2. Demographic and clinical characteristics in patients with psychosis (n= 903) and a population-based reference sample (n=7238).

Variable	Patients		Reference group		
	n	(%)	n	(%)	p
Women	406	45.0	3949	54.6	<0.001
Age (Years) Mean	47.2	-	51.2	-	<0.001
Range	21-84	-	18-84	-	
Alcohol, g per week					
0	370	41.2	1353	19.3	<0.001
1-199	421	46.9	5485	78.2	
≥200	106	11.8	176	2.5	
Missing	6	-	224	-	
Smoking					
Smoker	378	42.2	1392	19.4	<0.001
Non-smoker	518	57.8	5767	80.6	
Missing	7	-	79	-	
Body Mass Index-kg/m ²					
≤25	256	28.8	3884	56.5	<0.001
26-30	333	37.5	2246	32.6	
31-35	182	20.5	567	8.2	
>35	117	13.2	183	2.7	
Missing	15	-	358		

The main finding of study I was that patients suffering from psychosis had significantly lower HRQoL in comparison with the population-based reference group. According to the definition by IDF (2006), one of the risk factors for metabolic syndrome, elevated blood pressure, was associated with lower HRQoL in the patients. Several other factors not included in the definition of the metabolic syndrome showed a relationship with lower HRQoL. High BMI,

high LDL- cholesterol level, female gender, lower GAF, lower CGI, as well as being older than 44 years of age were all significantly related to lower EQ5D index. The metabolic risk factors among patients with psychosis are presented below.

Table 3. *Metabolic risk factors among the patients with psychosis (n= 903).*

Variable	N	(%)	Mean	Median	SD	IQR
Antipsychotic treatment in years				16.0		18.0
Triglycerides, high ¹	325	36	1.5	1.4	0.8	1.1
HDL cholesterol low ¹	360	40	1.2	1.1	0.4	0.4
LDL, cholesterol high ¹	418	46	3.5	3.4	1.0	1.2
Glucose fasting high ¹	554	61	5.6	5.3	1.4	1.0
Elevated blood pressure ¹	531	59	n	n	n	n
Waist circumference ¹	571	63	n	n	n	n

IQR= Interquartile range

¹according to IDF criteria

The patients had significantly lower ratings in the EQ5D index compared to the reference sample. The dimensions of EQ5D revealed that the patients had lower ratings, in other words, poorer HRQoL than the reference group in all dimensions (mobility, self-care, usual activities, and anxiety/depression), with one exception. The reference group had somewhat lower rating in pain/discomfort. Besides lower HRQoL, the overall situation therefore illustrates that there are increased risks of physical comorbidity among patients, which is why efforts to manage the situation are required.

Study II

The aim of study II was to study the effects of a lifestyle intervention on HRQoL and metabolic risk factors in persons with psychosis. The intervention participants (n=42) were compared to a matched reference sample (n=84). The matching procedure took into account sex, age, and BMI class. Table 4

provides a baseline description of socio-demographics and lifestyle factors in the intervention and reference sample.

Table 4. A baseline description of socio-demographics and lifestyle factors in the intervention ($n=42$) and reference sample ($n=84$). Mean and (SD) are given unless otherwise stated.

Variable	Intervention group $n=42$	Reference sample $n=84$	P value
Age (years)	45.5 (10.2)	47.2 (8.7)	0.32
Duration of illness (years)	18 (11.7)	20 (9.4)	0.30
Living alone (%)	69	67	0.99
University or higher education (%)	21	38	0.06
At least one risk factor for Mets (%)*	100	100	
Teetotallers (%)	51	71	0.03
Smoking (%)	33	38	0.60
Snuff (%)	19	21	0.73

*Metabolic syndrome according to IDF (2006)

Bold value denote significance

The main finding was that the intervention participants improved in HRQoL, ($p=0.05$) as shown by the EQ-VAS (Figure 2). At baseline, the intervention group had a higher frequency of reported problems in usual activities. In contrast, the reference sample had more frequent problems in pain/discomfort and in anxiety/ depression. No statistical differences were found when comparing the EQ5D dimensions between baseline and the one-year follow-up. Nor did the EQ-Index show any significant change.

Figure 2. EQ-VAS (Mean, SD) in the intervention group at baseline and the one-year follow-up.

At baseline, all intervention participants had at least one of the IDF criteria for metabolic syndrome. A large majority (93%) exceeded the limit criterion for waist circumference. The metabolic risk factors were changed to a small extent after the intervention. Significant differences were detected in HDL-cholesterol as the concentration increased when comparing baseline and one-year follow-up data within the intervention group. A calculation of delta values also showed significant differences in HDL-cholesterol between the intervention and reference sample, in favour of the intervention participants. Another risk factor, blood pressure, was significantly lowered among women in the intervention group compared with the reference sample at the one-year follow-up.

Despite the improvement in HRQoL demonstrated by the EQ-VAS and small improvements in metabolic risk factors, it can be concluded that the intervention was not powerful enough to influence the metabolic risk factors to a more comprehensive extent.

Study III

The aim of study III was to explore the prerequisites for a healthy lifestyle as described by persons diagnosed with psychosis. The main finding highlighted a striving to live like everybody else and taking part in society. Achieving these goals met with internal and external obstacles. Here, health care professionals could be of assistance in the transition from thought to action and in meeting the need to take part in the society.

Two categories emerged: **Individual prerequisites** with the associated subcategories stuck in planning, mental state, motivation, and knowledge and structure. The second category, **being a part of society** has the associated subcategories striving towards a normal and healthy lifestyle, daily life finances, and continuous social support. The first category, individual prerequisites (1), can be understood as containing the person's own resources. The second category, being a part of society (2), describes the goals and direction for the person's lifestyle and factors that hinder or create opportunities in the surrounding community in relation to adopting a healthy lifestyle. Together they constitute the prerequisites for a healthy lifestyle.

Clinical characteristics of the participants in the interview studies are presented below.

