# Linköping University Medical Dissertation

No 969

# **Quality of Care in the Psychiatric Setting:**

# Perspectives of the Patient, Next of Kin and Care staff

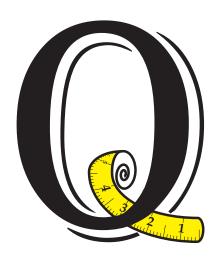
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# Quality of Care in the Psychiatric Setting: Perspectives of the Patient, Next of kin and Care staff

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"Never ever, ever, ever give up" Sir Winston Churchill

### **ABSTRACT**

Schröder A. 2006. Quality of Care in the Psychiatric Setting: Perspectives of the Patient, Next of kin and Care staff. Linköping University Medical Dissertation No. 969, Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences, Linköping University, SE–581 85 Linköping, Sweden. ISBN: 91-85643-46-7, ISSN: 0345-0082.

The overall aim of this thesis was to describe quality of care from different perspectives in the psychiatric setting, to develop an instrument for measuring quality of care from the in-patient perspective and to use this instrument empirically. A qualitative descriptive design involving a phenomenographic analysis was used in Studies I, III and IV, and a descriptive and comparative design with statistical analysis in Study II.

In Study I, 20 patients were interviewed. The results showed that quality of care was perceived as a positive, normative concept namely as *good* quality of care. Five descriptive categories emerged: the patient's Dignity is respected; the patient's sense of Security with regard to care; the patient's Participation in care; the patient's Recovery; and the patient's care Environment. In addition, two conceptions that had not explicitly emerged in previous studies on quality of care were identified: Being helped to reduce the shame and Being looked upon as like anyone else.

In Study II a definition of quality of care from a patient perspective was formulated on the basis of the results in Study I. A two-part instrument the Quality in Psychiatric Care (QPC) was developed for measuring the patients' expectations regarding quality of care (QPC-1) and their subsequent experience of it (QPC-2). One hundred and sixteen patients answered both parts of the instrument. Overall, the quality of care was rated high in both parts. However, experienced quality of care was significantly lower than the patient's expectations in all the dimensions of the instrument: Total dimension, Dignity, Security, Participation, Recovery and Environment. Patients who perceived that the time of discharge was consistent with the stage of their illness experienced significantly higher Recovery; patients with good psychiatric health also experienced this, but had in addition significantly higher levels of Participation. This new instrument exhibited too high Cronbach's alpha values (QPC-1 0.87–0.98, QPC-2 0.85–0.98), which means the instrument needs to be further tested in order to improve its psychometric properties.

Twelve next of kin were interviewed in Study III. The next of kin described quality of care mainly from their own perspective, but also to a large extent from the patient's perspective as well. They described it in both positive and negative terms. Five descriptive categories resulted: Dignity, Security, Participation, Recovery and Health-promoting surroundings. Good relations and communication between staff, patients and next of kin emerged as the central factors regarding the quality of care. The next of kin asked for information about mental illnesses and wanted to co-operate and participate in the patient's care. They avoided telling others about their family member's psychiatric illness because of a feeling of shame and guilt.

In Study IV, 20 care staff and care associates were interviewed. They described quality of care both from the patient's perspective and from a professional perspective. They perceived the concept as a positive one and as being of great importance for the patient's health and life situation. Four descriptive categories resulted: the patient's Dignity is respected; the patient's Participation in the care; the patient's Recovery; and the patient's care Environment plays an important role.

The main contribution of this thesis with regard to the concept of quality of care in the psychiatric setting is its emphasis on the significance of the different perspectives described above, as such knowledge is vital when planning and implementing and evaluating quality of psychiatric care. In addition, the descriptive categories that emerged in this thesis clearly highlight the importance of interpersonal relationships in the care situation. The new instrument (QPC) needs psychometric testing before it routinely can be used as a self-rating instrument for the purpose of improving psychiatric inpatient care and help guide the proper allocation of care resources.

Keywords: Care associates, care staff, instrument development, next of kin, patient, phenomenography, psychiatric care, quality of care.

### ORIGINAL PAPERS

This	thesis	is	based	on th	ne f	ollowing	papers	which	are	referred	to	hv	their	Roman	numerals:
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- Schröder, A., Ahlström, G. & Wilde Larsson, B. Patients' perceptions of the concept of the quality of care in the psychiatric setting: a phenomenographic study. Journal of Clinical Nursing 2006; 15: 93-102.
- II. Schröder, A., Wilde Larsson, B. & Ahlström, G. Quality in Psychiatric Care: an instrument evaluating patients' expectations and experiences. International Journal of Quality of Health Care Quality Assurance; Accepted for publication.
- III. Schröder, A., Wilde Larsson, B. & Ahlström, G. Next of kin's conceptions of the quality of care in the psychiatric setting: a phenomenographic study. International Journal of Mental Health Nursing; Accepted for publication.
- IV. Schröder, A. & Ahlström, G. Psychiatric care staff's and care associates' perceptions of the concept of quality of care: a qualitative study. Scandinavian Journal of Caring Sciences 2004; 18: 204-212.

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### **ABBREVIATIONS**

QPC The instrument "Quality in Psychiatric Care"

QPC-1 The questionnaire "Quality in Psychiatric Care — your expectations regarding

the care"

QPC-2 The questionnaire "Quality in Psychiatric Care — your experience of the

care"

# **DEFINITIONS**

#### Care associates

The term represents the Swedish *vårdgrannar*, literally care neighbours. These are people who work in primary care, the social services or municipal social-psychiatric care, or at the employment exchange or social insurance office, and who are concerned with psychiatric patients living at home (Swedish Institute for Health Service Development 1992).

#### Next of kin

In health care, next of kin are defined as the closest family and other close relatives: spouse, live-in-partner, officially registered partner, children, parents, siblings, grandparents, spouse's children etc. In certain cases, close friends can also be defined as next of kin (National Board of Health and Welfare 2005a).

#### Mental illness

This is an umbrella term covering a broad range of forms and degrees of mental trouble and suffering, from mental problems such as depression to psychosis (National Board of Health and Welfare 1997:8, 2005b).

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### INTRODUCTION

Mental illness is one of Sweden's major public-health problems (Government Bill 2002/03:35). It is estimated that 20–40% of the population are suffering from some form of mental illness, ranging from minor problems such as sleeping problems, anxiety, worries and anguish to major problems like psychosis and major depression (National Board of Health and Welfare 2001). Ten to fifteen percent of these people require psychiatric care. It is a well-know fact that the proportion of the population suffering from mental illness is expected to increase, as well as the number of people seeking care, both in Sweden (National Board of Health and Welfare 2005b) and in other Western countries. Being afflicted with mental illness is a deeply stressful experience often accompanied by feelings of shame and guilt and affecting the daily life not only of the individual (Crawford & Brown 2002, Vuokila-Oikkonen *et al.* 2002) but also of his or her next of kin (Östman 2004, Östman & Kjellin 2002, Tsang *et al.* 2003).

Nowadays patients have broad knowledge and great expectations with regard to what care is available (Campbell 1997, Shelton 2000), including effectiveness, quality of service and treatments (Campbell 1997), and they are more aware of their problems and diagnosis (Barker et al. 1996, Fourie et al. 2005, Noble et al. 2001). Good quality of care is considered to be the right of all patients, and the responsibility of all staff (Swedish Code of Statutes [hereinafter referred to as SCS<sub>1</sub> 1982:763), and systematic measurement and evaluation is a prerequisite for the delivery of high-quality care (Grol 1996). Defining, measuring and evaluating the quality of psychiatric care have received great attention both in Sweden and worldwide. But little attention has been given to describing the concept of quality of care from different perspectives, or to developing an instrument for measuring the quality of in-patient psychiatric care. In addition, the psychiatric patient's perspective has been under-represented in evaluations of the quality of care. Only a few studies have used a design directly addressing the patient perspective when identifying essential aspects to include when measuring quality of care or satisfaction (Björkman et al. 1995, Gigantesco et al. 2002, Hansson et al. 1993, Woodring et al. 2004). Therefore additional evaluative research is needed in order to ascertain whether the outcome of the care, from the patient perspective, is good or bad (IsHak et al. 2002) and to ensure that it is of the highest quality (Elzinga & Barlow 1991, Grol 1996, IsHak et al. 2002). This is especially the case in psychiatric care, which has during the last 20 years undergone extensive change, from being institutionalised to being more community-based, with more open forms of care. This has led to there being only a limited number of beds in acute in-patient facilities for acutely mentally ill patients which has shortened these patients' length of stay (Silfverheilm & Kamis-Gould 2000). Therefore research on quality of care and quality improvement is important in this area. Such research can lead to improvement of the quality of care in terms of professional practice, patient satisfaction and institutional performance (Grol 1996). In addition, a satisfied and well-informed patient finds it easier to follow medical instructions, reducing the need for medical visits (Nathorst-Böös *et al.* 2001).

