Dimensions of Health among Patients in Mental Health Services

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Abstract

Empirical studies focusing on the subjective experience of health among patients in contact with the mental health services are rare and most questionnaires are based on a medical model that emphasizes objectively observed disease-oriented health indicators. In studies I and II perceptions of the concept of health among patients and nurses in mental health services were explored and described using a phenomenographic approach. The perceptions and description categories that emerged from these studies were transformed into a number of items forming a questionnaire intended to measure subjectively experienced health among patients in mental health services. In study III, a randomly selected sample was used to test the psychometric properties of the new Health Questionnaire. A factor analysis revealed three factors labelled Autonomy, Social Involvement and Comprehensibility. The purpose of study IV was to examine the construct validity of the Health Questionnaire. The hypothesis was that subjectively experienced health would be positively associated to self-esteem, empowerment and quality of life, and negatively associated to psychiatric symptoms, perceived stigmatization experiences and perceived attitudes of devaluation and discrimination. This hypothesis was mainly confirmed insofar that overall health was positively correlated to self-esteem, empowerment and quality of life and negatively correlated to symptoms, attitudes of devaluation and discrimination and rejection experiences. The results of this thesis show that health is more than just an absence of disease and support a focus on health promotion interventions in mental health care.

Key words: Health, mental health services, nurse, patient, perceptions, phenomenography, questionnaire, reliability, validity, subjective experience

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"Freedom of thought cannot be reborn

without throes; language, art, morality

and science have all given us pain

as well as power"

(Langer 1942 p.318)

CONTENTS

LIST OF PUBLICATIONS

This thesis is based on the following studies, which are referred to in the text by their Roman numerals. The papers are reprinted with the kind permission from the respective publishers, Blackwell Publishing and Taylor & Francis.

I. Svedberg P, Jormfeldt H, Fridlund B & Arvidsson B. (2004). Perceptions of the concept of health among patients in mental health services. Issues in Mental Health Nursing, 25,723-736.

II. Jormfeldt H, Svedberg P, Fridlund B & Arvidsson B. (2007). Perceptions of the concept of health among nurses working in mental health services: A phenomenographic study. International Journal of Mental Health Nursing, 16, 50-56.

III. Jormfeldt H, Svensson B, Arvidsson B & Hansson L. Dimensions and reliability of a questionnaire for evaluation of subjective experience of health among patients in mental health services. Issues in Mental Health Nursing. In press.

IV. Jormfeldt H, Arvidsson B, Svensson B & Hansson L. Construct validity of a health questionnaire intended to measure the subjective experience of health among patients in mental health services. Submitted.

INTRODUCTION

The work with this thesis was initiated by an interest in the question "How are health processes promoted by nursing care in mental health services?" Obviously, health promotion in mental health care entails activities aiming to promote health within the client. Thus, a very important prerequisite to answer this question is a clearly defined concept of health. It has been maintained that the concept of health, even in the 21st century, is mainly viewed as an absence of disease (Hedelin & Strandmark 2001; Pavis *et al*. 1998). Nurses in mental health services sometimes express vague and ambiguous perceptions of the concept of health, which might be a result of the lack of a clearly defined concept of health (Jormfeldt *et al*. 2003). There may be a risk that such a perception contributes to a feeling of hopelessness and inactivity in nursing care, if the mental illnesses are judged as severe or incurable. It has been put forth that it is important that staff in mental health care are encouraged to see the patient as being in a process of personal development, and that they support the patient's possibilities and contribute to the realization of their own goals (Hummelvoll 1996). It has also been recognized that it is essential that the patient is seen as a subjective person in health care (Bertero 1998), and that the staff's ability to see the patient as a separate individual is related to their own professional self-image (Hellzén *et al*. 1995). Supervision is, due to the complexity of human relationships related to health issues, a tool to encourage nurses to reflect critically about their attitudes in order to increase their ability to promote health (Arvidsson *et al*. 2000; Magnusson *et al*. 2002).

Stress reactions are well known to be related to physiological, behavioural, cognitive and affective changes and health outcomes within individuals (Larsson *et al*. 1991), but stress or stress management are not always seen as important aspects of health in mental health care (Jormfeldt *et al*. 2003). This might imply that there is a gap between research and practice in care activities (Jones 2000). A new conceptualization of health and illness is needed in order to transform nursing care from its focus on problems and deficits to a focus on the patient's capacity and the promotion of health and recovery (Lindsey 1996). A clearly defined concept of health is a prerequisite if the implication of health promotion activities in mental health services is to be meaningful. The individual and the social context are mutually influenced by and dependent on each other in a complex interplay with existing economic and cultural conditions, which should be an integral part of the health concept (Macleod & Maben 1998).

A more developed definition of health could contribute to guidelines for mental health and clarify goals for care activities. A clearly defined concept of health should be able to be assessed and used as an outcome measurement in mental health services and support efforts aimed at quality assurance.

BACKGROUND

Defining health in mental health services

Many attempts have been made to define the concept of health by relating it to the concept of illness where the two concepts are viewed as contradictory or as two endpoints on the same continuum. Health has two common meanings in everyday use, one negative and one positive. The negative meaning represents the absence of disease or illness, while the positive meaning incorporates well-being, a capability to develop relationships and to achieve goals. The scientific biomedical model, which is described as the dominant professional view adopted by most health care workers during their training, emphasizes the negative meaning of health and tends to neglect the positive aspect of health (Downie *et al*. 1996; Naidoo & Wills 2000). Nursing science as well as mental health care in general contains both the humanistic paradigm which can be seen as a 'bottom-up' approach, where the patient's individual experiences are considered, and the biomedical model which can be regarded as a 'top-down' approach towards the patient, where the professionals are viewed as the experts (Lindsey & Hartrick 1996). Mental health services have been criticised for lacking systematic health-promoting interventions (McMullen O'Brien 1998) and for adopting a biomedical perspective that fails to adequately take account of the multidimensional complexity of the concept of health (Moyle 2003; Pavis *et al*. 1998). A distinction has been made between illness prevention, which can be described as the avoidance of disease, and health promotion, that comprises a number of activities seeking to expand positive potentials for health (Pender 1996). It has been maintained that, although a more holistic health perspective has been developed in nursing science in recent decades, nursing research sometimes still tends to characterise health as the absence of symptoms of disease or handicap (Hwu *et al*. 2001). Some researchers argue that a focus in health care that is mainly on illness and deficits tends to reinforce the patient's experience of illness and disability (Lindsey 1996; Simmons 1989), and appeal to staff in mental health care to respect the dignity of patients and to become aware of the patients' possibilities and resources (Svedberg *et al*. 2003). A tension has however been

recognized in the nursing discipline between these two contrasting healthcare paradigms (Malin & Teasdale 1991). This tension may well be characterised by the conflict between the ethical principles of autonomy and the benefits of paternalism (Breeze 1998) as well as in the conflict between the moral commitment to maintain the patient's trust while being confronted by actions that can violate that trust in mental health care (Lützén 1997). The adoption of a positive attitude, and focus on possibilities, are suggested to motivate people with long-term mental health problems to help them engage in and to take an active part in their own care (Repper *et al*. 1994).

The overall goal of treatment in mental health services should facilitate for the patient to influence his or her own life situation (Antony *et al*. 1996). The individual perspective on health as well as the subjective experience of being ill are essential aspects of this goal (Halldórsdóttir 2000; Thorne 1999). The need for a concept of health that renders mental health services to be process focused have been discussed (Svedberg *et al*. 2003), as well as the need of nursing care to develop a scientific foundation of care activities and goals (Barker *et al*. 1997). It has been proposed that the development and implementation of a holistic concept of health, that not just imply absence of illness or disease may imply something of a shift of focus from illness and deficits to individual health and resources (Read & Stoll 1998). The organizational processes such as deinstitutionalization and integration of patients in community-based mental health services may make the challenge to create a clear definition of health at all levels in mental health services even more essential (Magnusson *et al*. 2004).

Measuring health in mental health services

Most instruments designed to measure health in general health care today actually measure the absence of illness in terms of symptoms and disabilities, in line with the biomedical view of health (Christiansen & Kooiker 1999; Whitehead 2003). The difficulties to measure subjectively experienced health in individuals or in populations as well as in mental health services, without a clear definition of the positive dimension of health, has been illustrated (Naido & Wills 2000). In the subjective evaluation of health related phenomenon, one strong criterion has been found. This criterion is closely related to depressed mood and dissatisfaction with life as a whole, and it may be useful to establish the relationship between

this general appraisal factor and health itself (Fakhoury *et al*. 2002). Valid and reliable measures of a positive multidimensional concept of health in mental health services need to:

- Establish priorities and identify health needs as they are expressed by patients and their relatives in mental health services as a basis for mental health care. The one-sided use of only professional opinions as the base for measures of health will jeopardize the important component of subjective experience in health.
- Justify resources for promotion of health among patients in mental health services as opposed to viewing their problems as solely medical.
- Shape a basis for the planning of current and future mental health care.
- Assist the development of enhanced emphasis of the positive dimensions of health among different health care professions.
- Establish a more hopeful attitude towards outcome of care and prognosis of patients in mental health services (Naidoo & Wills 2000).

Two questionnaires that measure the subjectively experienced positive multidimensional concept of health constitute examples of measuring a positive concept of health. These questionnaires are "The Concept of Health Scale" intended to assess health among Chinese people with a chronic illness (Hwu *et al*. 2002), and the "Leddy Healthiness Scale" (Leddy 1996) measuring healthiness among women with and without breast cancer. No questionnaire aimed to measure the subjectively experienced positive multidimensional concept of health among patients in mental health services was found in the literature searches performed as part of the present thesis work.

Existing definitions of the concept of health

The World Health Organization has stated that "health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO 1947). This description of health has often been criticised as too broad and difficult to achieve (Pender 1996). The definition was later clarified by the definition that a group or individual has to be able to identify and understand their needs in order to be able to satisfy them, and as a consequence change or cope with their environment. Health is therefore seen as a resource in

daily life and not as the goal in life (WHO 1986). Health is referred to as a positive concept that underlines social ability and physical recourses and the concept of health as well as the concept of health potential include both physical and mental health and must be seen in the context of personal development through life (WHO 1991). Nordenfelt (1991) states that a person has complete health only when he/she is in a physical and mental state so that he/she can realize all her vital goals under the given circumstances. According to Tengland (1998), mental health is to have the ability to attain vital goals and to have abilities in cognitive capacity, in problem solving capacity, in appraising feelings and external stimuli as well as having social competence. A deficit in any aspect of these abilities will affect the overall health of the individual.