Table 5. *Clinical characteristics of the persons with psychosis who participated in the interview studies (III, IV).*

Variable	N	Median	%
Women	19		48
Age 27-65 y	40	46	
Diagnosis			
Schizophrenia	15		37.5
Schizoaffective disorder	10		25
Bipolar disorder	8		20
Psychosis not otherwise specified	4		10
Delusional disorder	3		7.5

Stuck in planning (1)

Failure to proceed from thought to action was a recurring description. Plans for a healthy lifestyle were verbalised, but for various reasons the time for implementing these was never quite right. Someone described this in terms of mental paralysis.

Mental state (1)

During difficult times, mental state could act as a barrier to a healthy lifestyle. Someone stated that the type of butter you eat on your sandwich is not important when you do not know if you want to live anymore. As a psychotic disorder can quickly change a person's living conditions, investments in their own health were described as uncertain. The mental pain or psychotic symptoms could also be reasons for comfort eating, which further complicated improvements.

Motivation (1)

Succeeding with healthy lifestyle changes created well-being and motivated the participants to manage health problems. When they experienced health benefits they felt stronger and that they could participate in society. In contrast, failure could impede continued motivation and self-esteem. A recurring phenomenon that seemed to impair motivation was that their physical health was out of their control. Family history, genetics, or a solid bone structure could create the belief that it was impossible to do anything

about the situation. Similarly, if they felt that God still decides when it is time, own efforts are meaningless.

Knowledge and structure (1)

Knowledge and structure was described as important for progressing from thought to action. Knowledge that can be applied in everyday life where a behaviour can be carried out regularly can make a difference. Inaccurate knowledge could lead to eating habits that the persons with psychosis thought were beneficial. Therefore, knowledge on good eating habits, regular physical activity, and strategies on how they can be transformed into a daily routine are important prerequisites.

Striving to gain a normal and healthy lifestyle (2)

There was a strong desire to live like everyone else and having a normal and healthy lifestyle. Participating in activities, spending time with healthy people, or managing some kind of job could be ways of becoming a part of the regular society, bringing the persons with psychosis closer to what they defined as normality. Even if they wanted to be involved and participate in activities offered by society, difficulties to participate on equal terms emerged. An extreme appetite and weight gain resulting from side effects of second generation antipsychotics created feelings of stigma and embarrassment.

Daily life finances (2)

Living with a psychotic disorder often involves limited private finances. Sometimes the persons with psychosis could not participate in the activities they preferred and had to prioritise. Another consequence was that they did not buy fruit and vegetables in the supermarket. On the other hand, limited funds could contribute to improvements in nicotine habits, as the expense rather than the health risks appeared to be a crucial reason for cutting down or stopping smoking.

Continuous social support (2)

In order to create better prerequisites for a healthy lifestyle, the overall situation requires support from family, friends, and health care professionals. Social interactions with friends and family were described as important resources and could facilitate a healthy lifestyle by encouraging any implemented changes. Health care professionals could also encourage and, above all, provide help and support on how to realise changes.

Study IV

The aim of study IV was to describe how persons with psychosis perceive participation in a lifestyle intervention and use these perceptions to present factors to be considered in future interventions. The main finding showed that content in moderation formed the basis for continued participation. Health care professionals need to find this individualised moderation and further facilitate the participants' ability to mirror themselves against healthy people in society by introducing activities that "common people" do.

The findings are presented in three categories with two subcategories each. The outcome space comprises these three related categories, which are presented below in the figure.

Figure 3. The descriptive categories and their interrelations

"Everything in moderation" is the foundation for participation, as well as for being able to assimilate the intervention. Content in moderation was perceived to be necessary as it created opportunities for further participation and thereby social interactions as described in "caring and comparing". It also formed the

prerequisites for a healthier lifestyle as described in “the continued journey”. In order to balance the moderation, a leader who could find an individualised level was required. A majority of the participants appreciated how the intervention provided an opportunity for social interplay, while others did not value the social dimension and participated in the intervention without considering themselves to be part of the social interaction. Others experienced new social contacts as crucial for “the continued journey”. Many mirrored their own performance in the intervention with the other participants, for better or worse, and told others who did not take part in the intervention about what they had learned. Participation could also have positive consequences for further efforts to achieve a healthy lifestyle. However, even the best of intent is not enough if a person is left with a sense of failure.

Content in moderation

Moderation is the fundament for starting and continuing working towards a healthy lifestyle and should therefore permeate both practical and theoretical elements. A sufficiently challenging level enabled the majority to participate, while many believed that they themselves could have managed more. While some appreciated the adapted level, others perceived a need to raise the intervention to a more challenging level. There were great opportunities to work with the intervention content and still classify the content within the moderation term. External actors and more activities outside the hospital could have allowed the participants to reflect on the reality outside psychiatric care. Concrete tools for changing behaviours, such as exercise and nutrition schedules, a pedometer, and weight control were appreciated, although it is evident that physical activities were perceived more meaningful than thinking about or discussing the situation.

The health coordinator should balance and individualise

For the group to function a good leadership was required, characterised by both acceptance of the participants’ differences and an ability to find individual solutions. Although the leadership was described as individualised, further individualisation in the content, process and support was requested. Some would have preferred more active coaching, while others took the opposite stance, which is why it is important to find out what the person thinks might work. To be seen and wanted, whether the person was present at one session or not, emerged as important. Phone calls and postcards telling the participants that they were missed were appreciated and could encourage them to participate in the forthcoming sessions.

Social interplay

The social interplay was experienced as one of the major benefits of participating in the intervention. Making friends and having someone to share their situation with could relieve the participants' boredom and loneliness, and create opportunities for being truly understood by someone who was also living with psychosis. Being part of a group was also experienced as difficult by some. Those who enjoyed being by themselves could become concerned if someone wanted to contact them between the sessions.

In comparison with others

It was common that participants compared themselves with other intervention participants. Level of achieved knowledge, mental state, or the ability to perform physical activities were subjects of comparison. These comparisons often resulted in participants considering themselves to be superior to the others, and a feeling of not being equally affected by illness. Some perceived these comparisons as stimulating for their own development, while others perceived them as hard. Some felt that the others could not benefit from the intervention, neither the theoretical part nor the physical activity. This also created a certain degree of agitation, as they felt that the others did not try to do their best.