My interest in this area of research derives from my having held posts in psychiatric care, where one of my tasks was to work on questions concerning quality. I found that there was no specific uniform definition of quality of care from the patient's perspective in a psychiatric context. Furthermore, an examination of the literature revealed that patients' own evaluation of psychiatric care had received little attention either in Sweden or elsewhere. Nor has there been much interest in how patients, next of kin or care staff perceive the concept quality of care in the psychiatric context. In addition, little attention has been devoted to developing an instrument for measuring the quality of in-patient care based on the patient's perspective. This perspective, however, should be taken into consideration in the development of an instrument for measuring quality of care, and patients should be involved in this development from the very beginning (Sixma et al. 1998, Wilde et al. 1993). It is important that patients, next of kin and care professionals should be included in the process of developing the concept of quality of care, as well as in the development of instruments for measuring such quality (National Board of Health and Welfare 1997:4). Therefore this thesis focuses on quality of care from patients', next of kin's, staff's and care associates' perspective in the context of Swedish general adult psychiatric care.

### BACKGROUND

#### Mental illness and health

Mental illness is multifactorial in its origins: it can be of genetic nature, it can result from illness or injury, or it can have a psychosocial background. Often it arises from a combination of biological and psychological factors in conjunction with certain external events (Cullberg 1991). It produces a lower level of mental well-being and functional capacity, producing in turn a lower level of quality of life together with social consequences both for the afflicted person and for his or her next of kin. It is also associated with feelings of shame and guilt, which also affect next of kin and staff (Vuokila-Oikkonen *et al.* 2002). Shame and guilt can prevent the person from seeking help (Wiklander *et al.* 2003) and are a problem for the person's recovery, quality of life and social integration (Vuokila-Oikkonen *et al.* 2002). Shame has been described in earlier studies as deriving from a sense of being abnormal because of the disease (Ahlström & Sjödén 1996, Goffman 1990). The terms shame and guilt are often used interchangeably (Tagney & Dearing 2002), but guilt is concerned with *what* one has done, whereas shame is concerned with *whom* one is (Tomkins 1987).

Finding oneself in a meaningful context, having a social network and a job or other occupation, can be psychosocial protective factors that reinforce self-esteem and the sense of identity, counteracting mental illness (Cullberg 1991). It is evident that a lack of social support and social network has a negative effect on physical health and is associated with a number of diseases (Cassel 1976). WHO (2001) has identified social networks and social support as promoting health. Social support can be described in terms of health and caring (Stewart 1993). The relation between social integration, social network and mental health has been described in several studies (Simmons 1994, Skärsäter *et al.* 1999).

Health can be subjective, objective or both (Ahlfors *et al.* 2001). In theories of nursing health is one of the four metaparadigms, the others being person, environment and nursing (Meleis 2005). From a philosophical point of view, two main perspectives on health are generally recognized, the bio-statistical and the holistic. In the bio-statistical view the biological body is in focus and health is considered as a state of normal physical functioning and absence of disease (Boorse 1977). WHO (1999) has defined health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. From this perspective, a person who has a mental illness cannot be in good health. In addition, from a

holistic perspective the individual is seen as a whole and understood as a person who has intentions and life-goals, which gives a broadened view of the nature of mental illness. The holistic perspective on health is partly in agreement with Nightingale's definition of health (1859), which focuses on the ability and strength of each individual to cope with everyday life, and partly in agreement with Nordenfelt (2000), who states that health is the balance between ability and goals in the maintenance of one's everyday life.

Mental illness is expected to increase, as well as number of people seeking care (National Board of Health and Welfare 2005b). Mental health should be a goal of psychiatric care but has not been afforded much attention (Cullberg 1991). When it comes to the study of the patient's perception of the quality of the care, important aspects, from a holistic perspective, are how the patient perceives his or her mental health and how it can be promoted in the care context.

# Psychiatric care in Sweden

In Sweden psychiatric care is governed by laws (SCS 1980:100, SCS 1985:562, SCS 1982:763, SCS 1991:1128, SCS 1991:1129), policies and regulations. Community mental health care is provided by two systems: treatment (and forensic service) is provided by the county councils' mental health providers, and generic service by the municipalities' social welfare system. Patients are free to contact the psychiatric care units without a referral from primary care (Silfverhielm & Kamis-Gould 2000). The distinguishing feature of the psychiatric care is the central role afforded the patient-staff relation. A further feature which distinguishes psychiatric from other care is the element of compulsion. By law (the Act on Compulsory Institutional Psychiatric Care and the Act on Forensic Care) psychiatric care can be forced on particular patients (SCS 1991:1128, SCS 1991:1129). Moreover, many psychiatric acute wards are locked and secured units. The patients are isolated from the external world and the external world is protected from the patients (Teising 2000). However, the overall purpose of psychiatric care is to promote healing, as well as coping in daily life, through support and understanding (Koivisto *et al.* 2004).

The changes which have occurred in psychiatric care during the last ten years point to the importance of increased collaboration between staff and care associates with regard to the particular patient, which in turn means that it is more important than ever that there should be a shared view of quality of care. Furthermore, there must be a continuing discussion of how to

improve this quality. Finally, improvement of the quality of care requires the systematic development of an instrument from a patient perspective, and the instrument should be simple to administer and not time-consuming for patients and professionals (Busch 2002).

### Quality of care

Regulation of quality of care and quality registers

A number of laws and regulations in Sweden indicate the importance of quality development. The Health and Medical Service Act (SCS 1982:763) states in § 28 that the health service shall be so organized as to ensure a high degree of patient security, care of good quality and cost-efficiency. In § 2 it is laid down that the care shall be of good quality and that the health service shall be systematically and continuously developed, with the ensuing enhancement of its quality. Furthermore, the Act states that care and treatment should be given in co-operation with patients as soon as possible. The care should be given with respect for the patient's self-determination and integrity and should promote contact between the patient and staff.

In recent years there has been increasing interest in the evaluation of quality of care, as also in quality assurance, and various measures have been taken at both the national (National Board of Health and Welfare Code of Statutes [hereinafter referred to as NBHWCS] 2005:12) and the international (World Health Organization's [WHO] 1988, 1991) level. Within the framework of one of the 38 goals adopted by the World Health Organization's committee for Europe, there is an emphasis on improving the quality of health care and medical treatment (WHO 1991). The regulations within what is known as the Quality System in Health and Medical Care, deriving from the National Board of Health and Welfare (NBHWCS 2005:12), are designed to ensure that the officially established standards of care are met and that patients' rights are safeguarded. The regulations state that the health service should have quality systems for planning, performing, evaluating and improving the care given, and that all staff should be involved in this work. It is the responsibility of management to initiate, facilitate and follow up quality improvement efforts (NBHWCS 2005:12). It is also the responsibility of management to ensure that staff has the required attitude and motivation regarding use of quality measurement instrument. An earlier study has shown that 67% (n=158) of the staff were disinclined to use the instrument despite knowing that the goal was to improve the quality of the psychiatric care (Walter et al. 1998). Quality of care can also been controlled by formal systems such as education, legislation, certification and qualification regulations (Erlingsdóttir 1996).

Several Swedish county councils have established quality committees to help hospitals to continue quality improvement and develop quality assurance efforts (Lindström 2002). Within psychiatric care quality registers has quite recently been developed. The purpose of such registers is to increase the quality of psychiatric care and it takes into account not only the medical treatment received but also the patient's and next of kin's opinion of the care given (<a href="http://www.kpvcentrum.se">http://www.kpvcentrum.se</a>). Within somatic care, quality registers have been in existence since the 90s, established on the initiative of the medical profession for the purpose of comparing different instances of care and treatment (Lindström 2002).

# Concept and definitions of quality and quality of care

Quality is basically a neutral concept derived from the Latin word *qualitas* (Bonniers 2006), but in everyday speech it indicates something positive and desirable (Wilde 1994). In the regulation on quality of care and patient safety, Sweden's National Board of Health and Welfare (NBHWCS 2005:12) has defined quality as "the degree to which an activity fulfils the requirements laid down" (my translation, here as elsewhere) (NBHWCS 2005:12, p. 3). Patient security here is laid down as a basic requirement regarding good care. Furthermore, it is emphasized that good quality in health care entails the provision of safe, knowledgebased, purposeful, patient-focused, efficient and equal care within a reasonable time frame (NBHWCS 2005:12). Van Maanen (1984) describes quality as the difference between the desirable quality level and the real one.

Quality of care is a complex and multidimensional concept (Andersson 1995, Donabedian 1996, Hansson 1989, Wilde *et al.* 1993). Many researchers have attempted to define it (Brook *et al.* 2000) and to find out what constitutes the core of it (Campbell *et al.* 2000). Donabedian, who is perhaps the foremost researcher in quality of care, maintains that the essence of such quality is constituted by the balance between benefit and harm (Donabedian 1979). Donabedian (1980) made a synthesis of earlier attempts to define quality of care where the patient's wishes concern three closely interrelated factors: technical care, interpersonal relationship and amenities in the care environment. Many researchers have set forth definitions containing one or more of Donabedian's factors. Campbell *et al.* (2000) define quality of care in terms of "the ability to access effective care on an efficient and equitable basis for the optimisation of health benefit/well-being for the whole population" (p.1617) and of "whether individuals can access the health structures and processes of care which they need and whether the care received is effective" (p.1614). The definition is twofold because

Campbell *et al.* (2000) differentiate between use of the concept quality of care with reference to the population and use of it with reference to the individual. They regard the latter use as being the more meaningful. This is in line with Wilde (1994), who considers that wideranging definitions of quality tend to be vague and difficult to operationalize and concretize. For the concept of quality of care to be clear, a more specific definition is needed.