Health definitions have been organized into four different models and called eudemonistic, adaptive, role performance and clinical. These models are used as standards against which the health of individuals is assessed (Smith 1981). Health has also been described from four other viewpoints; as a static condition, as a subjective experience, as personal resources, and as processes towards increased awareness and personal growth (Medin & Alexandersson 2000). Health seen as a condition is implicit as the basis of theories where the concepts of health and disease are viewed as opposites on a continuum. From this viewpoint, health is seen as a normal baseline and disease is viewed as deviant from this normality. From the biomedical model an individual's state of health is viewed as better or worse depending on where he/she is on the continuum. A person is viewed as ill or healthy, and these conditions can not exist simultaneously (Figure 1). Observed clinical status of health and functional ability are important components in this perspective.

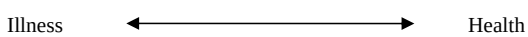

Figure 1

Antonovsky (1987) proposed that the concept Sense of Coherence could be seen as a determinant of the individuals' health and developed the Sense of Coherence Scale including the subcomponents comprehensibility, manageability and meaningfulness. Sense of Coherence in persons with a mental illness has been shown to be positively related to mastery, self-esteem and social support, and negatively associated to psychopathology (Bengtsson-Tops & Hansson 2001). The Sense of Coherence concept includes the ability to perceive

stimuli as consistent, predictable and comprehensible (Arnesson & Ekberg 2005). Antonovsky (1991) was of the opinion that health and illness can exist simultaneously and that the concepts do not constitute a dichotomy, in his view they are present on the same multidimensional continuum. His contribution is the salutogenetic perspective, as well as the view that health is created when the individual has a sense of coherence and ability to cope with turmoil and stress in the environment. It has been shown that Sense of Coherence is close to mental health and mental wellbeing since the concept has strong relationships with positive dimensions of health like optimism and hardiness and that it is negatively related to anxiety and depression. However the concept of Sense of Coherence is not seen as the same as health, even though it can offer an important contribution in health promotion and health care (Eriksson & Lindström 2006).

If health is perceived as processes towards increased awareness and personal growth, a disease or illness could be a starting point that enables a person to meet his or her situation in a new and healthier way (Long 1998). Health is a phenomenon that can not only be described and defined in terms of components that are relevant when describing the concept of disease. An individual can from this perspective experience health even though diagnosed with a disease and good health could have positive effects on the ability to stay well, as well as a positive effect on the ability to recover from injury or disease (Lindsey1996). The efforts to cope with an illness by means of communication and belonging with others can increase the individual's consciousness and view of life as meaningful, which is essential to health (Moch 1998; Thorne 1999). In this case the concepts of health and illness are not seen as dichotomies on a continuum but rather as two parallel processes that may affect each other (Figure 2).

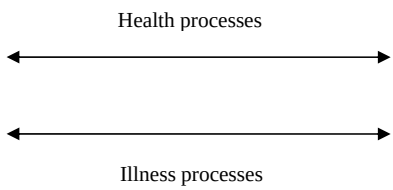

Figure 2

Eriksson (1984) maintains that the basis of health is faith, hope and love and that the individual's view of the nature of love is the foundation of health. The concept of health has been described as a three-dimensional movement between doing, being and becoming, where the dimension of doing implies that the person concentrates on doing and on external circumstances of behaviour for maintaining health. The dimension of being includes the person looking for reasons for being healthy or ill and concentrates on spiritual and physical balance. The third dimension, becoming, involves spiritual maturity and a conscious effort to better one's health. The dimension of becoming involves the struggle between hope and hopelessness and the three dimensions complement each another (Herbert & Eriksson 1995; Kärkkäinen & Eriksson 2004). Parse (1990) describes health as a process of development where the individual lives in accordance with his or her values and actively participates in the creation of meaning through interaction between the individual and his or her environment. According to this perspective, the individual is regarded as an active participant with an ability to make choices and changes in his/her life situation. Health is described as a personal commitment, created in the interplay with the environment and achieved through increased awareness and integration of the individual's innermost needs and desires. Integration presupposes consciousness, a feeling of power and importance, as well as a balance between autonomy and dependence (Eriksson 1984; Parse 1990). Eriksson (1984) illustrates how the concepts of health and disease are related to each other by the so called health cross (Figure 3).

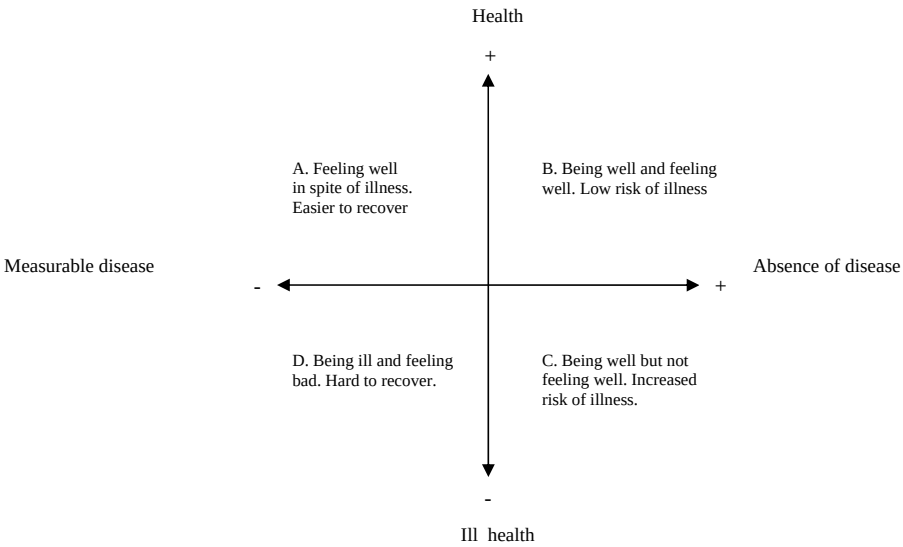

Figure 3 Modified from Eriksson (1984)

It has been described that the dominant model of health focuses on negatively conceived states and that health is being dichotomised into wellness and illness or viewed on a continuum from an ideal state of high-level wellness to terminal illness and death. Human interactions with the environment can pose potential threats to health from the viewpoint that human functioning operates in a rather narrow range of balance and stability. Alternatively, health can be perceived as a single process of ups and downs, where disease and non-disease are viewed as complementary facets of health (Leddy 2006). The present thesis attempts to grasp and evaluate a multidimensional positive concept of health.

Health related concepts in mental health services

When defining the concept of health it is essential to consider the relationships to other closely related concepts (Ryles 1999). This is crucial to develop a contextualized definition of health congruent with societal needs and the mission of mental health services (Jones & Meleis 1993).

Remission

As an example of measuring absence of symptoms of illness the construct of remission is described briefly in this thesis. The symptomatic remission criteria among patients diagnosed with bipolar disorder or schizophrenia is used as an assessment of reduction of symptoms. The underlying presumption is that remission is a prerequisite for everyday functioning among these patients. Remission is proposed to be a good measure of treatment outcome and it is also proposed that remission of clinical symptoms is a required first step toward functional recovery (van Os *et al*. 2006). The proposed standardized remission criteria in schizophrenia is decided by the use of eight items from the Positive and Negative Syndrome Scale (PANSS), in which none of the items the patient should have a score above three points (Helldin *et al*. 2006). This construct pays little attention to the subjective experience of the patient and the focus is entirely on the absence of symptoms of illness even though the concept of remission often is described as a positive concept related to recovery and quality of life.

Recovery

Recovery is described in this thesis as an example of a concept that emphasises the subjective experience, but never the less has its roots in the conceptual framework of something negative, since recovery has to start from a point of ill health to recover from, in order to be meaningful. The process of recovery is defined as a process, a way of life, an attitude, and a way of approaching daily challenges, and hope and empowerment are needed to start this process of recovery (Deegan 1988). The social construct of recovery, often referred to by former users of mental health services, has been shown to be positively associated with self-esteem, empowerment, social support and quality of life, and inversely associated with psychiatric symptoms (Corrigan *et al*. 1999 b). Recovery is defined as a dynamic process of personal growth and transformation dependent on supportive relationships, meaningful activities as well as effective treatment (Mancini *et al*. 2005). Recovery has been defined as the development of new meaning and purpose as one grows beyond the catastrophe of mental illness (Antony 1993). It has also been described as being important whether or not a person's symptoms can be cured (Repper & Perkins 2003). Hope is seen as an essential ingredient in recovery from severe mental illness (Kelly & Gamble 2005). Information and participation in decision-making as well as empowerment are vital components in order to inspire hope and recovery when suffering from mental illness.

Empowerment

Health has been defined as closely related to the concept of empowerment, thus highlighting the individual's right to self-determination and participation in decision-making (Jones & Meleis 1993). Empowerment is related to giving sufficient time to the patients, as well as information and power to appraise their situation, and to assist them when they use this appraisal to make their own decisions. Lack of knowledge and relevant information about the care create limitations for the patient's self-determination, which is also a key concept in the empowering process (Nordgren & Fridlund 2001; Sines 1993). The supportive aspects of relationships are described as being present, providing support, and showing understanding (Kirkpatrick *et al*. 2001). A strengthening relationship between the key-worker and the patient is characterized by susceptibility, trust, and reciprocity (Forchuk *et al*. 1998). In order to develop these characteristics of the relationship it is assumed that it is essential that the key-worker offers knowledge, encouragement and empowerment, and sees possibilities and believes in the patient's potential to develop and create his or her own health (Svedberg *et al*. 2003). The dimension of power has been described as a barrier to open and meaningful communication in the relationship between the key-worker and the patient (Hewison 1995), an issue that sometimes becomes obvious when the patient does not want to participate in the treatment. This is a central aspect in self-determination (Valimaki & Helenius 1996), and thus the concept of non-compliance has been questioned (Playle & Keeley 1998). An empowerment approach in mental health nursing seeks to attain patient participation through interaction in decision-making processes (Chadderton 1995). Self-esteem and autonomy as well as community and power have been proposed to be two superordinate factors of empowerment (Hansson & Björkman 2005). Empowerment is also associated with quality of life, social support, self-esteem, psychiatric symptoms and personal recourses (Corrigan *et al***.** 1999 a). Powerlessness, as opposed to empowerment, is a risk factor for ill health and a key factor towards the development of illness (Wallerstein 1992). Empowerment, which emphasizes the priorities of the person, may contribute to improved health and less symptoms (Lecomte *et al*. 1999), and in a longer perspective to enhanced self-esteem and a reduced amount of stigma (Link *et al*. 2001). Information is power and information sharing is power sharing, people who feel powerless can increase their sense of self efficacy by having access to information (Deegan 1996).