With gain or pain

The potential of a lifestyle intervention seemed far superior to the possible risks. The vast majority perceived that they had made changes for the better, which could further create conditions for other areas of improvement. Being selected and participating in an intervention conveyed the image of them as being worthy to invest in. Many perceived positive effects, both in terms of physical and mental health, and a feeling of success that supported the perception of being a capable person. At the same time, not everyone managed all the changes they had hoped for. Some experienced that the work involved was not worth the struggle, or that the focus on different foods increased their appetite, which thereby increased their weight. Further failures could create the risk of a vicious circle and a sense that change was impossible.

The butterfly effect

The intervention made the participants identify themselves with being healthy. This could create a sense of pride and lead to a new contributing role in the family, as participants shared the message of the intervention. In some cases the intervention therefore had a wider impact as families started doing healthy activities together or had healthier meals.

DISCUSSION

The general aim of this thesis was to study HRQoL and metabolic risk factors in persons with psychosis, and by a health promotion intervention and through the participants' own perspective contribute to an improvement in lifestyle interventions. This thesis presents new and clinically important results in the quest for ways that health care professionals can address the issue of physical health tailored to this group's needs, as well as knowledge of how lifestyle interventions in clinical psychiatry can be arranged in the future. Previous research has yielded very limited opportunities for persons with psychosis to express their views about how lifestyle interventions should be arranged and what actually contributes to a healthy lifestyle (Roberts & Bailey 2011). Nor have persons with psychosis prerequisites for a healthy lifestyle previously been studied. This discussion will focus upon the main findings in the thesis in the light of the theoretical and conceptual framework, including additional theories and research that may shed new light on the findings. The discussion aims to target how health care professionals in clinical psychiatry can work with health promotion interventions in the future, giving consideration to the findings in this thesis.

The main findings of this thesis demonstrate that taking part in society, living a life like everyone else, and engaging in activities that "common people" do should constitute the foundations in health promotion activities for persons with psychosis. The findings of this thesis thus indicated a possible path for future health promotion interventions or approaches in clinical psychiatry. Efforts should therefore be based on activities that mirror the opportunities that "common people" were described to have. With such a foundation, there is great potential to develop prerequisites for motivation, active participation, and capacity for self-care. This also ought to create opportunities to target metabolic risk factors and improve HRQoL. Therefore, the qualitative findings (III & IV) may be a key to reach the elusive problem of the metabolic risk factors which has been measured and demonstrated in the quantitative studies (I & II).

Future health promotion interventions are necessary and need to be developed

Study I showed that our participants had significantly lower HRQoL in comparison with the reference sample. This is not surprising as psychosis is one of the mental disorders with the highest decrease in HRQoL (Penner-Goeke et al. 2015). In addition, almost half of the patient group met the criteria for metabolic syndrome (Alberti et al. 2009). Compared with the general prevalence of the metabolic syndrome in psychosis, there was a relatively high frequency in study I. For example, the meta-analysis by Mitchell et al. (2013) showed that one third of patients with schizophrenia have developed the metabolic syndrome. However, a more surprising finding was that only one of the metabolic risk factors included in the definition of metabolic syndrome, elevated blood pressure, was associated with lower HRQoL. The association between the metabolic syndrome and HRQoL in schizophrenia is poorly documented (Medeiros-Ferreira et al. 2013). The findings in Study I confirmed the need to develop interventions targeting the prerequisites for a healthy lifestyle among persons with psychosis. Unfortunately, the subsequent intervention (II) was not powerful enough to influence the metabolic risk factors to a greater extent. An overall conclusion of these studies (I & II) highlights the importance of continuing to test and implement health promotion interventions for persons with psychosis.

The modest findings of the intervention study (II) require a reflection of what could have been done differently. It could be that two-hour meetings on a weekly basis perhaps were not enough. Although the intervention intended to go beyond the actual group meetings, not collaborating with other persons or caregivers who share the patients' daily living to a higher extent could be a weakness. An information meeting to explain the intervention was all that was offered. Our study design was based on the participants taking responsibility between the group sessions. The importance of cooperation between different actors has been described in earlier research. Interventions that aim to promote health need to be clarified and strengthened through cooperation between health care services and the local community (Hedberg & Skärsäter 2009). If cooperation in our study had been different and caregivers had been engaged in a more comprehensive way, perhaps this could have favoured the study outcome.

Future health promotion interventions should seek normality

One of the main findings in this thesis is the participants' description of the desire to live as normal a life as possible. This was manifested through descriptions of how they want to live their lives, their goals, or their thoughts about the content of health promotion interventions. The common denominator between these factors is normality. To ascribe the term normality and the opportunity to participate in society a crucial role requires an understanding of the group's morbidity and specific challenges, as for instance stigma and discrimination. It is possible to imagine that persons with psychosis may face a double stigma, partly from the psychotic disorder in itself, but also as a result of the metabolic syndrome and obesity. Together, these factors can make the striving to live like everybody else even harder. To consider the issue in the light of stigma and discrimination, and the understanding of the general human desire of wanting to belong can find answers in sociology and the conceptual term structuralism (Månsson 2014). This concept concerns the study of society from basic patterns of the way people live their lives. Every single person treads their own path, but makes their choice from the already trodden paths in the community structure. This social structure sets up crossroads. Most people will choose the wide pathways as human beings cannot and will not live outside a social context. Even if individuals are theoretically free to act as they want, they will usually act in a way that reproduces the social order in society (Månsson 2014). Thus, people tend to strive towards living within conventions as other behaviours could pose a threat to the individual. This is perhaps something that unites the majority of both animal and human life. Fish would swim straight into the shoal to blend in and avoid becoming an easy target. An injured cat or dog withdraws to avoid exposing their condition. Thus, it is assumed that we are dealing with a deeply rooted survival strategy.