There is a great deal of variability and confusion when it comes to how quality of care is conceptualized and operationalized. The concept of quality of care has often been used interchangeably with that of patient satisfaction. In the assessment of quality of care the concept has been operationalized as patient satisfaction (van Campen *et al.* 1995), but there has been debate as to whether this is appropriate (Längle *et al.* 2003). Certain researchers consider satisfaction too dependent on what the patient expects of the care (Bond & Thomas 1992, Williams 1994, Williams & Wilkinson 1995). In contrast, Sixma *et al.* (1998) are of the opinion that patient satisfaction is a multidimensional concept based on the relationship between expectations and experiences. Some researchers, however, concentrate on patient (dis)satisfaction instead of expectations and experiences. Regarding psychiatric care Ruggeri & Dall'Agnola (1993, p. 512) have defined expectation as "the importance attributed to the various aspects in order to receive satisfactory care". Lebow (1983a) defines patient satisfaction as the extent to which services gratify the desires of patients regarding structure, process and outcome.

Donabedian (1966) has described a three-dimensional model for measuring quality of care where he defines the concepts of structure, process and outcome. Structure refers to equipment and human resources and organizational structure. Process comprises what is done in giving and receiving the care and includes staff as well as patient activities, i.e. treatment, care and rehabilitation, diagnostic procedures. By outcome is meant the effect of care on the health status of patients and populations. Gaebel (1997, p. 79) maintains that "quality of care defined by the degree of adherence to standards and guidelines can be measured in terms of structure, process and outcome" in both in- and out-patient psychiatric care.

Specific definitions of quality in psychiatric care have been offered. Zastowny *et al.* (1995 p. 51) define it as "the degree to which health care services meet the needs, expectations, and standards of care of the patients, their families, and other beneficiaries of care". Ahlfors *et al.* (2001) consider that the central factors with regard to the quality of care are the patient's view

of the care provided, the treatment outcome, the staff's attitude, the environment of the ward and the mental health service.

To sum up, there seems to be a need to further clarify the concept of quality of care: what aspect of quality, quality for whom, and defined by whom (Vouri 1989). Definitions of quality of care in each country may be based on cultural values and national traditions (Kunze & Priebe 1998). Ljungren (1998) and Vouri (1989) point out that quality of care can, besides patient satisfaction, also include the perspectives of staff and next of kin.

# The patients' perspective on quality of care in the psychiatric setting

There has not been much investigation of patients' conceptions of, and assessment of, the content and quality of psychiatric care (Gigantesco *et al.* 2002, Thapinta *et al.* 2004, Woodring *et al.* 2004). Doubts have been expressed about the value of putting the relevant questions to, for example, mentally ill patients with a disturbed conception of reality or ones committed (Johansson & Lundman 2002, Thapinta *et al.* 2004). However, patients in psychiatric care *have* been asked (Meehan *et al.* 2002). Recently, the patient's view of quality of care has attracted more interest (Woodring *et al.* 2004). Only the patients themselves can describe their conceptions of quality of care regarding e.g., treatment, the staff and the accessibility of care. Such information can be used in the improvement of the care (Gigantesco *et al.* 2002, Woodring *et al.* 2004)

In spite of this, little is known about how patients perceive the quality of care in the psychiatric setting and how they evaluate the process and outcome of in-patient psychiatric care (Gjerden 1997). Only a limited number of studies have involved patients' opinions on quality of care or satisfaction with care (Björkman *et al.* 1995, Hansson 1989, Hansson *et al.* 1993, Meehan *et al.* 2002). Earlier studies in psychiatric care have not focused on the concept of quality of care but on what is important in care (Björkman *et al.* 1995, Hansson *et al.* 1993), on what is the ideal treatment (Hansson *et al.* 1993) and service (Elbeck & Fecteau 1990, Meehan *et al.* 2002) and on satisfaction with it (Ruggeri & Dall'Agnola 1993).

Previous research on the patient's perspective on quality of care or patient satisfaction has shown that the most important aspects appear to be the relationship between staff and patient (Cleary & Edwards 1999, Längle *et al.* 2003, Richmond & Roberson 1996) and respect for the patient's rights and privileges (Längle *et al.* 2003). Hansson *et al.* (1993) found that the

ideal treatment in in-patient care depended on six factors: staff-patient relationship, treatment content, patient co-influence, activities, ward atmosphere and staff competence. Björkman *et al.* (1995) found that the ideal treatment in out-patient care depended on eight factors: staff-patient relationship, continuity of care, the staff's professionalism, accessibility of care, treatment content, patient information/co-influence, treatment environment and cost of care.

In sum, no study to the author's knowledge has been published about patients' conceptions of the concept of quality of care in psychiatric care. It must surely be important, though, to acquire knowledge concerning such conceptions. Therefore there is a need for more research where patients in psychiatric care are involved. Patients' descriptions of what constitutes quality of care are important information for staff and the organization when it comes to the improvement of the quality of care and the development of interventions. In addition, the patients' conceptions of quality of care can be compared with those of the professionals and the next of kin, giving rise to an overall picture of quality of care in the psychiatric setting.

# Measuring quality of care in the psychiatric setting

Nowadays, an increasing number of hospitals are taking seriously the incorporation of patients' opinions of quality of care into evaluations of care (NBHWCS 2005:12, Sitzia & Wood 1998). The measurement of quality is an important part of psychiatric care as there is a need to show that the care fulfils the quality requirements (Shaw 1997). Setting quality standards is connected with what patients want and need (ibid.).

In the past 25 years, the field of the measurement of quality in the psychiatric setting has been developing (Gigantesco *et al.* 2003, Woodring *et al.* 2004). However, there are still few published instruments for evaluating quality of care in in-patient psychiatric care (Gigantesco *et al.* 2003, Woodring *et al.* 2004). Little attention has been given to involving the patients in the development of such instruments (Gigantesco *et al.* 2003, Hansson *et al.* 1993, Woodring *et al.* 2004). Few studies have used a design directly addressing the patient's point of view regarding what it might be important to include when measuring quality of care (Elbeck & Fecteau 1990, Gigantesco *et al.* 2003, Woodring 2004). Traditionally, instruments have been based on the professionals' views (Gigantesco *et al.* 2003, Hansson *et al.* 1993, Woodring *et al.* 2004). Today, many researchers are of the opinion that studies regarding quality of care which do not take account of the patient's perspective are without validity in that it is difficult to know whether the aspects they are measuring are relevant or important to patients in

psychiatric care (Ruggeri 1994, Thapinta *et al.* 2004). Donabedian (1980) is of the opinion that there are broad similarities between the views of patients and staff, whilst other researchers have shown discrepancies between patients' and staff's assessment of factors of importance for quality of care (Brooker & Dinshaw 1998, von Essen & Sjödén 1993).

There is no existing gold standard for measuring quality of care in the psychiatric setting and consequently one of the major problems in this area of research is the lack of uniform methods and instruments. This means that it is difficult to compare one set of results with another (Hansson 1989, Hansson & Höglund 1995, Ruggeri 1994). Certain instruments measure patients' opinions of quality of care, others patients' satisfaction with care; certain instruments measure ideal treatment characteristics, others measure attributes of service. Several of the instruments used have been of an ad hoc nature and psychometric properties have seldom been reported (Ruggeri 1994).

A survey of the literature reveals the following instruments — used for in-patient psychiatric care — in whose development patients have been involved:

- 1) Elbeck & Fecteau (1990) used a focus group method to generate attributes of ideal service from the patient's viewpoint. The instrument has 50 patient-generated items with use of a 7-point scale ranging from 1 (critical) to 7 (irrelevant). It has not been psychometrically tested and most of the participants in the focus group were limited to a schizophrenia diagnosis.
- 2) Hansson *et al.* (1993) interviewed in-patients concerning their views on the characteristics of ideal treatment, and from this a questionnaire was developed. The questionnaire have 48 items, with a 5-step fixed response scale of Likert type. The questionnaire is limited in that it measures treatment characteristics, which is to say just one aspect of quality of care. In this case, too, the questionnaire has not been psychometrically tested.
- 3) Meehan *et al.* (2002) used a focus group method to generate attributes of service from the patient's viewpoint. The instrument Inpatient Evaluation of Service Questionnaire (IESQ) has 29 items with the ratings "poor", "fair", "good", "very good" and "excellent". It has been psychometrically tested (Meehan *et al.* 2002). It measures patient satisfaction with services, which can be seen as one aspect of quality of care.

These instruments described above were developed by means of respondent methods with a clear patient perspective (Elbeck & Fecteau 1990, Hansson *et al.* 1993, Meehan *et al.* 2002). However, one of these has been psychometrically tested (Meehan *et al.* 2002). There is little in the literature when it comes to specific instruments developed from empirical studies of patients' perceptions of quality of care in the psychiatric setting.