Self-esteem

The concept of self-esteem is closely related and intertwined with the concept of integrity and integrity relates both to autonomy and a relationship to oneself and to others (Widäng & Fridlund 2003). Both physical and mental health is in the long term affected by the frequency and the intensity of the daily hassles and pleasures of life (Larsson *et al*. 1991). It is not enough just to consider physiological stress as important for how health is to be affected (Lazarus 1993) because the individual's feeling of meaningfulness, faith in personal abilities as well as existential beliefs, influences health and the personal ability to deal with situations that could be perceived as stressful (Lazarus & Folkman 1984). Thus, activities to help people increase coping skills also enhance their self-esteem and eventually their health potential. It has been proposed that self-esteem is enhanced by an empowerment approach in health care, which emphasizes the priorities of the person (Lecomte *et al*. 1999). Self-esteem has been shown to be one factor associated with empowerment (Corrigan *et al***.** 1999 a; Hansson & Björkman 2005). It has been maintained that stigma strongly predicts self-esteem among people who have a mental illness (Link *et al*. 2001). Positive self-esteem has been associated with mental well-being, happiness, success and satisfaction as well as recovery after severe illnesses. It has been asserted that the development of self-esteem, its outcomes, and its active protection and promotion are crucial to the improvement of both mental and physical health (Mann *et al*. 2004).

Quality of life

The World Health Organization has defined the concept of quality of life as: an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO 1997). Health related quality of life has been defined as the effect that the individual health has upon the individual's physical, mental and social functional ability. This definition of the concept also includes subjective well-being, satisfaction and self-worth (Bowling 1997).

The concept of quality of life is related to empowerment and embraces self-esteem, a positive view of the future as well as a feeling of power and a real ability to affect one's situation through action both in private life and in society (Rogers *et al*. 1997). Quality of life is affected by relationships to other people and involvement in the social environment as well as health (Chan & Yu 2004; Gee *et al*. 2003). No patient clinical background characteristics

seem to be associated with quality of life, but having at least one close friend is an objective indicator shown to be associated with global subjective quality of life (Hansson *et al*. 1999). It has been shown that an independent housing situation is associated with a better social network and a better quality of life compared with various sheltered housing alternatives (Hansson *et al*. 2002). Unmet needs in the domain of social relationships have been shown to be related to a worse quality of life (Hansson *et al*. 2003). Thus quality of life is considered as an important concept related to the concept of health. Determinants of quality of life have been shown to be psychopathology, such as symptoms of depression and anxiety, while the relationships to positive symptoms are unsure. Strong positive relationships have also been found between quality of life and aspects of social network and personality related aspects such as self-esteem and self-efficacy. To be married and to be employed have most often been shown to be positively related to subjective global well-being, as well as living in community settings as opposed to hospital settings (Hansson 2006). Subjective quality of life has been described as an important outcome measure of mental health care and different instruments are available for different purposes, though quality of life has been considered to be distinct from clinical status to reflect a holistic ethos in mental health services (Hewitt 2007).

Stigmatization

Patients in mental health services are often being treated as less competent and they often receive advice that in fact lessens their ambitions in life (Wahl 1999). These kinds of experiences can seriously harm the self-esteem of the patient and counteract health and recovery from mental illness. Self-esteem is strongly associated to stigmatizing experiences, thus an important intervention in order to reduce stigma would be to improve self-esteem (Link *et al*. 2001). Negative attitudes among staff within the mental health services have been described as common (Angermyer & Schulze 2001; Corrigan *et al*. 2001), and these attitudes may result in a sense of loss of value by the patient and cause a process of stigmatization, affecting the whole life situation of the individual (Link & Phelan 2001). The experience of stigma is characterized by shame, blame, secrecy, isolation, social exclusion, stereotypes and discrimination (Byrne 2000) and these kinds of human rights violations occur within society in general and in the health care sector in particular (Johnstone 2001). These experiences could easily be defined as the opposite to health, and stigmatization is therefore included as one of the focuses in this thesis and investigated in relation to the concept of health.

AIMS

The overall aim of this thesis was to elucidate the definition of the concept of health and develop a questionnaire in order to facilitate the use of the concept of health as a clearly defined goal for health care in mental health services.

- The aim of study **I** was to describe perceptions of the concept of health among patients in mental health nursing.

- The aim of study **II** was to describe perceptions of the concept of health among nurses working in mental health services.

- The aim of study **III** was to develop a Health Questionnaire, intended to measure patients' subjective experience of health in mental health services and investigate psychometric properties in terms of factor structure, internal consistency and test-retest reliability.

- The aim of study **IV** was to investigate construct validity of the Health Questionnaire, intended to measure the subjective experience of health among patients in mental health services. The hypothesis was that subjectively experienced health would be positively associated with self reported self-esteem, empowerment and quality of life and negatively associated with self-reported psychiatric symptoms and perceived stigmatizing rejection experiences and subjectively perceived devaluation and discrimination.

METHODS AND SUBJECTS

Both qualitative and quantitative methods have been used in this thesis in order to gain an understanding of dimensions of the concept of health. An overview of the different designs used in the studies in this thesis is presented in table 1.

Design – qualitative studies

Studies **I** and **II** had a descriptive qualitative design with a phenomenographic approach. This approach was chosen in order to determine qualitative variations in the participants' perceptions of the phenomenon. Phenomenography has been developed over the last 25 years, based on research findings in the area of learning within higher education, and has gained widespread acceptance in the fields of health care and nursing research (Fridlund & Hildingh 2000; Wenestam 2000). The approach is preferred when the intention is to ascertain qualitative variations in participants' perceptions of the phenomenon. Phenomenography distinguishes between the actual state of something and how it is perceived (Marton 1981) and the essence of phenomenography is how something is conceived to be. This means that a distinction is made between the first-order perspective, which starts with facts that can be observed from without, and the second-order perspective, which starts with the individual's experience of something, or how something appears to be. The phenomenographic approach uses the second-order perspective. Perceptions often represent something that is implicit, something that does not need to be verbalized or cannot be verbalized and has not previously been reflected upon (Marton & Booth 1997). Knowledge about how people perceive phenomenon is important because people plan their actions based on their perceptions (Svensson 1997). Permission to perform studies **I** and **II** was obtained from the Research Ethics Committee at Lund University, Sweden. All participants were guaranteed confidentiality, informed that participation was voluntary and that they could withdraw at any time. They were given oral and written information about the purpose and the structure of the study before they provided their informed consent in written form.

Design – quantitative studies

Studies **III** & **IV** used a cross-sectional design in order to develop a questionnaire intended to investigate the subjective experience of health among patients in mental health services. Study **III** was an investigation of factor structure and reliability in terms internal consistency and test-retest reliability and study **IV** investigated the construct validity of the questionnaire using empowerment, stigma, self-esteem, psychiatric symptoms and quality of life as validation measures. The participants were invited to take part in the study by their key worker. All participants were given oral and written information about the purpose and the structure of the study, after which they provided their informed consent in written form. The

information provided was specific about the fact that participation in the study was voluntary and that the ongoing care would not be affected by the individual's decision to participate or not in the study. Interviews were performed assessing perceived health and also included assessments of empowerment, quality of life, self-esteem, symptoms and stigmatization. The questionnaires were coded to secure the confidentiality of the participants. Studies **III** and **IV** were reviewed by the Regional Research Ethics Committee, Lund, Sweden.

Table 1. **Overview of the different designs used in the studies**

Study	Design	Sample	Data collection	Data analysis
Study **I**	Qualitative descriptive design	Patients with experiences from mental health services. (N=12)	Semi-structured interviews	Data analysis in accordance with the phenomenographic approach
Study **II**	Qualitative descriptive design	Nurses working in mental health services. (N=12)	Semi-structured interviews	Data analysis in accordance with the phenomenographic approach
Study **III**	Cross-sectional design. Investigation of factor structure and reliability of The Health Questionnaire in terms internal consistency and test-retest reliability	Patients in mental health services. (N=139, test-retest sample N=17)	The Health Questionnaire	Cohen's kappa, Cronbach's alpha Principal component analysis with varimax rotation.
Study **IV**	Cross-sectional design. Investigation of construct validity of The Health Questionnaire using empowerment, stigma, self-esteem, psychiatric symptoms and quality of life as validation measures	Patients in mental health services. (N=139)	The Health Questionnaire and other questionnaires measuring empowerment, stigma, self-esteem, psychiatric symptoms and quality of life	Pearson product-moment correlation. Stepwise multiple regression analyses

Participants

Participants of study I

The sample of study **I** consisted of 12 patients at a selected clinic in the south of Sweden. In the phenomenographic tradition, background variables are used to guarantee a maximum spread among the informants (Fridlund 1998). Accordingly, the patients were strategically chosen using the background variables; age, gender, marital status, education, diagnosis and years of experience of mental health services. The mean age among the 12 participating patients was 44 years, with a range between 20 and 62; six of them were male and six were female. Four of the patients were married or cohabiting and eight were living alone. Five patients had completed comprehensive school, five of them had finished upper secondary school and two had completed post secondary school education. Two of the patients were diagnosed with bipolar disorder, three with depression, two with eating disorder and two with psychosis while three were not diagnosed. Eight of the 12 patients had more than ten years of experience of mental health services while one had less than one year of experience of mental health services.