A recurring phenomenon in the qualitative studies (III and IV) was the participants' call for attention to their own capability. This was done by mirroring their behaviour and competence to perform physical activity with their opinion of the ability among the general population and others in the intervention. This is illustrated by statements about the level of the intervention being beneficial for some, but that they themselves could manage more. This phenomenon may have several explanations. Perhaps it was the

case that the participants wanted to appear competent and capable when facing the interviewers. The quest for normality has been described as central in previous research (Pickens 1999). Thus, this desire for greater challenges, challenges that are in line with what “common people” can handle, can be explained by the inherent desire to belong. One way to show that you belong might be to normalise your own health behaviours. The longing to be normal may to some extent surprise in an era where individualism and individual choices have shaped people's identity during the past decades (Triandis 1989). Perhaps it is the case that individual choices and decisions should be made within a context that has a positive value and in the ordinary crossroads set up by community structure (Månsson 2014). By making the right choices, people can present themselves as capable and competent.

The fact that persons with psychosis want to live like everybody else therefore seems to be the key prerequisite for a healthy lifestyle. Here lies a great challenge and opportunity for psychiatric care, namely to find solutions on how to make persons with psychosis feel as normal as possible and enable them to participate in regular activities related to health and lifestyle, or help them by contributing to meaningful occupation (Nordström et al. 2009). One way could be to offer activities that reflect trends in society. In retrospect, we can conclude that our intervention did not have these characteristics to a sufficient extent. There were certainly elements of person-centred care, empowerment, and an aspiration to eventually be able to participate in regular society activities, but maybe not enough. It could be argued that persons with psychosis take a salutogenic perspective (Antonovsky 1994), which should create favourable conditions for continued work towards better physical health. Failure to use this strong inherent power and desire would be irresponsible in future work.

Stigma and discrimination do not stop at being just a feeling. They may instead exert substantial impact and hamper the course and outcome of mental illness (Corrigan 2000). If we are to be able to help persons with psychosis towards normality, stigma must therefore be managed and reduced. Our intervention and subsequent qualitative studies may be one way to allow these persons' voices to be heard. This has not been a frequent occurrence in past research, but could increase the understanding of this group. Research has shown that psychiatric care cannot be free from responsibility. In the same way as in somatic care, there is stigma and discrimination where a paternalistic approach prevails (Mestdagh & Hansen 2014). However, health

care professionals within psychiatric care have an opportunity to lead the way by encouraging participation in society (Hedberg & Skärsäter 2009), and implementing activities in an environment where the person feels safe and has the financial capacity to manage. This way, discriminatory attitudes that could otherwise lead to a vicious circle might be reduced. If this is not the case, this discrimination may have devastating effects on the person's social relations, leading to feelings of loneliness and an undermined self-esteem. The low self-esteem will in turn reduce the ability to seek social support, which will further increase the sense of loneliness (Switaj et al. 2015).

The findings of this thesis demonstrate that a moderate intervention level should guide the design and content of interventions. It turned out to be complicated to define the moderate level as this is based on individual preferences. This finding, however, is also permeated by the concept of normality as a moderate level is in line with what participants perceived that "common people" do. The findings showed that a moderate level might be necessary for participation, both for themselves and others, and especially at times when the disease is more challenging. The level of moderation can therefore be considered crucial for the potential to target the metabolic risks, improve HRQoL and having an opportunity for social interactions. However, the moderate level must never be perceived to be condescending. Previous research has emphasised the importance of adapting the intervention programs to the participants' conditions as there are several barriers to overcome (Richardson et al. 2005). Against this background, a moderate level seems reasonable. Reasons for not participating in lifestyle interventions for persons with psychosis were presented in the study by Pearsall et al. (2014a). These reasons include not bothering about their physical health, or a perception that their physical health is under control. The health promotion model by Pender et al. (2015) revealed that both perceived benefits and perceived barriers to action are considered to have major motivational significance. A belief in successful consequences has proven to be of great importance. On the other hand, the perceived barriers serve as obstacles to taking action. These can consist of perceptions about inconvenience, expense, difficulty, or that physical activities takes a great deal of time. As barriers can be extensive and multifaceted in a psychosis context, which this thesis proves, they must be dealt with before an intervention, although this type of factors can be affected during the intervention period (Pender et al. 2015).

Future health promotion interventions should facilitate the transition from thought to action

The findings of this thesis show that persons with psychosis generally possess knowledge and an understanding of the need to act in the direction of a healthy lifestyle, which is consistent with earlier research (Hedberg & Skärsäter 2009). However, instead of acting they become stuck in a constant state of planning where they cannot move beyond thoughts like "I should" or "I would really". Some participants called it "a mental paralysis". It is well known that the disease itself causes difficulties with planning and carrying out daily activities as well as lifestyle changes. Future health promotion interventions for persons with psychosis must therefore facilitate the transition from thought to action, and it is also relevant to relate to normality and stigma. Mental illness is a two-bladed sword. On the one hand, the symptoms caused by the disease constitute a barrier to living an active life (Corrigan & Penn 1997). On the other hand, societal reactions result in stigma and discrimination which also constitutes a barrier to various living opportunities (Corrigan 2000). Therefore, it can be argued that stigma may be one part of the phenomenon of getting stuck in planning, as stigma leads to persons with psychosis avoiding to participate in various activities.

The modest findings of the metabolic risk factors in the intervention (II) could be viewed as a confirmation of the difficulties transitioning from thought to action. Although quality of life as demonstrated by the EQ-VAS was improved by the intervention, there was only a minor impact on the metabolic risk factors. Findings that are not in line with expectations may entail the risk of hastily drawn conclusions and questions might be raised if interventions such as this one are reasonable for persons with psychosis. At this stage, it is important to remember that changing lifestyles is generally very difficult for anyone, irrespective of disease (Sniehotta et al. 2005). One condition for success is that the person has the intention to change their lifestyle. However, good intentions do not guarantee a movement from thought to action (Sheeran 2002). Orbell and Sheeran (1998) described a gap between intentions and actual behaviour, and that planning and realising are two different processes. Here, future health promotion interventions can make a difference; health care professionals can attempt to facilitate the transition by being available and constantly maintaining physical health as an important area.