In addition, none of the instruments described above measures patients' expectations regarding care and their subsequent experiences of it. Of particular importance when measuring quality of care, however, is the discrepancy between these expectations and experiences, which can be presented as the disconfirmation model (Crow *et al.* 2002, Noble *et al.* 2001). "Patients' expectations may be either confirmed (if patients' perceived services is delivered as expected) or negatively/positively disconfirmed (i.e. if perceived service is delivered worse/better than expected)" (Crow *et al.* 2002, p. 33). Development and testing of alternative approaches that measure perceived differences between expectations and experiences are required (Crow *et al.* 2002). Both expectation and experience are important concepts when it comes to measuring quality (Crow *et al.* 2002, Loan *et al.* 2003, Sixma *et al.* 1998). In addition, Donabedian (1966, 1980) is of the opinion that quality of care involves two components, a normative one (what things ought to be like) and an empirical one (what things are like), the two being of equal importance when one seeks to measure quality.

Since measuring quality of care in the psychiatric setting could be based on the disconfirmation model, there is a need to collect information about patients' expectations and experiences. This can be done using separate questionnaires for expectations and experiences (Crow *et al.* 2002). However, there is still need of an instrument for measuring patients' expectations and experiences in the specific case of in-patient psychiatric care and based on theory deriving from empirical studies concerning what patients understand by quality of care. Such an instrument could be used on wards for the routine assessment of quality of care.

### Development of an instrument

It has been recommended that the development of an instrument should be preceded by conceptual analysis, conceptual synthesis or the derivation of concepts (Mishel 1998). The operationalization of a concept usually occurs in three steps: (1) formulation of a theoretical definition, (2) specification of variables on the basis of this definition, and (3) development of

an instrument with measurable variables (Mishel 1998). The variables obtain some degree of quantification in most cases, at least on an ordinal scale (Donabedian 1988).

A new instrument needs to be psychometrically tested. By the psychometric characteristics of an instrument are meant its reliability and validity, including sensitivity and specificity. Both reliability and validity involve many different aspects and assessment approaches. Reliability is a question of the instrument's producing stable, consistent and replicable results if used correctly and under the same conditions. Validity is a question of the instrument's measuring what it is designed to measure and of there being no systematic measurement error. A good instrument will have a theoretical foundation, contain sub-scales and show a high degree of reliability and validity (Streiner & Norman 2003). It needs also to be simple to administer and fill in.

These characteristics of a good instrument may be more easily achieved in psychiatric care if the instrument includes relevant and important aspects of quality of care from the patient's perspective.

# The next of kin's perspective on quality of care in the psychiatric setting

There has been little investigation of the next of kin's conceptions of, and assessment of, the content and quality of psychiatric care (Gigantesco et al. 2002, Ruggeri 1994, Wallace et al. 1999). The next of kin are not only the providers but also the collateral recipients of care, for instance when being involved in the formulation of a treatment plan for the patient, and are often close to the patient in the course of the illness and in the care. Unfortunately, next of kin have seldom been seen as a customer group. Instead they have been a neglected group in most cases, without involvement in the treatment and care of the patient (Jubb & Shanley 2002, Kaas et al. 2003). Further, research carried out in the 1950s identified next of kin as being responsible for the patient's mental illness (Guarnaccia & Parra 1996), and in the 1970s they were described as having a negative influence on the patient's mental health (Vaughn & Leff 1976, Miklowitz et al. 1988). Nonetheless, nowadays they are regarded as needing to be seen as partners in the psychiatric care and as making for improved quality of care in that they have important information about the patient (Leavey et al. 1997). Furthermore, in many cases the patient-family interaction has proved to have a positive influence on the progress of the patient's recovery from illness (Goldman 1982, Kaas et al. 2003), and family involvement in health care and decision-making may be effective in reducing the patient's illness (Lam 1991, Lefley 1996). Perreault *et al.* (1999) found that many patients wanted their next of kin to be in contact with, and receive support from, the staff during the hospitalization period. However, some patients did not even want to have any contact with their next of kin (and also the other way round) (Perreault *et al.* 1999). The next of kin can refuse to be involved, and one explanation of this given in earlier studies is the next of kin's experience of heavy burden, sorrow, shame and guilt (Bibou-Nakou *et al.* 1997, Östman & Kjellin 2002). Other barriers to participation such as conflicts and lack of information from the staff have been reported (Rose *et al.* 2004).

In spite of the growing interest in measurements designed to improve the quality of care or satisfaction with care in the psychiatric setting (Gigantesco *et al.* 2002, Ruggeri 1994), little is known about how next of kin perceive the concept quality of psychiatric care. There are few published studies examining how the next of kin of psychiatric patients perceive the quality of the care (Gigantesco *et al.* 2002, Leavey *et al.* 1997, Ruggeri 1994, Wallace *et al.* 1999). Previous studies have focused of next of kin's satisfaction with the care (Gigantesco *et al.* 2002, Leavey *et al.* 1997, Ruggeri 1994), their expectations (Ruggeri 1994) and how they perceived the outcome of the care received (Wallace *et al.* 1999).

To sum up: from previous research there has emerged no clear pattern in respect of how the next of kin perceived the concept quality of care in the psychiatric setting. It appears important to acquire further knowledge in this area, as next of kin are usually regarded as resources nowadays, and as having important information to offer regarding the care. Such information can lead to improvement of the care such as to benefit both patients and next of kin. In addition, the next of kin's conceptions of the quality of care can together with the patients' and professionals' conceptions generate an overall picture of the concept of quality of care in psychiatric care.

### The professionals' perspective on quality of care in the psychiatric setting

Little attention has been given to the investigation of professional's conceptions of, and assessment of, the content and quality of psychiatric care (De Marco *et al.* 2004, Valenstein *et al.* 2004). It has been shown, however, that the different professions involved have dissimilar views on what characterizes quality of care (Campbell *et al.* 2000, De Marco *et al.* 2004, Donabedian 1969). In spite of this discrepancy, they are expected to co-operate in order to give the patient a good quality of care and service. They shall also be able to fulfil the

requirements regarding quality assurance and evaluation in accordance with the law (SCS 1982:763) and regulations (NBHWCS 2005:12). Andersson (1995) states that is therefore necessary to map out the meanings attributed to the concept of quality of care by different professionals and thereafter to reach a consensus. Donabedian (1980) is of the same opinion, and says further that the meaning given to quality of care within the particular context must be specified before such quality can be evaluated.

Thus little is know about professionals' conceptions of quality of care (De Marco *et al.* 2004) or their views on quality assurance (Valenstein *et al.* 2004), few studies having been concerned with these matters. Previous studies have focused on comparing psychiatrists and other physicians in respect of delivering a high quality of care (Edlund *et al.* 2005), on comparing psychiatric team members' perceptions of quality of care with discharged clients' perceptions (DeMarco *et al.* 2004), on obstacles to quality of care (Mason *et al.* 2002), and on the measurement of professionals' satisfaction with community-based psychiatric services (Ruggeri & Dall'Agnola 1993). There are also data concerning what professionals state as being quality as indicated in legislation, regulations, quality registers (NBHWCS 2005:12, SCS 1982:763).

To sum up: Similarly to the research on the perspective of next of kin, no clear pattern with regard to how professionals perceived the concept quality of care has emerged. Nor has any study been found concerning how patient and next of kin perceived the concept quality of care. There would thus appear to be a clear need for more research in this area with the goal of elucidating how care staff and care associates on the one hand, patient and next of kin on the other, perceive the concept quality of care in the psychiatric setting, this in order to obtain an overall picture of what such quality is taken to imply.

# Problem areas

As has been discussed and elaborated above, there seems to be a need for research regarding the concept itself and the development of instruments in the area of quality of care. Donabedian (1988) emphasizes that by establishing what is good quality of care one is in fact establishing an ethical norm. For this reason it is desirable that those affected by this norm should have the opportunity of themselves affecting its meaning. The views of mentally ill patients have an important role to play in the identification of problem areas where improvement is called for. It is also imperative that the needs and views of the next of kin

should be taken into account, including the need for professional help and support. The reform of psychiatry in Sweden in 1995 meant that there must be an increased co-operation between psychiatric staff and care associates in order to reach high-quality care and service. The National Board of Health and Welfare (NBHWCS 2005:12) has emphasized the need for the development of care and the improvement of its quality. The work of development and improvement calls for both professional knowledge and knowledge concerning factors relevant to improvement, such as the patient's and next of kin's perspective. It seems of high priority to clarify the concept quality of care from different perspectives and to develop a measuring instrument for in-patient psychiatric care from the patient's perspective.

# AIMS OF THE THESIS

The overall aim of this thesis was to describe quality of care from different perspectives in the psychiatric setting, to develop an instrument for measuring quality of care from the in-patient perspective and to use this instrument empirically. This overall aim was expressed in four specific aims:

- To describe how patients perceived the concept of quality of care in psychiatric care (I).
- To develop an instrument to measure quality of care in the psychiatric setting from an inpatient perspective and to describe quality of care by means of this instrument. A further aim was to investigate the influence of background variables and expectations on the experience of care (II).
- To describe how next of kin perceived the concept of quality of care in the case of psychiatric care (III).
- To describe how the psychiatric care staff and care associates perceived the concept of quality of care in the case of psychiatric care (IV).