Participants of study II

The informants of study **II** were 12 nurses with Swedish as their first language, working at a selected psychiatric clinic in the south of Sweden. In accordance with the phenomenographic approach background variables were used (Fridlund 1998). Consequently, the nurses were strategically chosen using the background variables; age, gender, number of years in the profession, nursing education, outpatient or inpatient care as well as type of nursing intervention. The mean age among the 12 participating nurses was 37 years, with a range between 20 and 59; three of them were male and nine were female. Four nurses had basic nursing education while eight of them had psychiatric nursing education. The mean length of time as nurses in the profession was 11 years with a range between 12 months and 20 years. Three nurses worked with inpatient care and nine with outpatient care, and their nursing interventions ranged from short acute encounters to rehabilitation programmes lasting more than one year.

Participants of study III and IV

Studies **III** and **IV** included outpatients in contact with the mental health services in a county in the south of Sweden. The total number of patients in this population was 1,195, of whom 20% were randomly selected and invited to take part in the study by their key workers. The recruitment of participants started in January 2005 and ended in February 2006. Inclusion criteria were experience of outpatient care, ability to understand and read the Swedish language, and aged over 18 years. A total of 239 patients were approached of whom 37 declined to participate, resulting in an external drop-out rate of 15.5 %. Sixty-one patients who had agreed to participate did not complete the interviews, thus the internal drop out was 30.2 %. The final sample consisted of 141 patients, representing 59 % of those initially approached, of whom two failed to complete the health questionnaire. The analyses were thus performed on 139 patients; constituting 58% of the original sample. The test-retest reliability study of the Health Questionnaire was intended to be performed on a random sub-sample of 24 patients willing to participate in this part of the study. However, only 17 patients were finally interviewed twice with an interval not exceeding four weeks between the interviews. Of the total number of subjects, 39.3 % were in some form of competitive employment, while 34.6 % stated that they received a disability pension. Most subjects, 90.6 %, lived in their own apartments, 69 % lived alone and 64 % were women. In terms of diagnosis, 51.8 % had an affective disorder, 19.6 % schizophrenia, 11.6 % were diagnosed with eating disorder and 17 % with other psychiatric diagnoses. Background characteristics of the total sample and the test-retest sample are presented in Table 2. No significant differences were detected between the test-retest sub-sample and the others with regard to sociodemographic and clinical background characteristics, or with regard to any measures used at the interview.

Table 2. Background characteristics of the sample in study III & IV (n = 139) and the test-retest sample (n=17)

	Total		*Test-retest*
	n	***%***	***n***
Gender			
Male	50	36	6
Female	89	64	11
Age (n=138)			
(m, range)	41 (17 - 72)		25 (19 - 62)
Education (n = 138) (test-retest, n=16)			
Primary school	54	39.1	9
Secondary School	47	34.1	5
University	37	26.8	2
Civil status			
Single	73	52.5	11
Married/co-habiting	43	30.9	3
Divorced/separated	21	15.1	3
Widow/widower	2	1.4	-
Housing Situation			
Own apartment	126	90.6	15
Rented accommodation	7	5.0	1
Supported housing	2	1.4	1
Other	4	2.9	
Work Situation (n = 104) (test-retest, n = 11)			
Competitive employment	33	31.7	3
Sheltered employment	4	3.8	1
Unemployed	16	15.4	-
Student	11	10.6	-
Disability pension	36	34.6	2
Part-time work	4	3.8	5
Diagnosis (n = 112) (test-retest, n = 14)			
Schizophrenia	22	19.6	3
Affective disorder	58	51.8	5
Eating disorder	13	11.6	2
Other diagnosis	19	170	4
Psychiatric care history (n = 127) (test-retest, n = 15)			
Years since first admission (m, range)	14 (1-40)		14 (2 - 40)

Data collection

Study I

Study **I** was conducted to explore and describe perceptions of the concept of health among patients in mental health services. The first author (PS) informed the managers of the units at the psychiatric clinic about the study, both orally and in writing, and the managers informed the nurses at their units. The nurses then informed the patients who met the inclusion criteria of the study, both orally and in writing. The first author conducted the interviews at a place chosen by the participant; 11 were interviewed in their homes and one at the clinic. The interviews lasted 30-90 minutes. The interviews were open and semi-structured. A pilot interview was conducted to test the questions. The intention of the interviews was to achieve an open communication to increase the understanding of the participant's perception of the phenomenon. The introductory questions were:

- What is health for you?
- How would you like to describe the concept of health in mental health nursing?

Study II

Study **II** was conducted to explore and describe perceptions of the concept of health among nurses in mental health services. The first author (HJ) informed the staff and the managers at the units about the study. The participants who met the inclusion criteria and were willing to participate in the study were invited both orally and in writing to an interview by their managers. The interviews were audio-taped and used open questions, according to phenomenographic practice (Fridlund & Hildingh 2000). Each interview lasted for approximately one hour at a place chosen by the participant. All twelve nurses were interviewed at work with permission from their managers. The questions, which were tested in a pilot interview, were chosen in order to cover relevant aspects of the participant's conception of the phenomenon. The intention was to increase the understanding of the interviewee's conception of the phenomenon by means of an open conversation. The introductory interview questions in study **II** were as in study **I**:

- What is health for you?
- How would you like to describe the concept of health in mental health nursing?

Studies III and IV

Staff at the chosen units was given detailed information about the study, both orally and in writing. The staff elected a key person who informed the patients about the study with guidance from a detailed description of the study. Patients willing to participate were put into contact with the investigator by the key person, the former later contacted the patient to make an appointment to carry out the interview. The participants were informed both orally and in writing about the study.

Measures

The interviews comprised six questionnaires apart from the Health Questionnaire. The questionnaires focused empowerment (Making decisions scale), stigma experiences (Devaluation/ discrimination, Rejection experiences), psychiatric symptoms (Hopkins symptom checklist-25), subjective quality of life (MANSA), and self-esteem (Rosenberg Self-esteem Scale).

The health questionnaire

The questionnaire examined in the present thesis, the Health Questionnaire (HQ), was developed from the results of studies **I** and **II**. The qualitatively different perceptions and descriptive categories that emerged in these two qualitative studies were transformed into a number of variables to embrace the perceptions and categories described by both patients and staff. The Health Questionnaire evaluates the subjective experience of health among patients in mental health services. The subjective experience of health is in each item rated on a five-point scale from 1 = never, to 5 = always. To ensure that the meaning and wording of the items was plausible and clear they were discussed in the group of co-authors. The new questionnaire was also pilot tested using a sample of 15 patients in mental health services during the autumn of 2004. The purpose of the pilot study was to test the feasibility and usefulness of the questionnaire as well as to explore whether the items communicated the intended meaning or not. The risk for misinterpretations and inclusion of items with a tentative high internal rate of missing responses was in this way reduced. The results of the pilot test indicated that the number of items could be reduced from 43 to 25. Further testing of the new questionnaire will be the subject of studies **III** and **IV**.

Rosenberg self-esteem scale

Self-esteem was measured using the Rosenberg self-esteem scale (Rosenberg 1965). The scale comprises ten statements about self-worth which are responded to using a 4- point scale. The Rosenberg self-esteem scale is frequently used in research studies (Corwyn 2000). The original version of the Rosenberg self-esteem scale comprises five positively worded and five negatively worded items. Analyses have indicated that the original version, fit a two-factor model but when the original scale was reworded in two versions comprising 10 positively worded or 10 negatively worded items it fitted into a one-factor model. All three versions had high validity for different ethnic groups (Greenberger *et* al. 2003).

The Hopkins symptom checklist-25

Psychiatric symptoms were rated using the Hopkins symptom checklist-25. The HSCL-25 is a 25-item self-rating scale containing symptoms related to psychiatric illness. Symptoms are rated on a four-point severity scale (Derogatis *et al*. 1974) The Hopkins symptom checklist-25 has been widely used in different settings and a Swedish validation study showed results comparable to those obtained in international studies (Nettelbladt *et al*. 1993).

Making Decisions

Empowerment was measured using a 28–item questionnaire, the Making Decisions scale, developed by Rogers *et al*. (1997). Statements are responded to on a four-point agreement scale. The making decision scale has five subscales: self-efficacy-self-esteem, power-powerlessness, community activism, righteous anger, and optimism-control over the future. The overall scale and the subscales have a good internal consistency with a possible exception for the subscale power-powerlessness. A factor analysis of the Swedish version of the scale revealed two superordinate factors, self-esteem and autonomy, and community and power, with a satisfactory internal consistency. These two factors also have been shown to have good construct validity (Hansson & Björkman 2005).

Manchester Short Assessment of Quality of Life (MANSA)

Quality of life was measured by the Manchester Short Assessment of Quality of Life scale (MANSA) containing 16 questions, four of them investigating objective quality of life

indicators and the other 12 assessing satisfaction with life as a whole, work situation, financial situation, friendships, leisure activities, accommodation, personal safety, family and health. Satisfaction is rated on a seven–point scale, and an overall score of subjective quality of life may be calculated. MANSA has been tested for concurrent and construct validity and has shown satisfactory psychometric properties (Priebe *et al*. 1999). The Swedish version has also been tested regarding its reliability and validity (Björkman & Svensson 2005).

The rejection experience questionnaire

Stigma experiences were assessed by self-report questionnaires measuring perceived rejection experiences, and beliefs about devaluation and discrimination. The rejection experience questionnaire has 11 items and was developed by using six items from a rejection scale developed by Link *et al*. (1997) and adding five items from a similar scale developed by Wahl (1999). The questionnaire measures experiences of being rejected due to mental illness in various life domains. The statements are rated on a five-point response scale of occurrence.

Devaluation and discrimination

Devaluation and discrimination was investigated by using a questionnaire developed by Link (1987) containing 12 statements concerning negative beliefs among the general population towards people with mental illness. Attitudes are measured on a four- point agreement scale.

Data analysis

Study I and II

The analysis of data in both studies **I** and **II** was performed by the use of the following seven steps; familiarization, condensation, comparison, grouping, contrasting, labelling, and articulating (Dahlgren & Fallsberg 1991).

1. *Familiarization* is the first step of the phenomenographic data analysis, meaning that the tape-recorded and transcribed interviews were read through several times.
2. The analysis proceeded with *condensation* and search for statements related to the aim of the study.

3. The next step was to *compare* and search for similarities and differences among the statements, which had a low level of abstraction at this time and still included the words of the respondent's expressions.
4. The search for similarities and differences resulted in preliminary perceptions, which could be lifted out of their context and be seen *grouped* as separate statements.
5. The preliminary perceptions were *contrasted* and revised to be as qualitatively different as possible.
6. When the perceptions showed qualitative similarities, they were *labelled* and summarized into a category.
7. The categories that emerged were *articulated* in a way that described the new context.