In an attempt to make an overall interpretation of the findings of the intervention (II) and the qualitative studies (III and IV), it is possible to view certain findings that were previously interpreted differently as steps in a process of change. The findings referred to are partly those explaining that "a lifestyle change is not worth the struggle", and the phenomenon of "getting stuck in a state of planning", without taking action towards a healthy lifestyle. It may even provide explanations why some succeeded in the intervention and others did not. These examples can possibly be understood in the light of The Transtheoretical Model (TTM) of Change. TTM is a theoretical framework that is useful for identifying predictive factors for physical activity and for structuring physical activity interventions. TTM is mainly based on stages of change (Prochaska & DiClemente 1983). The five-step model represents different levels of motivation to change a behaviour. The first step, precontemplation, is characterised by not having any intention to change a behaviour, neither now or in the foreseeable future. This step is accompanied by contemplation, which is characterised by an awareness that there is a problem and thoughts about what can be done about it, but with no commitment to action. The third stage is called the preparation stage and deals with moving from thought to action. In this step, attempts for change may occur, with or without success. The fourth step is action, in which major change occurs. Finally, step five, maintenance, is about maintaining profits from the action stage by preventing relapses (Prochaska et al. 1992).

The features in the qualitative studies (III and IV) that are attributed problems in the transition from thought to action and cognitive difficulties may also be interpreted as "the ball is rolling." The intervention may thereby have sown the seeds for changing behaviours, which may be in line with general human reactions to change. Perhaps these people found themselves in one of the first three steps. The findings showed that efforts should focus on the third step, the preparation stage, as many are aware of the problem and know what to do about it, but do not continue from thought to action. Even small changes towards a healthy lifestyle should be seen as a success, as they may indicate the starting point for a process of change (Rubak et al. 2005). If a bad habit is changed for the better, this is a partial victory as several unhealthy habits at the same time imply a multiplicative increase of risk (The National Board of Health and Welfare 2011a).

There are components in self-care that ought to support the transition from thought to action. The ability to reflect upon self-care needs is something that can be learnt by the individual. Learning the symptoms or signs, and assessing how to deal with them contributes to effective self-care monitoring (Riegel et al. 2012). This thesis and the intervention can therefore be considered contributions that can enable persons with psychosis to improve their self-care ability. Self-care within psychosis is an important area to develop. Previous research has shown that persons with psychosis are less likely to perform self-care or participate in health promotion activities (Holmberg & Kane 1999). Research regarding self-care and psychosis is also very limited. Dashiff (1988) was the first to address the importance of self-care in psychiatric nursing, and a very limited numbers of research articles have focused on psychiatric nursing (Seed & Torkelson 2012). If persons with psychosis should have the opportunity to live a life like everyone else and be able to take the step from thought to action, the ability to self-care needs to be taken into consideration. It is, however, important to bear in mind that persons with severe mental illness may have difficulties performing independent self-care, which is why support from health care professionals might be required (Riegel et al. 2012). The self-care deficit nursing theory is oriented towards creating therapeutic, non-hierarchical relationships that are focusing upon recovery (Seed & Torkelson 2012). Research has shown that the ability to self-care has the potential to reduce re- hospitalisation and improve QoL (Cutler 2003).

The nurse plays a crucial role in future health promotion interventions

The findings of this thesis show that support by health care professionals is a prerequisite for persons with psychosis to change their lifestyle. A central starting point for future efforts is that mental health nurses or other health care professionals within psychiatric care must be ready to take responsibility also for physical health. Research has shown that there is sometimes a perception that physical health belongs to the somatic care (Blythe & White 2012, Gray 2012). However, there is research that shows that mental health nurses are generally in favour of physical health care being a part of their role as nurses (Happell et al. 2012b). In order to fulfil a holistic approach in health care that is based on individual needs, it is presumed that both physical and mental health is taken into account.

The findings in this thesis demonstrate that nurses or other health care providers could serve as role models in different situations, maintain order in the group, or help finding individual solutions to various health and lifestyle problems. Through their position, mental health nurses can implement physical activity in everyday mental health care (Happell et al. 2011). Health care professionals can thereby be the key in the search for normality and facilitate the transition from thought to action. Study IV showed that participants appreciated a close relationship with the HCs, a relationship where the person was seen and listened to. Denhov and Topor (2011) have argued that there is a risk to overlook other beneficial components in treatment interventions when following a particular method and its components. They state that the focus in psychiatric treatment must be broadened, and that the quality of the relation between health care professionals and patients is a central area. As the support by nurses and other health care professionals has been attributed with great importance by the thesis participants themselves, it is relevant to discuss nursing approaches and theoretical approaches that may be reasonable choices in future health promotion interventions for persons with psychosis.

The theoretical standpoints for the intervention (II), MI and CBT can be useful approaches for nurses and health care professionals in the work with health promotion interventions. There is extensive research to support the success of MI in a wide range of areas focusing on lifestyle change (Martins & McNeil 2009, Rubak et al. 2005). The method is proven to be cost-effective and flexible in the sense that it can be performed by different professions and implemented in various contexts of health care (Lundahl et al. 2013, Martins & McNeil 2009). Motivational interviewing is based on four principles that are partly about empathy and developing discrepancy. This discrepancy is about visualising inconsistencies between their individual behaviour and own values. The principles also entail avoiding an argumentative approach and supporting the individual in their belief in their own ability to implement and succeed with change (Miller & Rollnick 2002). As previously discussed regarding both the longing for normality and the problem with transitioning from thought to action, the MI principles are seen as reasonable methods to use. To visualise the difference between the behaviour and their own values can be a key to action. Strengthening a person's belief in their own ability can be understood as a way to reach individual goals and thereby approach normality.