### **METHODS**

# Study design and analysis approaches

This thesis has a descriptive and comparative design and involves the empirical testing of a new instrument, Quality in Psychiatric Care (QPC), for measuring quality of care from the patient's perspective. The studies included have as their point of departure the individual's conception of quality of care, which have been investigated using both inductive and deductive approaches. Three studies were based on qualitative data (I, III, IV) and used a phenomenographic approach. One study (II) has a quantitative approach. In order to elucidate and describe different aspects of quality of care, qualitative and quantitative methods of data collection and analysis have thus been combined in this thesis. "The qualitative and quantitative research complement each other because they generate different kinds of knowledge that are useful in nursing practice" (Burns & Grove 2001, p.27). The idiographic sciences, which focus on understanding the underlying meaning of individual, unique experiences (Nilstun 1995), have inspired the inductive approach, since the qualitative studies in this thesis are directed towards acquiring a description and understanding of care staff's and care associates', patients' and next of kin's conceptions of quality of care. The nomothetic sciences, which focus on comparison of and differences between data (Nilstun 1995), have inspired the deductive approach, since the aim here is to acquire knowledge about the differences in patients' ratings of the quality of care in terms of expectations and experiences and to attain generalization of this knowledge. The design and methods are presented in Table 1.

The studies presented in this thesis involve 168 participants from the central part of Sweden. In studies I, III and IV the participants (n=52) were from one county. In study II the participants (n=116) were from general adult psychiatric care hospitals in two counties. The total population of the two counties together is about 550.000, and the two together have 110 in-patient beds.

Table 1. Overview of the papers

Study	Design	Participants	Data collection	Methods of analysis
I	Descriptive	20 patients	Qualitative interviews	Phenomenographic analysis
II	Descriptive Comparativ	116 patients	Questionnaires - QPC-1 - QPC-2	Statistical analysis - Descriptive - Cronbach's alpha - Kruskal- Wallis test - Mann-Whitney U test - Wilcoxon Signed Ranks test - Chi-square test
III	Descriptive	12 next of kin	Qualitative interviews	Phenomenographic analysis
IV	Descriptive	10 care staff 10 associates	Qualitative interviews	Phenomenographic analysis

### The qualitative studies (I, III and IV)

Selection of participants (I, III and IV)

Study I. A strategic sampling of patients was used, and the participants differed with regard to background characteristics such as sex, age, education, diagnosis, experiences of care (in- and outpatient care and voluntary/in-voluntary care), and period of care. The participants were recruited from a general psychiatric clinic with in- and out- patient care, being responsible for patients with more serious types of mental problem. The criteria for inclusion were: a psychiatric diagnosis, having been discharged after more than three days of in-patient care or having finished out-patient care, and being able to speak Swedish. The participants were chosen by the nurse in charge after instruction by the researcher. After oral and written information had been given, 22 individuals were asked whether they were willing to

participate, and two of them said no. Thus the total number of participants was 20 (14 inpatients and 6 out-patients). Characteristics of the participants are presented in Table 2.

Study III. Next of kin were purposefully designated by the patients in study II. The criterion for inclusion was: been in direct contact with the patient during in-patient or out-patient general psychiatric care. After written and oral information had been given, all twelve designated next of kin agreed to participate (6 parents, 4 spouses/cohabitants and 2 friends). The participants differed in background characteristics such as sex, age, education and relationship to the patient. Characteristic of the participants are presented in Table 2.

Study IV. Strategic sampling of psychiatric staff and care associates was used in line with the phenomenographic approach. In order to obtain the maximum amount of variation, participants were looked for who had different background characteristics such as sex, age, education, profession (psychiatrist, nurses, hospital orderlies, hospital senior orderlies, hospital social worker, psychologist, occupational therapist, physiotherapist, district nurses, rehabilitation investigators, welfare advisers) and years in the profession. The participants were recruited from a psychiatric in- and out-patient clinic, primary care, the social services, the municipal social-psychiatric services, an employment exchange and a social insurance office. The criteria for inclusion were: in the case of staff, permanent employment lasting at least 6 months; in the case of care associates, being currently concerned with a psychiatric patient. The participants were chosen by the supervisor at the person's work-place, this after instruction by the researcher. After written and oral information had been given, 21 people were asked whether they were willing to participate, and one of them said no. Thus the total number of participants was 20 (10 psychiatric staff and 10 care associates). Characteristics of the participants are presented in Table 2.

Table 2. Background characteristics of the staff and care associates, patients and next of kin

Variables	Patients (I)	Patients (II)	Next of kin (III)	Staff and care associates (IV)	
	n=20	n=116	n=12	n=20	
Sex					
Female	14	80	7	13	
Male	6	35	5	7	
Missing data		1			
Age					
Mean (range)	41,6 (24-58)	41 (18-81)	43,1 (24-75)	44,6 (35-62)	
Education					
Elementary school		7	3		
Nine-year school		27			
Vocational school		6			
Upper secondary school	9	45	3	7	
College/					
University	11	20	6	13	
Missing data		11			

# *Method description (I, III and IV)*

Phenomenography is a qualitative explorative approach, developed in the early 1970s by Marton and his research group at Göteborg University, Sweden. Phenomenograpy has its roots in cognitive-psychological theory and has been developed within the field of education as a means of studying learning (Fridlund & Hildingh 2000). It is similar to phenomenology in that both focus on human experience and awareness, but there are important differences too (Marton 1994, Sjöström & Dahlgren 2002). Phenomenography is substance-oriented and differs from phenomenology in that it is basically methodological and/or philosophical, when it focuses on the essence of experiences. Phenomenography seeks to characterize, understand, describe and conceptualize the variation of people's conceptions (Marton 1986, 1994) in the world around them (Marton 1981). The conceptions have their origins in individual interviews (Marton 1996) and the variation in the conceptions can depend on different cultural and social contexts (Svensson 1997). Even though the individual's conceptions of a phenomenon is what is central to phenomenography, the analysis generates a description of the phenomenon on a collective level in the form of distinct descriptive categories which capture variations within and among individuals (Marton 1981).

Phenomenography makes a distinction between what something is — the first-order perspective — and how something is conceived to be — the second-order perspective (Marton 1981). The first-order perspective is directed towards the phenomenon as such. The second-order perspective concerns how people describe their experience of something or how something appears to someone (Marton 1981, Marton & Booth 1997). Marton (1996) states that the words "conceptions" and "experiences" can be used synonymously in phenomenograpy.

The method most commonly used to collect data in a phenomenographic study is semi-structured interviews with use of an interview guide involving a few basic questions (Dahlgren & Fallsberg 1991, Sjöström & Dahlgren 2002). During the interview the informants should describe their view of the phenomena in such a way that the researcher can obtain a clear understanding of this view. The researcher should ask follow-up questions in order to obtain a more precise description of the phenomena (Sjöström & Dahlgren 2002). A phenomenographic approach never starts from predefined categories or models (Marton & Booth 1997). Instead the researcher describes data in the form of descriptive categories arising from the research. The descriptive categories are a condensation and abstraction of the interview text, keeping as close to the data as possible and bringing out the meaning of the phenomena (Marton 1981, 1986). Distinctive of phenomenography is that it allows of great variation in methodological application, whereby the procedure varies depending on what is being investigated (Starrin & Svensson 1994). The phenomenographic approach has been used with increasing frequency in health-care and nursing research during the last ten years (Fridlund & Hildingh 2000, Sjöström & Dahlgren 2002).

# Data collection (I, III and IV)

### Interviews

The same interview schedule was used in these three studies (I-III) and developed by two of the researchers (AS, GA), one of whom (AS) performed the semi-structured interviews in line with the phenomenographic approach (Sjöström & Dahlgren 2002). In the interviews the participants reflected on their conceptions of the phenomenon (quality of care) in order to understand the individual meaning of this experience (Entwistle 1997). Before the interview the researcher chatted to the subject in order to create a relaxed atmosphere. Thereafter the main question was asked "How do you perceive the concept of quality of care in the psychiatric care?" Follow-up questions were asked, their scope and number depending upon

how precisely and fully the person had answered the main question. The follow-up questions were e.g. "What do you mean?", "Can you explain?", "Can you tell me more?", "Is there anything more you want to say, anything I haven't asked you about?" The interviews were conducted in the form of conversations, tape-recorded and transcribed verbatim. They were conducted during the periods May - November 2002 (I), June - December 2002 (III) and August 2000 - March 2001 (IV). Thus the interview study concerning the staff and care associates (IV) was performed first, followed by the interview studies with the patients (I) and the next of kin (III). All the data collection was performed in each study before the analysis started.

The participants in studies IV and III chose the locations of the interviews, and for the most part it was a secluded place besides the interviewer's office. In the case of study IV the average effective duration of an interview was 75 minutes, in the case of study III the effective duration varied between 30–80 minutes. In study I, the interviews were conducted in the participants' homes or at a secluded place near the interviewer's office, and took 45–80 minutes.