To increase plausibility and trustworthiness in the analysis, the transcribed interviews were analysed by the main author (PS in study **I** and HJ in study **II**), who had personal comprehensive knowledge about the nature of the phenomenon and methodology. This knowledge, however, can jeopardize the author's ability to notice new perceptions of the phenomenon. The process of categorizing the data material was therefore scrutinized by all the authors, with long experience of the topic and methodology, aiming at consensus, in order to enhance accuracy (Göransson *et al*. 1998).

Study III

A combination of two rules was used in order to calculate an adequate sample size. The subjects-to-variables ratio should be no lower than 5 (Bryant &Yarnold 1995) and at least 100 subjects should be included in the analysis (Hatcher 1994). A principal component analysis (PCA) with varimax rotation was used to test the factor structure of the Health Questionnaire. The Kaiser-Meyer Olkin's test for sampling adequacy was performed in order to investigate whether any super ordinate factors could be identified. In addition, Bartlett's Test of Sphericity was employed to verify that the correlation matrix did not indicate an inappropriate factor model. In accordance with the Kaiser criterion an eigenvalue of >1 was used as a cut-off point for inclusion of factors and only items with a factor loading of >.45 were analysed further (Altman 1991). Items loading high in two factors were removed from the analyses (Burns and Grove 2001). Internal missing data were in general low in the items of the HQ (range 0.7-1.4 %) but in order to retain all participants in the analyses missing data were replaced by group means. Cronbach's alpha was used to test the internal consistency of

relevant subscales and Cohen's Kappa to assess test-retest reliability. Kappa coefficients of <.20 were considered poor, between .21-.40 fair, .41-.60 moderate, .61-.80 good and between .81-1.00 very good (Altman 1991). The statistical software package used was SPSS 14.0 for windows.

Study IV

Pearson product-moment correlation was employed to investigate associations between variables. Validation variables having a significant correlation to subjectively experienced health as measured by the Health Questionnaire ($p<.05$) were tested in stepwise multiple regression models using overall health scores and the different subscale scores as dependent variables. A recommendation put forth by Altman (1991) concerning calculations of an adequate sample size in multiple regression analyses is that the number of independent variables used should not exceed the square root of the sample size. The square root of the sample size in the present study is 11.8, which is well above the number of independent variables used in the regression analysis. The statistical software package used was SPSS 14.0.

RESULTS

Results of study I

The data material of study **I** contained 213 statements, from which 11 conceptions emerged forming three descriptive categories, showing how patients in mental health services perceived the concept of health. All perceptions had emerged at least once within the analysis of the three first interviews.

The descriptive category ***Autonomy*** included autonomy and independence as basic elements in the concept of health. Important prerequisites in having autonomy were managing every day life, having power over oneself and being able to make decisions. It also was important to believe in oneself, as well as feeling that one was equal to and important for other people. The category embraced four perceptions; functioning in one's own situation, being free, believing in oneself and making own decisions.

The descriptive category ***Meaningfulness*** included the importance of experiencing well-being and having hope for the future in order to see meaning in life. Enjoying one's life situation and at the same time having goals for the future was essential elements in the concept of

health. The category embraced three perceptions; having meaning, being at peace and looking forward.

The descriptive category ***Community*** included the aspect that a functional social life is an important element in the concept of health. This meant participating in a social context, feeling love and companionship, as well as being able to give to others. The category embraced the perceptions; participation in a social context and giving to others.

Results of study II

The data material of study **II** contained 145 statements from which 10 perceptions emerged forming three description categories, showing how nurses working in mental health services perceived the concept of health. All perceptions had emerged at least once within the analysis of the three first interviews.

The description category ***Health as autonomy,*** described by all twelve nurses, comprised the nurse's perceptions of an independent life as a central part of the concept of health. Health as autonomy embraced the following perceptions: well-being irrespective of disease, being free to choose, functioning in one's own situation, and trusting oneself.

The description category ***Health as a process*** represented the nurses' perceptions of personal growth related to the concept of health and was expressed in all twelve interviews as well. The category comprised the underlying perceptions: health is growth, health is independent of growth, and health is a prerequisite for growth. Also the perception that health includes suffering was seen by nurses as a motivator for personal development.

The description category ***Health as participation,*** expressed in all but one of the interviews, included the nurses' perceptions of the importance of participation in life itself and in a social context regarding the concept of health. The category comprised the following perceptions: experiencing trust and being part of a social context. Description categories and conceptions as analysed in studies **I** and **II** are presented in table 3.

Table 3. Description categories and conceptions related to health in mental health services, as analyzed in studies I and II

	Patients			Nurses		
Description categories	**Autonomy**	**Meaningfulness**	**Community**	**Autonomy**	**Process**	**Participation**
Conceptions	Functioning in one's own situation	Having meaning	Participating in a social context	Well-being irrespective of disease	Health is growth	Experiencing trust
		Being at peace				
	Being free		Giving to others	Being free to choose	Health is independent of growth	Being part of a social context
		Looking forward				
	Believing in oneself			Functioning in one's own situation	Health is a prerequisite for growth	
	Making one's own decisions					
				Trusting oneself	Health includes suffering	

Results of study III

The results of study III showed that the sample was suitable for conducting a factor analysis according to the Kaiser-Mayer-Olkin test for sampling adequacy and the Bartlett Test of Sphericity. The final questionnaire, after removing three items due to loadings on two factors or a factor loading of < .45, included 22 items distributed into three factors cumulatively explaining 65.1% of the total variance.

Cronbach´s alpha was calculated as a measure of internal consistency. The final questionnaire was found to have high internal consistency (Cronbach´s alpha = .95). The first factor was labelled Autonomy (Cronbach´s alpha = .96) and comprised fourteen items. The second factor was labelled Social Involvement (Cronbach´s alpha = .84) and included five items. The third factor, labelled Comprehensibility (Cronbach´s alpha = .65), included three items. Test-retest reliability according to Cohen's Kappa was considered good in 7 items, moderate in 10 items, fair in 3 items and poor in 2 items.

Results of study IV

Overall health showed positive correlations to self-esteem, empowerment and quality of life, and negative correlations to symptoms, discrimination and rejection experiences.

Empowerment, self-esteem and quality of life were positively correlated to all three subscales, Autonomy, Social Involvement and Comprehensibility. Psychiatric symptoms and discrimination and rejection experiences were negatively correlated to overall health and all three subscales of the Health Questionnaire (Figure 4).

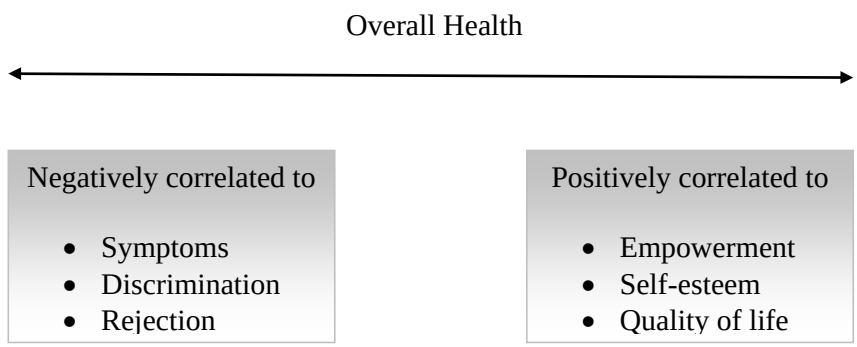

Figure 4. Illustration of correlations of overall health with validation measures

In order to analyze the relative importance of the above set of measurements and characteristics as determinants of health, stepwise multiple regression analyses were performed using overall health and the subscale scores as dependent variables.

Self-esteem, symptoms, empowerment and quality of life altogether accounted for 70% of the variation of overall health. Self-esteem, symptoms and empowerment accounted for 73% of the explained variance of the subscale of Autonomy. Self-esteem, quality of life and empowerment accounted for 40% of the explained variance of the subscale Social Involvement. Self-esteem was the most important factor related to health, accounting for 60% of the variance in overall health, 64% of the variance in Autonomy and 30% of the variance of Social Involvement. Empowerment was to a lower degree related to all three subscales as well as to overall health. Furthermore, empowerment was the only factor related to the subscale Comprehensibility accounting for 10 % of the variance. Quality of life was

positively associated to the subscale Social Involvement where it accounted for 30% of total variance explained, and to a lower degree to overall health. Symptoms were to a relatively low degree negatively associated to overall health, accounting for 5% of total variance and to the subscale Autonomy where it explained 6% of the variance (Figure 5).

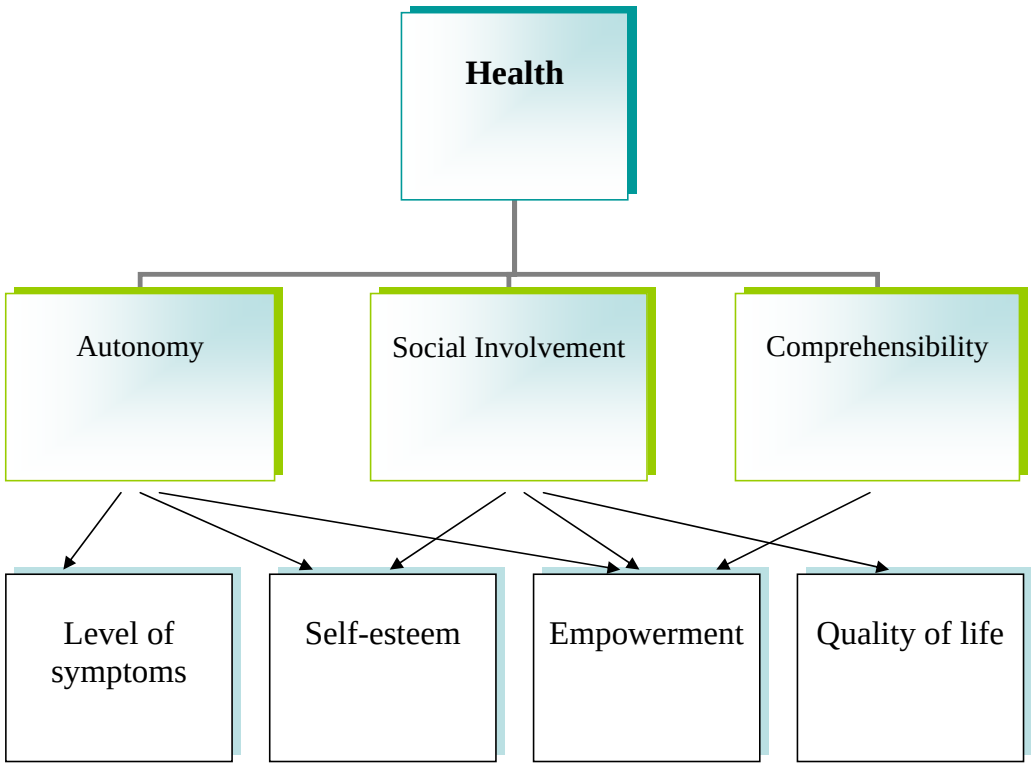

Figure 5. Illustration of health and its subscales in relation to other concepts used as validation measures

DISCUSSION

Methodological aspects of the qualitative part of the thesis

A qualitative design with a phenomenographic approach was used for studies **I** and **II**. The process of examining the reliability of a qualitative design, such as the phenomenographic approach, can be aided by using the concepts of *applicability*, i.e. the ability to identify, *trustworthiness*, *reasonableness* and *conscientiousness* (Fridlund & Hildingh 2000).