A CBT approach also seems to be a reasonable choice in the context of lifestyle changes for persons with psychosis. In CBT there is a belief that the person has a free will and that he/she is competent to be in charge of his/her own actions. The degree of consensus or disagreement regarding the intrinsic components in CBT for persons with psychosis has long been unclear. A study by Morrison and Barratt (2010) presented important components in CBT for psychosis. Several of the elements identified were factors that could be related to many forms of psychotherapy, such as the need for collaboration and a good therapeutic relationship. Further elements should be directed towards the specific challenges associated with psychotic disorder, where the therapist should meet the different areas of symptoms to enable treatment. A CBT approach that promotes cooperation and emphasises the patient's own resources can also be argued to be in line with the findings of this thesis, namely to be taken seriously and be someone to be reckoned with. Furthermore, they should be allowed to see themselves as "common people" who can take responsibility for their choices.

The wish for a more active leadership that emerged in the findings (IV), where the leader would "push harder", can partly be considered to be in conflict with the methods described above. A somewhat more authoritarian leadership might be justified given the extraordinary challenges faced by this group, as highlighted in this thesis. However, efforts should not be made without reflection when trying to help someone who does not have the same power and opportunities. Health care professionals must manage this balancing act between authority and shared decision-making, together with an understanding of the unique situation that these persons face. The intention of the intervention (II) was to individualise, starting from persons with psychosis own goals. However, the findings show that there was a wish for further individualisation. Perhaps future interventions should be based on the concept of person-centred care to meet this request. Person-centred care is a mindset that goes beyond diagnostic criteria, where health care professionals strive to get to know the person, not the patient. The approach thereby promotes partnership and shared decision-making (Borg et al. 2009). Thus the method can be considered reasonable in relation to the findings of this thesis and the previous discussion about stigma and the persons with psychosis striving to be like everybody else.

The findings of this thesis may be used to understand persons with psychosis and their specific prerequisites for lifestyle changes, which Pender et al. (2015)

declared to be of importance when designing health promotion interventions. Careful reflection is required when planning interventions in vulnerable populations such as persons with psychosis as specific potential barriers must be taken into account (Pender et al. 2015). The contribution to knowledge offered by this thesis can therefore facilitate future interventions and approaches in everyday clinical routine.

Methodological considerations

The silver thread running through this thesis takes its starting point in the cross-sectional cohort study (I) that describes metabolic risks and HRQoL in the studied population. It continues through an intervention study that is evaluated with both quantitative (II) and qualitative methods (III, IV) in order to answer the general aim. The different methods used can be viewed as method triangulation, and through this the weaknesses of a single methodological approach can be reduced (Patton 2002, Polit & Beck 2012). There are, however, some methodological limitations that should be considered.

As study I had a cross-sectional design it was not possible to draw any conclusive causal relationships. Another limitation in this study was the difference in administration of the questionnaires between the patients and the general population. The population group answered the questions at home, while the patients' questionnaires were completed at the clinic. The circumstances therefore differed. In these processes, there were two possible sources for error. We cannot know if the data the population group provided were filled in by themselves, which would certainly not be unique to this study. Patients may also have felt uncomfortable when answering the questionnaires in the presence of staff, even though the staff tried to give the participant privacy. It can also be beneficial to be able to answer any questions raised by the patients directly, indicating a duality in the presence of staff.

In the intervention study (II), randomising individuals to intervention or treatment as usual was not considered. This decision was based on the relatively small access to potential participants. Earlier research has also demonstrated that it is difficult to recruit people with schizophrenia to health promotion trials, as there is a distrust of randomisation as such (Abbott et al.

2005). The analysis aimed to follow the intention-to-treat principle, a commonly used standard in intervention studies (Montori & Guyatt 2001). The intention-to-treat principle was taken into consideration in the sense that attendance rate did not matter for being part of the analysis. Despite this ambition, two participants were excluded from the study. One of them underwent gastric bypass surgery, which made it unreasonable to include this participant. The reason for exclusion in the second case was due to unwillingness to cooperate regarding the intervention content. Our chosen approach can be criticised for not being consequent as the intention-to-treat principles clearly stipulate that non-compliance or protocol deviations should be ignored (Gupta 2011). However, with a relatively small sample size, there was a concern that these participants would cause a non-valid result.

To allow for a larger sample size, participants from two different regions were included in the intervention study (II). Due to organisational limitations, it was not possible to perform an intervention with the same number of meetings in the two regions. As far as possible, we have therefore attempted to perform the group meetings in an identical way, except for the numbers of meetings, and the interventions were based on the same concept, "Solutions for Wellness". Still, this is a limitation that cannot be ignored. However, including persons with psychosis and HCs from different geographical areas can be viewed as a strength. It ensures validity as the risk of an outcome coloured by a particular local culture is reduced. When considering the number of completed group meetings as well, it can be concluded that the difference became smaller, on average 8 vs. 13.

The significant change in HDL-cholesterol shown in study II should be interpreted with caution. The fact that we only had access to data on 23 participants limits the trustworthiness of the calculations of the HDL values. In retrospect it may also be considered unfortunate that we did not measure physical capacity and aerobic fitness during the intervention (II). Consequently, we do not know whether the intervention had such an impact or not. As the intervention participants were equipped with pedometers, there would have been a possibility to follow any developments. There is also research in support of pedometers being a valid option for assessing physical activity in research and practice (Tudor-Locke et al. 2002). As the quality of the product was not known and the reported data very modest, we chose not to present these data. Using a pedometer can nevertheless be justified, as research has shown that it provides motivational support (McNamara et al. 2010).

When involving persons with psychosis in interviews and research, it can be argued that they may not be in a position to give informed consent (Van Staden & Krüger 2003). With this in mind, the starting point was that possible participants needed to understand the purpose and meaning of giving informed consent. To ensure that the person had not deteriorated in the time span between the intervention and the interviews, their regular outpatient caregivers made a clinical assessment of their mental health before they were asked to participate in the interview. In these processes, the GAF (American Psychiatric Association 1994), served as guidance. This way we could ensure an ethical inclusion approach and, as far as possible, avoid answers that were coloured by psychotic experiences.