Data analysis (I, III and IV)

### Phenomenographic analysis

The phenomenographic analysis was carried out in four phases as follows (Marton 1994, Marton *et al.* 1993):

- (1) The tape was listened to in order to make sure that the interviews were correctly transcribed. Thereafter the transcribed interviews were read several times in order to identify statements relevant to the aim of the study and to find an answer to the following question: "What are the different ways of perceiving the phenomenon (quality of care)" (Marton 1999) and to identified statements in accordance with the aim of the study. The next step was to identify and label statements in the different interviews and compare them with each other. The numbers of statements that emerged were 466 (I), 325 (III) and 480 (IV).
- (2) The labelled statements were compared with one other in order to identify similarities and differences between the ways the informants described the phenomenon (quality of care). From this preliminary comparison conceptions emerged, and they were named in such a way as to catch what the informants perceived as quality of care.

- (3) The conceptions were compared with one another. They were then grouped in order to obtain an overall picture of what links there might be between them. Thereafter preliminary descriptive categories emerged and were named.
- (4) In this last phase the focus shifted from the relationship between the conceptions to the relationship between the descriptive categories. The latter were scrutinized in order to ascertain whether they were in agreement with the conceptions and to ascertain the attributes of each category as well as what distinguished them from one other. Through interaction between the whole and the parts, five (studies I and III) and four (study IV) final descriptive categories emerged. All were empirically based on the interview data. Descriptive categories are the main result of a phenomenographic study (Marton 1981, 1986).

# The quantitative study (II)

Method description (II)

The procedure for development of the instrument contained four steps. The instrument was designed to measure expectations and experiences in respect of quality of care in the case of in-patient psychiatric care from the patient's point of view based on a previous study (I).

### Step 1. Development of a definition

The instrument was based on patients' conceptions of good or high quality of care. The development of the instrument started with the formulation, deriving from the results of Study I, of a definition of high quality of care from a patient perspective. Consequently the following five dimensions constitute high quality of care:

- 1. *The patient's dignity is respected* implies a good relationship between patient and staff. The patient is respected through being confirmed, understood, seen as no different from anyone else and assisted in the reduction of feelings of shame and guilt by competent staff.
- 2. The patient's sense of security with regard to care implies a high level of accessibility, continuity and trust vis-à-vis staff and the care organization.
- 3. *The patient's participation in the care* involves him or her receiving relevant information, close patient–staff collaboration and having the opportunities for self-determination.
- 4. *The patient's recovery* has to do with evidence-based medical treatment and conversational therapy, supportive guidance, opportunities for occupation and post-care follow-up.

5. *The patient's care environment* is a question of personal space, aesthetics, calm atmosphere and degree of security. These dimensions represent the conditions that must be fulfilled within psychiatric care in order that the patient shall see this care as being of high quality.

### Step 2. Development of the instrument

Thereafter the definition were operationalized to produce an instrument, "Quality in Psychiatric Care" (QPC), in two parts (QPC-1, QPC-2) for measuring the quality of care from the patient's perspective. QPC-1 measures patients' expectations regarding care and QPC-2 measures patients' experiences of care received. The 266 items initially in the instrument were derived from the 466 interview statements in the five dimensions. After discussion with two other researchers (GA and BWL) the number of items was reduced to 127. All the items started with "I expected that..." (QPC-1) or "I experienced that..." (QPC-2). The items were scored on a 4-point Likert scale with the endpoints 1 = Totally disagree and 4 = Totally agree. The instrument also included background questions about demographics and general clinical characteristics, and an open question at the end of each part inviting any other views on quality of care.

# Step 3. Pilot study

The preliminary version of QPC-1 was tested through face validity (Bowling 2005) by six people who had received psychiatric in- and out-patient care before. Certain of them also had experience of involuntary care. These six people were asked to fill in the questionnaires at home, in addition to a check-list about the comprehensibility of the items, the possible responses being "Clear and easy to understand", "Acceptable" and "Unclear and hard to understand". Each item's importance for quality of care was also rated in each dimension on a 5-point scale with the endpoints 1 (Very important) and 5 (Of little importance). Thereafter the participants were invited to take part in group discussions (one lasting 2½ hours and the other 3). In the case of one of the participants the discussion was carried out over the phone. The discussions followed an interview guide and the main questions were: (1) What's your general impression of the questionnaire? (2) What do you think of its structure? (3) How relevant and useful do you think the background questions and items are in relation to quality in psychiatric care? The two group discussions result in a reduction of the number of items from 127 to 69 and also a rewording of certain items.

## Step 4. Empirical test of QPC

# Selection of participants and procedure

The inclusions criteria were (1) able to answer QPC-1 within three days from admission to hospital, (2) cognitively able to answer the questionnaire in a valid way as appraised by the nurse or hospital orderly in charge at the time of admission, (3) able to understand and express oneself in Swedish, and (4) at least a three-day stay in the ward before discharge (only QPC-2). Of 564 patients from 8 general adult psychiatric wards from two counties with 110 beds, 431 fulfilled the inclusion criteria (Figure 1). A nurse or a hospital orderly in charge recruited the patients. All patients were informed both orally and by letter about the aim and design of the study, and about confidentiality. The patients who gave their verbal consent to participate estimated their expectations of quality of care by means of QPC-1 upon admission to hospital. On discharge, they estimated the quality of the care they had received by means of QPC-2. All patients who consented to participate returned the answered questionnaires in a sealed envelope, to a locked letter-box on the ward. A total of 116 patients (mean age 41 years) answered both parts of the instrument during the period May–December 2005. Characteristics of the participants are presented in Table 2.

# Data analysis (II)

### Statistics

Statistical analysis was performed using the software SPSS V 12.01 for Windows. All data were treated as non-parametric because the sample was small and the data were obliquely distributed. In addition to the descriptive statistics, internal consistency, i.e. the reliability of the five dimensions was tested by means of Cronbach's alpha (Nunally & Bernstein 1994, Streiner & Norman 2003). Non-parametric tests used were the Kruskal-Wallis test and the Mann-Whitney U test to analyse group differences in background characteristics. The Wilcoxon Signed Ranks Test was used when data were paired and to ascertain whether there was a statistically significant difference between expectations and experiences in respect of quality of care. To test if the data differed significantly from each other, a Chi-square test was used. In this thesis differences were considered significant at a p-value of < 0.01 (two-tailed). Uneven distribution emerged in the case of high scores in QPC-1 and QPC-2. Some analyses were therefore based on dichotomized answers in two categories: agreement or high score (3-4) and disagreement or low score (1-2). The scores on the Likert scale were interpreted as follows: 1 = Lowest quality (Totally disagree), 2 = Quite low quality (Partly disagree), 3 = Quite high quality (Partly agree) and 4 = Highest quality (Totally agree).

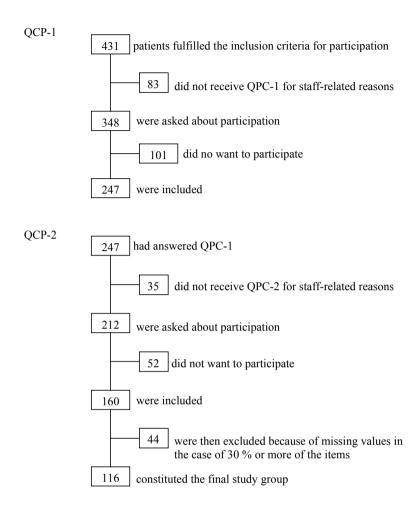


Figure 1. Overview of recruited patients in Study II.

#### **Ethical considerations**

The research for this thesis has been done in compliance with the common principles governing human clinical research, i.e. the principle of respect for autonomy, the principle of non-maleficience and the principle of beneficence (Beauchamp & Childress 2001, Northern Nurses' Federation 2003). Written and oral information was given to all potential participants concerning the voluntary nature of participation and concerning their right to withdraw at any time without needing to provide any explanation. Confidentiality was assured, which means that the data could not be linked to the individual. Informed consent was obtained from all participants prior to the studies, all of whom were legally competent to give their consent.

There was no dependent relationship between the participants and the researchers (I-IV). The qualitative interviews were tape-recorded, made unidentifiable and coded without name or birth registration number (I, III and IV), as in the case of the questionnaire (II). All data were locked in a safe. The studies have been approved by the research ethics committee of Örebro County Council, Sweden.

#### RESULTS

The most important results of each study are presented below. The detailed results are available in the papers (I-IV). The patient's perspective is presented first through the results of a qualitative and a quantitative study (I, II), while the perspectives of next of kin and staff are presented last (III, IV).