The phenomenographic approach has been recommended to have high *applicability* to identify different human perceptions and it is often used in nursing research (Marton & Booth 1997). The approach has been shown to give clear, qualitatively different perceptions of the actual phenomenon (Fridlund & Hildingh 2000). Informants were selected strategically to achieve as wide a range of perceptions of the concept of health as possible. Most of the participants in study **I** had been in contact with mental health services for a long time, and all the nurses in study **II** were working in the same county, employed by the same services. This fact can be seen as a limitation of the study because the result could depend on the presence of a homogeneous working climate (Svensson 1997) at the clinic, and that other perceptions could be found if informants from other clinics were included. As in most qualitative studies, the findings can not be generalized without further investigations with quantitative approaches.

Trustworthiness can be regarded as a measure of the study having been carried out correctly (Fridlund & Hildingh 2000) and can be examined in terms of the description of the analysis and in terms of the perceptions of the respondents being exemplified by quotations. The trustworthiness in the present study is considered to be satisfactory as the data collection and the interpretation process are described in detail and the emerging perceptions are illustrated with quotations.

The *reasonableness* of the findings, which means that the study measures what it is supposed to measure, was enhanced by the fact that pilot interviews with one patient and one nurse were conducted to test the feasibility and usefulness of the questions. The reason for choosing the interview as data collection method was to gain a deeper understanding of the phenomenon in accordance with the phenomenographic tradition. The interview questions were based on theoretical framework of health to ensure that the questions were relevant to the explored phenomenon. The use of semi-structured interview questions involves a risk that aspects of the phenomenon that are not in accordance with generally accepted theoretical assumptions are overlooked. However the introductory questions were used to encourage an open conversation to increase the understanding of the informant's perception of the phenomenon.

The concept of saturation may be questioned when using a phenomenographic approach. In these studies the concept of saturation could be employed to confirm that no new perceptions

were continuing to emerge during the analysis of the final interviews, since this might indicate that a larger sample of informants should be needed. Saturation in these studies was considered after analyzing all the interviews and saturation was reached before half of the interviews were analyzed. Thus the perceptions have been expressed by several informants, which increases the probability that nurses really have these perceptions and enhance the reasonableness of the result (Svensson 1997).

Conscientiousness is concerned with describing the precision throughout the research process. To ensure conscientiousness, the data has been read repeatedly to reflect on statements to identify similarities and dissimilarities in the perceptions and in the descriptive categories. The interviews and the data analysis were conducted by the first author, in study **I** (PS) and in **II** (HJ) who were familiar with the data, to increase both reasonableness and trustworthiness. However the author's pre perceptions of the phenomenon could be a threat to conscientiousness in the data analysis, thus the first author analyzed the data before the analysis of the data was judged by all the co-authors to reinforce the conscientiousness.

Methodological aspects of the quantitative part of the thesis

Validity issues

In these studies it was decided to use a 20 % random sample of the target population of 1,195 patients in contact with outpatient mental health services in the county investigated. This was done in order to reduce the risk of systematic sampling bias and thus increase the validity of the study (Burns & Grove 2001), and also to ensure that all the patients from the included units had an equal and independent chance to be selected. In total, 239 patients were randomly selected to participate. There was an external drop-out of 37 patients who declined to participate, and an internal drop-out of 61 patients who agreed to participate but did not complete the interviews. The final sample consisted of 141 patients, representing 59 % of those initially approached, of whom two failed to complete the health questionnaire. The analyses were thus performed on 139 patients; constituting 58% of the original sample. The drop-out rate was 42% and it is unknown why some of the informants, who had given oral consent to participate, declined participation. There might be a risk that the final participants differ in important aspects from those intended for inclusion. They might for example be healthier than those who declined to participate. Earlier studies have found that there are

differences between those who do or do not respond to a questionnaire, with non-responders usually being less healthy (Altman 1991). Another suggestion is that healthier persons had a more sporadic contact with the units and therefore had not been in contact with the unit during the last year, which was the upper limit for inclusion in the random selection of patients. A relevant question is therefore whether the participants in studies **III** and **IV** are representative of the sample intended for inclusion. Background characteristics of those who did not want to participate in the study or did not complete the questionnaires is not known. It was considered unethical to collect information about subjects who had not given their written informed consent to participate in the investigation, or consent to collect such information. This consideration is in accordance with the importance of protecting the rights of human research subjects (Burns & Grove 2001). However, it is a drawback of this part of the study that no calculations of the representativeness of the participants with regard to demographic, social and clinical characteristics were possible to perform. On the other hand, participants showed a great variation with regard to a number of sociodemographic, social and clinical characteristics indicating that they represented a wide range of patients in contact with the services.

External validity is concerned with the extent to which the findings can be generalized beyond the sample in the study, to other settings or samples (Burn & Grove 2001; Kazdin 2003). The most conservative estimation should be that the findings of these studies would be meaningful only for the participants of the study. The sample represents adults with a variation in terms of diagnosis, education, housing and work situation, and contact with outpatient mental health services. The results may primarily be generalized to outpatient mental health services in Sweden. Further proof of the validity of the findings of this study with regard to the structure of the Health Questionnaire and its construct validity require further validation studies.

Another threat to validity concerns the way instructions and information about the study are given to the participants in the interview situation (Kazdin 2003). It is important that the information given does not differ between individual participants. If the information about the study and the invitation to participate differ between potential participants, this could affect the willingness to take part in the study and result in a bias in the sample. There might be a risk that the participants' willingness to participate was influenced by the fact that they were in a state of dependence on their key worker asking them to participate, referring to the

principle of autonomy. This is an ethically and methodologically important question. Thus efforts were made to ensure that the same information and instructions about the study was given to all the participants at each unit by using a single and selected key person at the respective unit to guarantee the same information and invitation to participate in the study were given to all in the random sample. This key person was informed both orally and in writing about how to invite participants and what information to give them from a detailed written description about the study and its aims and purposes.

Examinations of validity and reliability also refer to whether instruments included in the study actually measure what they are meant to measure. In order to assess domains of interest such as empowerment, stigma, psychiatric symptoms, quality of life and self-esteem used in the investigation of construct validity of the Health Questionnaire in study **IV,** efforts ware made to only include instruments with a record of an acceptable reliability and validity. In each instance internal consistency in terms of Cronbach's alpha was examined based on the ratings of the participants of the present study.

The Health Questionnaire was developed from the results of studies **I** and **II**. The categories from these studies were transformed into a number of items. To secure that the meaning and wording of the items was plausible and clear they were discussed in the group of co-authors. The new questionnaire was also pilot tested using a sample of 15 patients in mental health services during autumn 2004. The purpose of the pilot study was to test the feasibility and usefulness of the questionnaire as well as whether or not the items communicated the intended meaning. The risk for misinterpretations and inclusion of items with a tentative high internal rate of missing responses was in this way reduced and the pilot study resulted in a reduction of items from 43 to 25.

Validity also has a relationship to statistical power of analyses performed. The sample size in studies **III** and **IV** was 139, which was considered sufficient to examine the psychometric properties of the 22-item scale. Various recommendations defining the ratio between variables used in multivariate analyses and the sample size have been put forth. Calculation of an adequate sample size for factor analyses is a complicated issue with no straight forward scientific answer, and differing answers between methodologists. A number of alternative

arbitrary "rules of thumb", not mutually exclusive, have been presented. In the present study a combination of two rules was used in order to decide on the adequacy of the sample size. The subjects-to-variables ratio should be no lower than 5 (Bryant &Yarnold 1995) and at least 100 subjects should be included in the analysis (Hatcher 1994). Furthermore sampling adequacy was ensured by using the Bartlett test of sphericity and the Kaiser-Meyer-Olkin measure of sampling adequacy. These showed that the Kaiser – Meyer- Olkin (KMO) value was .93 and the significance of Bartlett's sphericity test was <.001, indicating that the sample met the criteria for performing a factor analysis.

Concerning calculations of an adequate sample size in multiple regression analyses a recommendation put forth by Altman (1991) was used, stating that the number of independent variables used should not exceed the square root of the sample size. The square root of the sample size in the present study is 11.8, which is well above the number of independent variables used in the regression analyses in study **IV**.

Reliability issues

The reliability of a measure concerns the stability and consistency of measures obtained in the use of a particular instrument. Reliability testing examines the amount of random error associated with measurement (Burns & Grove 2001). Stability between raters concerns interrater reliability which was not an issue in the present study. Stability over time is concerned with the consistency of repeated measures, and therefore a test-retest reliability study was performed on a sub sample of 17 patients who were interviewed twice with an interval of four weeks using the Health Questionnaire. Cohen's Kappa was used to assess test-retest reliability and considered moderate or higher in 17 of the 22 items, fair in three and poor in two items, "Seeing suffering as a natural part of life" and "Seeing illness as a motivating force". The latter finding requires further investigation.