Another aspect of interviewing persons with psychotic disorder that is worth discussing is whether the descriptions that emerge are truthful. Previous research has shown that persons with psychosis fight a constant battle to reach normality in order not to appear as being different (Syrén & Hultsjö 2014). On the other hand, the interviews were experienced to be highly exposing and honest. The same interview guide formed the basis for both the qualitative studies (III & IV). The large number of interviews and the extensive body of text made it possible to analyse data with two different aims and methods of analysis.

In study III, transferability may have been affected as the prerequisites for a healthy lifestyle may have changed by participating in the intervention. Persons with psychosis who participated in an intervention may therefore not be seen as representing the group as such and persons with no experience of the intervention could have contributed to further aspects.

Clinical implications

Persons with psychosis have extensive mental health problems. The extra challenges of psychiatric symptoms create a substantial burden in many aspects of life. Historically, psychiatric care has focused on psychiatric symptoms. However, it is time for a holistic approach where physical health is also on the agenda, and where it is understood that the body and soul belong together. By testing and evaluating health promotion interventions it is possible to identify approaches that are tailored to the needs of this group. By

contributing to a better understanding of these people, psychiatric care may be adapted and possibly more cost-effective. In such a scenario there are only winners. The person with psychosis has the potential to achieve better physical health and quality of life on an individual level. On a group level, they could avoid stigmatising attitudes through a movement towards a healthy lifestyle. At a societal level, health care services could make financial savings. Psychiatric health services should therefore take into account weight gain and other metabolic risk factors due to second generation antipsychotics, and lifestyle habits should therefore be taken into account in every individual in psychiatric care.

Identifying perceptions of participation in a lifestyle intervention can increase the understanding of how to design and manage future interventions, an aspect that is important to consider also in everyday clinical practice. Content in moderation should be the foundation for lifestyle interventions targeted at persons with psychosis. The current thesis also supports the assumption that the introduction of activities that “common people” do underpins a feeling of being capable. This can make the person with psychosis come one step closer to fulfilling the desire for a healthy lifestyle and normality. The findings showed that support from health care providers is a prerequisite for this, which is why health care professionals must be prepared to provide this support. This is a vulnerable group and efforts should target the transition from thought to action, as the findings showed that this transition is problematic.

The findings of this thesis also highlight a wish for allowing the issue of physical health to be constantly present in psychiatric care. In clinical psychiatry, staff can show the way by allowing the issue to be focused upon by being role models or by having knowledge of the metabolic risks that persons with psychosis face. Although the intervention in this thesis failed to influence the metabolic risk factors to a greater extent, health-related quality of life was significantly improved. The psychiatric care services should consider quality of life as a treatment goal when a total recovery from psychosis seems unlikely.

Future research

Persons with psychosis will face physical health challenges also in the future. There is very little or nothing to suggest that this development will be overturned. With this in mind, further research is required in order to come closer to a solution to the problem. We can hope for the development of antipsychotic drugs with less metabolic side effects, but this is, however, beyond the control of nurses. Nonetheless, a positive fact is that this research field has grown substantially in recent years. Research has provided a lot of knowledge about, for example, how clinical psychiatry should screen and monitor cardiovascular risks. Therefore, it is problematic that research has also demonstrated that these guidelines are not used to their full potential, and that there is a structural discrimination of the type of care these persons have access to. There seems to be a gap between research and clinical application. The first suggestion for future research is therefore to study how this gap can be bridged. This may be studied primarily with qualitative interviews with staff involved in everyday clinical practice, or through interviews aimed at care unit managers and those who distribute resources, who can thereby facilitate or impede this work.

Another future research option in order to close in on an overall grasp of perspectives on the design of lifestyle interventions to suit this group, would be to return to the HCs who acted as group leaders in the intervention presented in this thesis. They can probably provide insights into what works and thus make a contribution that could be added to the experiences and descriptions of the persons with psychosis.

Finally, a logical continuation of this thesis would be to design, implement, and evaluate an intervention based on the participants' views provided by this thesis. This way, much consideration would be given to this group's prerequisites and wishes. It would be very exciting to follow.

CONCLUSIONS

- (I) Almost half of the patient group met the criteria for metabolic syndrome and thereby demonstrated great additional risks for physical comorbidity. Patients suffering from psychosis had significantly lower HRQoL regarding all dimensions in EQ5D, except for the pain/discomfort dimension, when comparing with the reference sample. One risk factor included in the metabolic syndrome, elevated blood pressure, was associated with lower HRQoL. Other factors, such as raised LDL-cholesterol, low GAF, older age, high BMI and female gender was also related to lower HRQoL.
- (II) The lifestyle intervention containing theoretical education and physical activities improved HRQoL when comparing baseline and one-year follow-up data in the intervention group. The intervention also resulted in some improvements in metabolic risk factors among patients. The HDL-cholesterol significantly increased and the blood pressure was lowered among female participants. In the context of lifestyle changes for persons with psychosis, small changes can be considered a success. However, it can be concluded that the intervention did not influence the metabolic risk factors to a greater extent.
- (III) Persons with psychosis prerequisites for a healthy lifestyle should be taken into account when designing interventions tailored to the needs of the group. A wish to take part in society and live like everybody else is a key prerequisite for a healthy lifestyle. Internal and external factors create obstacles for fulfilling this wish. As many described how they got stuck in a constant state of planning for a healthy lifestyle instead of taking action, efforts by mental health nurses and other health care providers should target the transition from thought to action. Efforts should also be made to meet the need to take part in society and thereby come closer to living a life like others do.

- (IV) When designing an intervention for persons with psychosis, content in moderation is a central starting point. A moderate level can facilitate continued participation, which is a prerequisite for gaining health benefits and finding new social contacts. Finding a moderate level is a challenge. It must not underestimate a person's capacity or place unreasonable demands on the participants. Support by health care providers is therefore necessary in individualising the content and goals. This support should also facilitate the participants' ability to mirror themselves against healthy people in society by introducing activities that "common people" do. This underpins a feeling of being capable and can make the person come closer to normality and a healthy lifestyle.

In summary, lifestyle changes for persons with psychosis are essential, but hard to achieve. Health promotion interventions require attention to their prerequisites, that the level is in moderation, and that the activities mirror the type of activities that "common people" do.