### Patient's perspectives on quality of care

Patient's conceptions of quality of care (I)

On the basis of the interviews with the patients, the following five descriptive categories of quality of care emerged: *Dignity, Security, Participation, Recovery* and *Environment*. Five conceptions of quality of care were unique to the patients. *Being understood* by staff was imperative, even though patients could find it difficult to express themselves. *Trust* was a question of patients' being able to talk to staff in confidence, without fear of disclosure. Personal chemistry was very important here, and the trusted staff member was an important person. There should be *continuity* in the care, such that the patient is able to meet the same staff on the ward, or as an out-patient, enabling the patient to feel a sense of security. Continuity also means that the communication among staff should be such that the patient does not have to repeat the account of his or her problems to a large number of people. The patient should be offered *conversational therapy and supportive guidance*. These enhance self-esteem, and the conversation gives the patient an opportunity to put feelings into words, which can speed up recovery. When it comes to *medical treatment* it is a question of quickly being taken care of, receiving a diagnosis and being offered different types of treatment (and being told about their possible side-effects) (Study I).

### The instrument Quality in Psychiatric Care (II)

An instrument, "Quality in Psychiatric Care" (QPC), was developed from patient perceptions of quality of care in Study I. QPC comprised two parts, one for measuring the expectations (QPC-1) and one for measuring the experiences (QPC-2). Both parts of the instrument consist of six dimensions: "The patient's dignity is respected" (20 items), "The patient's sense of security with regard to care" (9 items), "The patient's participation in the care" (13 items), "The patient's recovery" (16 items), "The patient's care environment" (11 items) and "Total dimension" (69 items). The answers were scored on a 4-point Likert scale. Furthermore, both parts of the instrument included background questions and an open question inviting the

participants to offer further views on quality of care. Cronbach's alpha indicated very high internal consistency: Total QPC-1 0.98 (QPC-2 0.98), Dignity 0.95 (0.95), Security 0.87 (0.85), Participation 0.93 (0.93), Recovery 0.94 (0.91) and Environment 0.87 (0.88). The instrument is for self-administration by in-patients and intended for routine assessments on the psychiatric wards.

### Assessment of quality of care

QPC was empirically tested on 8 general psychiatric wards in two counties (n=116, mean age 41 years). Sixty-nine per cent of the participants were female and 40% unmarried. Fifty-eight per cent did not know their diagnosis, while 22% stated that they suffered from depression. For 32% of the patients this was their first admission, and for 28% the length of hospital stay was less than a week. Eighty-five per cent were admitted to the ward voluntarily, 58% of the patients answered that they did not know whether there had been a change from voluntary to involuntary treatment, or vice versa, during the care episode. Sixty-six per cent agreed that the date of discharge was consistent with the stage of their illness and 37% stated that their psychiatric health at discharge was neither good nor bad.

The patients' ratings of what their expectations had been at the time of admission to hospital were generally high, whilst their ratings of their experiences, after discharge, were somewhat lower. The total dimension in OPC-1 had a Md of 4, that in QPC-2 a Md of 3, out of the maximum score of 4. Even if there were small differences in the ratings between the five dimensions the result indicate high ratings of quality of care with regard to the dimension Dignity mean 3,5 (SD±0,59) in QPC-1 and, in QPC-2, the dimension Security mean 3,3 (SD±0,61).

The lowest scores in the case of QPC-1 were for the items "All the staff have the same view of what was the best care and treatment for me" (Md 3, q1; 2 and q3; 4), "I'm not disturbed by the other patients" (Md 3, q1; 3 and q3; 4) and "Receive help in finding occupation before discharge" (Md 3, q1; 2 and q3; 4). The lowest scores in the case of QPC-2 were for the items "I got information about different treatment alternatives so that I could take up a definite position as to which treatment was best for me" (Md 2, q1; 1 and q3; 4) and "I received help in finding occupation before discharge" (Md 2, q1; 1 and q3; 4).

The results showed lower levels of experiences of quality of care as compared with expectations on quality of care and these differences were significant in all five dimensions. In order to highlight this discrepancy, table 3 contains dichotomized data on the proportion of patients who *disagreed* in their answers on individual items. Experienced quality of care was lower than expected in the case of 64 of 69 items (93%), *significantly* lower in the case of 30 of the 64 (Table 3). For example, 13% of the patients did not expect (rating disagreement) that "Treatment leads to getting better", while 47% did not experience (rating disagreement) "getting better". The difference was in this case 34% (p-value .000). In addition, the mean differences (%) between expectations and experiences in the respective dimensions were the following: Dignity 19%, Security 10%, Participation 27%, Recovery 30%, Environment 17%.

Sex, age, marital status, education, profession, diagnosis, knowledge of diagnosis, previous admissions, length of hospital stay, form of admittance (voluntary/involuntary), change of care (voluntary/involuntary and vice versa), patients that experienced the time of discharge being consistent with the stage of their illness and perceived psychiatric health at discharge were used in analyses in order to investigated if these background variables influence the patients ratings of quality of care in the different dimensions. The result show significant higher score of dimensions Participation (p=0.004) and Recovery (p=0.003) when they experienced their psychiatric health at discharge as very good. Patients who experienced that the time of discharge was consistent with the stage of their illness showed significantly higher score in Recovery (Study II).

Table 3. Differences (%) between patient's expectations and experiences with regard to disagreeing with item content.

Dimensions and items	Expectations %	Experiences %	Differences %	P-value
Dignity (10 of 20 items significant*)	Expectations 70	Experiences 70	Differences 70	1 -value
Sees my individual needs	17	31	14	.001
Shame and guilt must not get in	13	27		
the way	13	21	14	.002
Helps me understand	13	22	9	.005
Has time to listen	13	24	12	.005
Shows understanding	10	23	13	.003
Respects me	5	15	10	.002
Shows empathy	8	19	11	.005
Skilful professional	10	21	11	
Helps me handle my emotions	19	36	17	.005 .001
	8	20		
Takes me seriously	0	20	12	.007
Security (1 of 9 significant)				
Staff are accessible	9	21	12	.003
Start are accessione		21	12	.005
Participation (9 of 13 items)				
Knowledge about mental troubles	17	39	22	.000
Take part in the planning of my care	15	34	19	.000
Given information in a way that can	14	37	23	.000
be understood				
Staff collaborate with me	9	22	13	.000
Assessment of individual needs	9	36	27	.000
Recognize signs of deterioration	12	41	29	.000
Take part in decision-making about	16	35	19	.001
my care				
My view of the right care is	16	29	13	.009
respected				
Influence over my care	22	38	16	.004
Recovery (6 of 16 significant)				
Information about treatment	19	47	28	.000
alternatives				
Meaningful occupation during care	24	40	16	.007
period				
Discharged when I can cope	14	28	14	.006
Treatment leads to getting better	13	47	34	.000
Putting my feelings into words	11	37	26	.000
Get best possible treatment	14	29	15	.001
•				
T				
Environment (4 of 11 significant)	4.4	25		
There's a secluded place	14	27	13	.008
Restful environment	13	30	17	.000
Chance of own room	24	35	11	.003
Not disturbed by fellow-patients	18	36	18	.000

Note: Dichotomized data; disagreeing is a combination of the ratings "totally disagree" and "partly disagree". Difference between expectation and experience on individual items is considered statistically significant at a p-value of <0.01.

### Next of kin's perspectives on quality of care

Next of kin's conceptions of quality of care (III)

The next of kin describe quality of care from their own, as well as from a patient perspective, and both positive and negative conceptions emerge. The following five descriptive categories of quality of care were created on the basis of the interviews: *Dignity, Security, Participation, Recovery* and *Environment*.

Five conceptions of quality were unique to the next of kin. First, *getting support*: the patient and next of kin shall get support in the form of adequate resources and rehabilitation measures, so as to be able to cope with the vulnerability and the burden. Young children of a mentally ill person shall not be forgotten, as they also need support and guidance. Second, *getting help with the responsibility*: the next of kin shall receive such help when the patient is temporarily at home or has been discharged; the next of kin want to be in control of their situation and feel secure when the patient is at home. Third, *being protected*: the patient must be protected from being physically and emotionally injured due to lack of insight into the nature of his/her illness and the ward routines and the staff's behaviour shall be such as to give both patient and next of kin a sense of security. Fourth, *finding opportunities of giving information despite secrecy*: the staff shall find such opportunities in order to enable the next of kin to become more involved in the care through learning about the patient's condition. Fifth and last, *maintaining one's identity*: the patient shall receive support and encouragement from the staff in order to maintain his/her sense of identity during the entire illness period (Study III).

## Professional's perspectives on quality of care

Care staff's and care associates' conceptions of quality of care (IV)

The care staff and care associates describe quality of care chiefly from the patient's point of view but also both implicitly and explicitly from the point of view of their own professional role. The following four descriptive categories of quality of care were created from the interviews: *Dignity, Participation, Recovery* and *Environment*.

Three conceptions of quality were unique to the care staff and care associates, the first being *closeness in the case of compulsory measures*. This conception involves patients who cannot see that they are ill and have difficulty in coming to decisions of their own and they shall be offered a choice before compulsory measures are undertaken. In the case of compulsory

measures, the staff should be close to the patient and have full consideration for the patient's situation. The patient shall have *the best possible individual treatment* and be offered different possibilities of treatment. Staff may have different ideas as to what is good care and treatment, but there must finally be a consensus in respect of the particular patient. The staff refer to *the social network's importance* with regard to successful care and treatment, and this network shall be mapped out in consultation with the patient in in-patient or out-patient care (Study IV).