In terms of internal consistency of the Health Questionnaire, reliability as investigated by Cronbach´s alpha was acceptable for both the overall scale and the subscales, with the possible exception of the third subscale, Comprehensibility. The internal consistency of this subscale could not be improved by attempts to remove one of the three items, which may imply that the lower consistency is not due to contradictory content.

Discussion of the findings

The results of the four studies in this thesis show that health represents more than just absence of illness and that the concept incorporates Autonomy, Social Involvement and Comprehensibility. This three-factor solution links with the findings of Hwu *et al*. (2002), who developed a Concept of Health Scale for Chinese people with chronic illness. Hwu's health scale factors were Independence and Physical functioning, Contentment in Social Interaction and Zest for life, Serenity and Meaning. This may imply that the concept of health contains dimensions that can be generalised irrespective of variations in life circumstances and illness, although the complexity of the concept of health requires further investigation. Jones and Meleis (1993) have previously described similarities between the concepts of health and empowerment. Two of the subscales in the Health Questionnaire, Autonomy and Social Involvement, have obvious similarities with the two superordinate factors of empowerment revealed by Hansson and Björkman (2005), where the first factor was labelled Self-esteem and Activism and the second Community and Power. The concept of health is very similar to the concept of recovery, when defined as dynamic processes of personal growth and transformation dependent on supportive relationships, meaningful activities as well as effective treatment (Mancini *et al*. 2005). The finding of study **IV** revealed that self-esteem, symptoms, empowerment and quality of life altogether accounted for 70% of the variation of overall health. Symptoms were to a relatively low degree negatively associated to overall health, accounting for 5% of total variance. Devaluation and discrimination as well as rejection experiences, were more weakly correlated to overall health and the subscales than empowerment. It is, however, reasonable to assume that stigmatization has a considerable effect on symptoms, self-esteem and quality of life, factors that are essential to health and a healthy life situation.

Autonomy

Autonomy, as revealed by the findings from studies **I** and **II,** incorporated ability to function in daily life, self-esteem and to feel positively about one's self. Perceptions among nurses and patients in mental health services were very much alike. However one difference between nurses and patients was that patients expressed that feeling that one was equal to and important for other people was related to a feeling of self-worth and health, which nurses did not mention. Patients in mental health services have described the importance of being looked upon just as anyone else as well as the need for help to reduce the shame of having to request

and receive psychiatric care in order to reduce stigmatisation and enhance health (Schröder *et al*. 2006). Long and Baxter (2001) state that the innermost self in human beings is what gives meaning and makes life worth living. To be able to function in one's situation without being limited and to be able to trust oneself without letting the individual decision-making be taken over too much by others are important aspects of health related to autonomy. A risk to individual health is that the individual adjusts too much to external demands, because of being too dependent on and influenced by cultural values as well as adjustment to the social life situation (Polakoff & Gregory 2002). Webster and Austin (1999) describe two important fundamentals for the individual to stay healthy when a situation is stressful. These are to experience control by using cognitive, social and practical skills, and to feel engagement in health-promoting activities and to appraise them as challenging rather than stressful. Sörgaard *et al*. (2002) found that overall self-esteem was predicted by being satisfied with family relationships and that having at least one close friend was a predictor of positive self-esteem, while being able to cope without friends was associated with superior self-esteem. The findings of study **IV** revealed that self-esteem as measured by the Rosenberg self-esteem scale was most strongly associated to the subscale Autonomy. Psychiatric symptoms were to a minor extent negatively associated to the subscale Autonomy where they explained only 6% of the variance. This latter finding is in accordance with the assumption of Hedelin and Strandmark (2001) stating that health cannot be explained in a negative way as absence of symptoms because such an explanation tends to neglect the positive aspects of health (Downie *et al*. 1996; Naidoo & Wills 2000).

Social Involvement

The Social Involvement subscale integrated experiences of attachment to others and being both a recipient and a donor of social support. This subscale could be recognized in the category *community* in study **I,** and the category *health as participation* in study **II.** The patients expressed the perceptions participation in a social context and giving to others, while the nurses expressed the perceptions experiencing trust and being part of a social context. Hedelin and Jonsson (2003) describe mutuality in relationships between people as a major element in the experience of mental health. The essence of mental health has been defined as the experience of confirmation by means of being noticed, respected and regarded as a valuable person by others (Hedelin & Strandmark 2001). Studies **I**, **II** and **III** revealed that one important aspect of health is to feel included in a social network. Since processes of participation and self-directed activities are crucial for the enhancement of autonomy, self-

esteem and empowerment (Arnesson & Ekberg 2005), it is important that the kind of employment offered to persons with a history of mental illness is motivating and empowering (Fitzsimons & Fuller 2002). Effective empowerment strategies in workplaces and society as a whole may depend as much on the leadership of the people involved as on the overall context in which they are carried out (Wallerstein 2006). The validation measure in study **IV** which was most strongly associated with the subscale Social Involvement was quality of life as measured by the Manchester short assessment of quality of life (MANSA), while self-esteem and empowerment accounted for a minor part of the explained variance. According to Hwu *et al*. (2002), a zest for life, harmony and satisfying relationships are important intertwined aspects of health. The findings show no evidence that Social Involvement is associated with psychiatric symptoms, which is supported in the study of Hansson *et al*. (1999) who did not find that any clinical characteristics were associated with global subjective quality of life, while one objective indicator, i.e. to have at least one close friend, was associated with quality of life. This finding is also in line with Hansson *et al*. (2003) when highlighting that unmet needs in the domain of social relationships are related to a worse quality of life.

Comprehensibility

The Comprehensibility subscale includes the understanding and awareness of one's situation, how the situation emerged and a view of how to get the situation changed. Comprehensibility could be recognized in the category of *meaningfulness* in study **I** where the perceptions were having meaning, being at peace and looking forward, and in the category *health as a process* in study **II** where the perceptions dealt with health related to personal growth and that suffering could be a motivating force. The perception that health includes suffering in the result of study **II** seems to incorporate an understanding of health as a process where the suffering can be a motivator for development towards change and increased awareness, as described by several researchers (Herberts & Eriksson 1995; Lindsey 1996; Long 1998). The findings of study **IV** show no evidence that comprehensibility is related to psychiatric symptoms, the single validation measure that was associated with this subscale was, empowerment, which was also associated to all the other subscales as well as to overall health. However, it seems reasonable to assume that self-esteem and quality of life in some way are associated to the subscale Comprehensibility because these validation measures are related to empowerment. Jones and Meleis (1993) claimed that increased self-esteem, which is often enhanced through empowerment, is essential in order to gain the energy that is needed

to be able to fully use one's personal health capacity. When the individual, in interplay with the environment, has the opportunity to find his or her own balance between autonomy and participation, this may lead to a process towards increased awareness in the individual. This process towards increased awareness and enlarged personal meaning could be compared to the term transition, which may be encouraged through communication of thoughts and needs (Skärsäter & Willman 2006). A number of researchers view health as an increased awareness and a foundation for increased well-being (Eriksson 1984; Long 1998; Moch 1998; Parse 1990). This awareness can in turn lead to more constructive behaviour in accordance with individual wishes related to the environment. Health as becoming, meaning that the person becomes whole on a higher level of integration (Herberts & Eriksson 1995), has clear similarities to the view of health as a process. According to this reasoning the concept of health is beyond the limits of the wellness–illness continuum (Hwu *et al*. 2002; Moch 1998).

Relevance for clinical practice

It has been put forth that caring science requires humanistic knowledge with a hermeneutical dimension to achieve real progress in caring (Eriksson 2002), although one problem is to find an evidence base for this kind of knowledge. It has been stated that the majority of acceptable scientific evidence available regarding mental health care interventions pertains to pharmacy therapies because medication trials are simpler to evaluate. Thus most evidence-based models appear to understate the importance of non-pharmacological interventions and a lack of knowledge about such interventions are recognized (Hayman - White & Happel 2007). The findings of this thesis may imply that the key to enhanced health among patients in mental health services is to support them regarding self-esteem, empowerment and quality of life. To view the goal of mental health care mainly as reducing symptoms should not be sufficient when health is to such a low extent explained by psychiatric symptoms. Patient choice is shown to be important to patients and improves engagement with services even though studies on outcomes show varying results (Laugharne & Priebe 2006). This reinforces the relevance of the use of the concept of empowerment in nursing care as stated by Jones and Meleis (1993). Processes of participation and self-directed activities are crucial for the enhancement of autonomy, self-esteem and empowerment (Wallerstein 2006). Johnstone (2001) illustrates that the consequences of stigmatization gives a high incidence of human rights violations that occur within society in general and in the health care sector in particular. It has been

suggested that it is important for patient empowerment that patients are ensured relevant information and counselling before they take part in discharge planning conferences in order to be able to participate in decision making regarding their own future life (Efraimsson *et al*. 2006). With regard to the findings of this thesis, mental health services may put more efforts to support patients on their journey back towards a life in society since health is shown to be related to social involvement. Further investigations of the concept of health may contribute to enhanced empowerment strategies in health care in particular as well as in society in general in order to embrace all people irrespective of symptoms of illness.

IMPLICATIONS

Further research

- It seems essential to conduct further research concerning the comprehensibility subscale, since the findings concerning this subscale were less conclusive than for the other subscales of the Health Questionnaire, even though it is assumed to be an important aspect of overall health.
- To conduct further research concerning the effects and effectiveness of empowerment approaches in mental health services.
- To conduct further research concerning the causal relationships between psychiatric symptoms and health in order to develop intervention approaches to be implemented in mental health services.

Clinical practice

- To extend the use of an empowerment approach where the individual autonomy is respected in mental health services.
- To emphasize the importance of strengthening and supporting the social environment of patients diagnosed with a mental illness and to shed further light on the role of this in community-based mental health services.

MAIN CONCLUSIONS

- The Health Questionnaire, developed to evaluate the subjective experience of health among patients in the mental health services included 22 items comprising three factors, labelled Autonomy, Social Involvement and Comprehensibility. The questionnaire showed in general satisfactory reliability in terms of internal consistency and good test-retest reliability.
- Perceived health as measured by the Health Questionnaire in terms of Overall Health, Autonomy, Social Involvement and Comprehensibility, is a meaningful and valid construct, which would be useful for measuring health in both clinical mental health care practice and in mental health services research.
- Subjectively experienced health is one important outcome measure of the quality of care provided to patients in the mental health services.
- The questionnaire will enable further research on subjectively experienced health, and may in this respect be included as an outcome measure of health care interventions. It could also be a useful tool for quality assurance programs in mental health services.
- The Health Questionnaire may support a change towards an enhanced focus on health and resources among patients and reinforce the perspective of health within mental health care practice and research.