SAMMANFATTNING PÅ SVENSKA

Personer med psykossjukdom har ofta kognitiva funktionsnedsättningar som gör att deras fysiologiska och psykologiska behov inte alltid tillgodoses vad gäller nutrition, sömn, aktivitet och balans mellan ensamhet och sociala kontakter. Personerna medicinerar med andra generationens antipsykotiska läkemedel. Dessa i sig ökar risken för viktökning och hyperglykemi via biverkningar så som ökad aptit, vilket ytterligare ökar egenvårdskraven och skapar en mångfacetterad problematik som bidrar till en stor risk för metabolt syndrom, kardiovaskulära sjukdomar och förtida död.

Tidigare livsstilsinterventioner har visat varierande resultat. Forskning har framfört önskemål om att utvärdera mera holistiska livsstilsinterventioner, då flera tidigare studier valt att fokusera på något eller några enskilda livsstilsfaktorer. Tidigare forskning har också konstaterat att de interventioner som genomförts inte alltid anpassats till målgruppens funktionsförmåga. Om hälsofrämjande insatser identifieras som tar i beaktande dessa personers uppfattningar och erfarenheter kan det leda till en individuellt anpassad vård och ökad hälsorelaterad livskvalitet tillsammans med bättre egenvårdskapacitet och minskat behov av vård till följd.

Det övergripande syftet med avhandlingen var att studera hälsorelaterad livskvalitet och metabola riskfaktorer hos personer med psykossjukdom och genom en hälsofrämjande intervention och via deltagarnas egna perspektiv bidra till utveckling av livsstilsinterventioner.

Den första delstudien var en tvärsnittsstudie som genomfördes på olika psykiatriska öppenvårdsenheter i Sverige. Syftet med studien var att jämföra hälsorelaterad livskvalitet hos patienter med psykossjukdom (n=903), speciellt schizofreni, med en referensgrupp från normalpopulationen och utforska förhållandet mellan hälsorelaterad livskvalitet och metabola riskfaktorer bland dessa patienter. Patienternas funktionsförmåga mättes med GAF, en skattningsskala som beaktar psykologisk, social och yrkesmässig funktionsförmåga. Hälsorelaterad livskvalitet mättes med EQ5D hos såväl patienterna som referensgruppen. Fysiologiska markörer relevanta för det metabola syndromet mättes, tillsammans med livsstilsvanor och andra kliniska karaktäristika.

De tre följande delstudierna tar utgångspunkt i den livsstilintervention som genomfördes. Intentionen med livsstilsintervention var att främja en hälsosammare livsstil. Interventionen kombinerade teoretisk utbildning med fysiska aktiviteter. Interventionen behandlade också rökning och alkoholkonsumtion för att minska förbrukningen i riktning mot en hälsosammare livsstil. Studie II var en longitudinell interventionsstudie med en matchad referensgrupp som syftade till att studera effekterna av en livsstilintervention på hälsorelaterad livskvalitet och metabola riskfaktorer hos personer med psykosjukdom. Resultatet av interventionen baserades på 42 deltagare. För att göra så relevanta jämförelser som möjligt, matchades två individer per deltagare ur referensgruppen ($n = 84$). Referensgruppen matchades för kön och BMI klassificering och så nära i ålder som möjligt. Sociodemografiska data och metabola riskfaktorer, relevanta för det metabola syndromet mättes. Svårighetsgraden av personernas symtom mättes med hjälp av CGI och hälsorelaterad livskvalitet utvärderades genom EQ5D. Mätningarna gjordes vid baslinje och som ettårsuppföljning.

Delstudie III, och särskilt studie IV kan ses som kvalitativa uppföljningar av interventionen, dock med olika syften och analysmetod. Studie III var en kvalitativ explorativ studie med syftet att undersöka förutsättningarna för en hälsosam livsstil såsom beskrivits av personer med psykosjukdom. Data samlades in genom individuella intervjuer ($n = 40$), med hjälp av en semistrukturerad intervjuguide. Data samlades in 6-7 månader efter interventionen hade avslutats. Konventionell innehållsanalys användes för analys. Även Studie IV baserades på dessa 40 intervjuer och syftade till att beskriva hur personer med psykosjukdom uppfattar deltagande i en livsstilsintervention och använda dessa uppfattningar för att presentera faktorer för beaktande i framtida interventioner. En fenomenografisk ansats valdes för analys.

Avhandlingens resultat visar att den totala situationen för personer med psykosjukdom är problematisk då de uppvisar stora risker för fysisk ohälsa. Nästan hälften av patientgruppen uppfyllde kriterierna för metabolt syndrom. Dessutom uppvisar personer med psykos betydligt lägre hälsorelaterad livskvalitet i jämförelse med en referensgrupp från normalpopulationen. Interventionsstudien (II) visade att hälsorelaterad livskvalitet förbättrades vid jämförelser mellan EQ-VAS vid baslinjen och ett års uppföljning inom interventionsgruppen. Interventionen uppvisade små och få förbättringar i

metabola riskfaktorer. Därför kan konstateras att interventionen inte var tillräckligt kraftfull för att påverka de metabola faktorerna i omfattande utsträckning. Baserat på deltagarnas egna perspektiv framstår en önskan att delta i samhället och en längtan att leva som alla andra som förutsättningar för en hälsosam livsstil. Tyvärr finns allvarliga hinder att övervinna. Många fastnar i ett konstant tillstånd av planering i stället för att vidta åtgärder gentemot en hälsosam livsstil. Stöd av vårdgivare är därför en förutsättning och bör hantera övergången från tanke till handling och underlätta deltagarnas förmåga att spegla sig mot friska människor i samhället genom att introducera aktiviteter som personer med psykossjukdom erfar att "vanligt folk" ägnar sig åt. Utmaningen för vårdpersonal är att hitta en lagom nivå som inte underskattar eller överskattar personens kapacitet. En anpassad nivå kan underlätta fortsatt deltagande, och deltagarna kan därmed uppnå hälsovinster och hitta nya sociala kontakter.

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