SVENSK SAMMANFATTNING/SWEDISH SUMMARY

Psykiatrisk vård har av tradition varit sjukdomsfokuserad och begreppet hälsa ses ofta som liktydigt med frånvaro av sjukdom eller ur ett ensidigt somatiskt perspektiv där hälsobegreppets mångdimensionella komplexitet inte tillräckligt beaktas. Bristen på en begreppsmässig enhetlighet i vård, behandling och rehabilitering av psykiskt funktionshindrade personer hindrar att patientens hälsa och välbefinnande främjas systematiskt ur ett individperspektiv i psykiatrisk vård. De instrument som idag används för att mäta och utvärdera den vård som ges mäter följaktligen oftast frånvaro av symtom och funktionsbrister. Dessa instrument anses mäta hälsa eller hälsorelaterad livskvalitet, medan de i själva verket mäter frånvaro av ohälsa. Det bakomliggande antagandet är att frånvaro av ohälsa är liktydigt med hälsa. Psykiatrisk omvårdnad skall främja hälsa, vara kvalitetssäkrad kostnadseffektiv, och i enlighet med patientens behov och preferenser. Därför är det av största

vikt att begreppet hälsa är tydligt definierat för att kunna användas som konkret, realistiskt mål i psykiatrisk vård. Likaså är det angeläget att undersöka hur begreppet hälsa är relaterat till andra närliggande begrepp som har betydelse för patientens möjligheter till hälsa och återhämtning. Den kunskap som finns blir på detta sätt mer systematiserad, överskådlig och lättillgänglig för implementering i den praktiska psykiatriska vården.

Världshälsoorganisationen definierar hälsa som ”ett tillstånd av fullständigt fysiskt, psykiskt och socialt välbefinnande och inte bara frånvaro av sjukdom och handikapp”. Denna definition kompletteras med en beskrivning av hälsopotential som innefattande ”både fysisk och psykisk hälsa och måste ses i ett sammanhang av personlig utveckling genom livet”. Samspel med omgivningen är avgörande för att individen skall uppnå balans och växt. Därför bör individ och omgivning i samspel beaktas då hälsobegreppet skall användas som mål för omvårdnaden. För att patienten ska få bättre möjligheter att utnyttja sina hälsofrämjande resurser och kunna ta mer ansvar för sin livssituation krävs mer information och ökad delaktighet i vården. Begreppet empowerment står i relation till livskvalitet och självkänsla och innefattar självförtroende och optimism inför framtiden medan maktlöshet, som kan ses som motsatsen till empowerment, är en riskfaktor för att utveckla sjukdom. Livskvaliteten hos personer med psykiska funktionshinder påverkas starkt av relationer till andra människor och delaktighet i samhället. En vård med tydlig empowermentansats som utgår från klientens egna prioriteringar, bidrar till ökad hälsa och mindre symtom.

Stigmatisering innebär att skilja ut och behäfta mänskliga skillnader med negativa egenskaper liksom att dela in människor i ”vi” och ”dem”, vilket resulterar i statusförlust och diskriminering för individen. Att bli behandlad som mindre kompetent eller att få rådet att minska ambitionerna i livet på grund av psykisk sjukdom är stigmatiserande upplevelser som skadar självkänslan allvarligt och motverkar återhämtning från psykisk ohälsa. Fokus på sjukdom och problem tenderar att leda till ökad inriktning på just detta, det är därför viktigt att sjuksköterskor är medvetna om vilket perspektiv de använder sig av. Negativa attityder har visat sig vara vanliga också bland personal i vården, även i psykiatrisk vård.

Syftet med denna avhandling är att förtydliga definitionen av begreppet hälsa i psykiatrisk vård och att skapa ett tillförlitligt mätinstrument för att mäta subjektiv upplevelse av hälsa hos patienter i psykiatrisk vård.

Avhandlingsarbetet börjar med delstudie **I**, en kvalitativ deskriptiv studie med fenomenografisk ansats. Syftet var att beskriva hur patienter i psykiatrisk vård uppfattar begreppet hälsa. Tolv patienter deltog i semistrukturerade intervjuer och det insamlade datamaterialet omfattade 213 utsagor, ur vilka 11 uppfattningar framstod som formade tre beskrivningskategorier. Resultatet visade att patienter i psykiatrisk vård uppfattade att Autonomi, Meningsfullhet och Gemenskap innefattas i begreppet hälsa. Patienterna uttryckte dubbeltydiga uppfattningar om huruvida den egna hälsan är möjlig att påverka eller ej. En slutsats är att psykiatrisk vård i större utsträckning bör bygga på en process- och målinriktad omvårdnad med fokus på individens subjektiva hälsa.

Syftet med studie **II** var att beskriva hur begreppet hälsa uppfattas av sjuksköterskor i psykiatrisk omvårdnad. Datainsamlingen byggde på intervjuer med tolv sjuksköterskor i psykiatrisk omvårdnad och data analyserades även här med en fenomenografisk metodansats. Datamaterialet omfattade 145 utsagor ur vilka 10 olika uppfattningar av fenomenet framstod, vilka formade tre beskrivningskategorier: Autonomi, Process och Delaktighet. Resultatet visar att hälsa uppfattas som något annat än frånvaro av sjukdom, samtidigt uttrycks uppfattningar där hälsa blir liktydigt med frånvaro av sjukdomssymtom, detta tyder på att hälsobegreppet är svårdefinierat. Ett otydligt definierat hälsobegrepp leder till att sjuksköterskor tenderar att fokusera mer på sjukdomsprevention än på processer som främjar hälsa. En slutsats är att ett holistiskt hälsobegrepp måste definieras tydligare och integreras i den psykiatriska vården för att kunna tjäna som målsättning för omvårdnaden. Likaså behöver effekten av att ett förtydligat hälsobegrepp används som mål i psykiatrisk omvårdnad mätas på ett tillförlitligt sätt med en kvantitativ metod för att resultatet skall kunna generaliseras.

Ett frågeformulär avsett att mäta subjektiv upplevelse av hälsa hos patienter i psykiatrisk vård konstruerades utifrån resultaten från studie **I** och **II**. De kvalitativa dimensioner och kategorier som framkom översattes till ett antal påståenden i ett frågeformulär som kallas Hälsoinstrumentet (HI). Frågeformuläret besvaras med hjälp av en femgradig skala som sträcker sig från 1= aldrig till 5= alltid. En pilotstudie genomfördes för att pröva frågeformulärets begriplighet och genomförbarhet och utifrån det kunde antalet påståenden reduceras från 43 till 25. I den kvantitativa delen av undersökningen användes ett slumpmässigt urval på tjugo procent av alla patienter på 8 utvalda psykiatriska

öppenvårdsenheter i södra Sverige, sammanlagt deltog 139 patienter i undersökningen. Demografiska variabler för patienterna var: ålder, kön, civilstånd, bostadssituation, utbildning, arbete, försörjning, diagnos, pågående kontakt i vården, år för första slutenvårdstillfälle samt antal vårdtillfällen i slutenvård.

Studie **III** fokuserade på frågeformulärets reliabilitet. Hälsoinstrumentets reliabilitet bedömdes genom skattningar av intern konsistens och stabilitet genom test-retest reliabilitet. Studien av test-retest reliabilitet genomfördes på de första 17 patienterna genom att de besvarade formuläret ytterligare en gång 2-4 veckor efter första tillfället. Resultatet visade att Hälsoinstrumentet har tillfredställande test-retest reliabilitet. Vidare genomfördes faktoranalyser för att studera de underliggande dimensioner som mäts genom frågeformuläret. Dessa undersökningar visade att begreppet hälsa har tre dimensioner; Autonomi, Social Delaktighet och Begriplighet.

I studie **IV** undersöktes hälsoinstrumentets begreppsvaliditet. Det nykonstruerade instrumentet validerades med hjälp av instrument som fokuserar på närliggande områden som förväntades ha ett samband med begreppet hälsa. De områden som användes för att validera frågeformuläret omfattade symtom, självkänsla, livskvalitet, empowerment och stigmatisering. Den hypotes som fanns var att begreppet hälsa skulle samvariera positivt med livskvalitet, empowerment, och självkänsla, och samvariera negativt med symtom och stigmatisering. Denna hypotes bekräftades i huvudsak och styrker antagandet att hälsa är ett mångdimensionellt begrepp som inte kan förenklas och göras liktydigt med frånvaro av sjukdom.

Resultatet i denna avhandling pekar på att den psykiatriska vården bör förstärka resurser inriktade på insatser som stödjer patienterna i deras resa tillbaka till livet i samhället eftersom hälsa har visat sig stå i en tydlig relation till delaktighet i sociala sammanhang. Ytterligare undersökningar av begreppet hälsa med hjälp av Hälsoinstrumentet kan bidra till utökade empowermentstrategier i vården specifikt, såväl som i samhället generellt.

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APPENDIX

Subjective experiences of health

This questionnaire contains a number of statements related to subjective experiences of the health situation. State your view on the statements by drawing a circle around the figure that best illustrates your experience. One circle per statement is enough.

I experience that …

1. I am able to manage my daily situation

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

2. I am able to manage my daily tasks

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

3. I am able to grow as an individual

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

4. I am free in spite of illness

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

5. I am aware of my worth

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

6. I am able to trust my ability

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

I experience that …

7. I am able to make my own decisions

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

8. I feel secure in myself

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

9. I am in a position of self-determination

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

10. I am experiencing harmony in my life

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

11. I am experiencing meaningfulness in my life

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

12. I have a peaceful and positive feeling inside me

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

13. I experience hope for the future

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

14. I have goals in my life

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

I experience that …

15. I experience attachment to others in my life

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

16. I feel I am appreciated by others

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

17. I can share my free time together with others

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

18. I am being able to care about others

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

19. I am able to receive support from others

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

20. I can see that suffering is a natural part of life

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

21. I realize what caused the illness or what I am feeling bad about

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always

22. I can see illness as a motivating force to make things better

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always