### Quality of care from all three perspectives combined

In summary, the results of the meaning of the concept quality of care from the three qualitative studies by patients (I), next of kin (III), care staff and care associates (IV) follow below. All study groups generally thought of quality of care in positive, normative terms, i.e. as *good* quality of care. However, next of kin also had experiences of quality of care in a negative way. The care staff and care associates perceived it as being important in respect of the patient's health and everyday life, whilst the patients themselves emphasized the importance of the patient–staff relationship. In the case of the next of kin good relations and communication with staff and patients emerged as the central factors regarding quality of care. The next of kin also wanted to co-operate together with both staff and patient and wanted to have information about mental illness. Aspects brought out by patients and next of kin which are not made explicit in earlier studies on quality of care were *Being helped to reduce the shame* and *Being looked upon as like anyone else*. The latter aspect was also brought out by the staff and care associates. The significance of the interpersonal relationship emerged as central in the results of all three studies (Table 4).

In a comparison, the three qualitative studies show mostly similarities but also differences in the conceptions of quality of care. There was one more descriptive category in the patient (I) and next of kin (III) studies, namely *Security*. There were 13 conceptions to be found only in one of the three studies. In Study I alone, there were *Being understood, Trust, Continuity, Conversational therapy and supportive guidance* and *Medical treatment*. In Study III alone, there were *Getting support, Getting help with responsibility, Being protected, Finding opportunities of giving information despite secrecy* and *Maintaining one's identity*. Finally, in Study IV alone, there were the conceptions *Closeness in the case of compulsory measures, The best possible individual treatment* and *The social network's importance*. An overview of

the conceptions contained in the five different descriptive categories from Studies I, III and IV is presented in Table 4.

Table 4. The participant's conceptions of quality of care

Descriptive categories	Patient's conceptions (I)	Next of kin's conceptions (III)	Staff and care associate's conceptions (IV)
Dignity	-Being confirmed -Being looked upon as like anyone else -Encountering competent and committed staff -Being helped to reduce the shame -Being understood*	-Being confirmed -Being looked upon as like anyone else -Encountering competent -Being helped to reduce the shame	-Being confirmed -Being looked upon as like anyone else -Closeness in the case of compulsory measures* -Easy to reach
Security	-Accessibility -Trust* -Continuity*	-Having access to psychiatric care -Getting support* -Getting help with responsibility* -Being protected*	
Participation	-Knowledge about their own health -Co-operation in the planning of care -Self-determination	-Getting knowledge -Co-operation -Finding opportunities of giving information despite secrecy*	-Knowledge about their own health -Co-operation in the planning of care -Self-determination -Meaningful occupation
Recovery	-Follow up after discharge -Meaningful occupation -Conversational therapy and supportive guidance* -Medical treatment*	-Being follow up after discharge -Having a meaningful occupation -Maintaining one's identity*	-Follow-up after discharge -The best possible individual treatment* -Encountering competent staff -The social network's importance*
Environment	-Calm atmosphere -Aesthetics -Personal space -Secure environment	-Being in a secure environment -Being in a pleasant environment	-Calm Atmosphere -Aesthetics -Personal space

<sup>\*</sup> Item unique to this particular perspective

The results of Studies I, III and IV show that five descriptive categories, and their accompanying conceptions, may be considered to constitute the core of quality of care in the psychiatric setting. Frequently similar conceptions emerged in all of the explored perspectives, including the patient, next of kin and staff. Figure 2 is an attempt to highlight similarities found among the categories, which also are recapitulated as follows: (1) Dignity, with the conceptions Accessibility, Being confirmed, Being looked upon as like anyone else and Encountering competent staff; (2) Security, with the conception Accessibility; (3) Participation, with the conceptions Co-operation, Getting knowledge and Meaningful occupation; (4) Recovery, with the conceptions Encountering competent staff, Follow-up after discharge and Meaningful occupation; and (5) Environment, with the concept Being in a pleasant atmosphere (Figure 2).

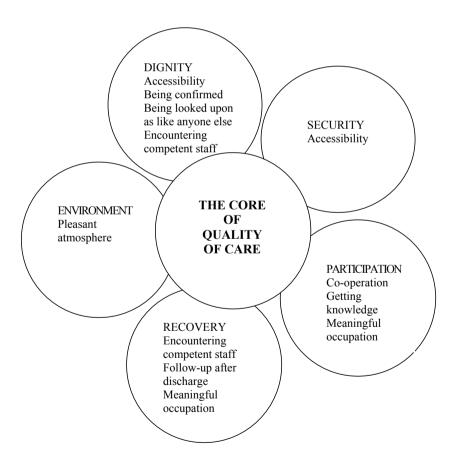


Figure 2. Illustration of the core of quality of care from, patient's, next of kin's and staff's perspective

## **DISCUSSION**

### Methodological discussion

The qualitative studies (I, III and IV)

In Studies I, III and IV a qualitative descriptive design involving a phenomenographic analysis was used. This type of analysis was considered to be that which best corresponded to the aim of the studies, which was to describe how patients, next of kin, care staff and care associates perceive the concept of quality of care in the psychiatric setting. The choice of this analysis was governed by the following goals. Firstly, to identify similarities and differences of the participants' conceptions (Marton 1981) of quality of care in the psychiatric care. Secondly, to catch a broad variation in the descriptions of quality of care (ibid.) in order to map out the concept quality of care from different perspective (Studies I, III and IV). Thirdly, to use the broad variation of description of quality of care from Study I in the development of an instrument for measuring quality of care in the in-patient psychiatric care from a patient perspective (Study II). The advantage of the research approach in this thesis is that it is based upon what patients, next of kin and staff think about, and understand by, the phenomenon under investigation (here, quality of care) (Fridlund & Hildingh 2000).

Validity and reliability in qualitative studies are usually described in terms of trustworthiness, and Polit & Hungler (1999) maintain that there are four scientific criteria by which to judge trustworthiness: credibility, dependability, confirmability and transferability. Credibility has to do with the plausibility of the data, data collection, data analysis and research design. In order to obtain variation among the participants a strategic sample was used in the data collection in Studies I and IV, which is in agreement with the phenomenographic approach (Marton 1981). One can only speculate as to whether the results of Study IV were influenced by the fact that the staff participants were chosen by their supervisors. Perhaps the supervisor made a point of choosing people who had a positive attitude and thereby perceived the quality of care as a positive concept. In Study III a purposeful sample was used in that the next of kin participants was chosen by the patients included in Study I. The interviews were conducted by the same researcher and started with an informal conversation to create a relaxed atmosphere and a trust between researcher and participant. The interview took place in a quiet room with no interruptions. All participants in the studies were given the same main questions and had the opportunity to freely describe their conceptions of quality of care. An independent coassessor, a nurse and teacher of nursing with experience of the phenomenographic approach, checked the credibility of Studies I and IV by assessing to what extent the descriptive categories were distinct. The use of a co-assessor is a means of ensuring the credibility of the analysis and the results, reducing bias attributable to the researcher's own pre-understanding (Kvale 1997). Additionally, in the case of Studies I, III and IV the researcher had in-depth discussions with one (I) or two (III, IV) co-researchers in the course of the analysis concerning conceptions, descriptive categories and quotations. All subject participation was preceded by informed consent.

Dependability has to do with the stability of data over time and correspond to reliability in quantitative studies (Polit & Hungler 1999). To guarantee dependability all patients were given the same main questions. The same interview guide was used in Studies I, III and IV. All interviews were conducted by an experienced psychiatric nurse (AS). This may have meant that the participants felt a sense of confidence, perhaps reflected in open and trustful answers. However, it cannot be excluded that the interviewer's background caused the participants to say what they thought the interviewer wanted to hear. An effort was made to avoid social desirabilly response set (Polit & Hungler 1999) by asking follow-up questions, prompting participants to be reflective and speak freely. In order to confirm that the interviews were correctly transcribed, the main author simultaneously listened to the tape and read the text several times. The researchers read the data and checked all steps of the analysis and had no dependent relationship to the participants that could influence the results.

Confirmability has to do with the repeatability of the data collection and analysis (Polit & Hungler 1999). For this reason the present thesis includes a careful description of both procedures. Data was organized by means of the software program Microsoft Word together with coloured pencils and post-it slips. Notes were made during the entire procedure of analysis. According to Marton (1981, 1999) variation in the data should appear during this procedure. In line with the phenomenograpic approach, patterns of similarity and of dissimilarity were identified in the information collected in the course of analysis (Marton 1994, Marton et al. 1993). In addition, in order to illuminate the findings, all conceptions were exemplified with quotations, which confirmed each concept.

*Transferability* has to do with the extent to which the results can be carried over to other groups or settings (Polit & Hungler 1999). The transferability of the results of Studies I, III and IV to other groups of care staff, care associates, patients and next of kin is uncertain as

the participants were Swedish, middle-aged and mostly had a degree in higher education. Furthermore, most of the patients in Study I were in-patients, most had been diagnosed as suffering from depression, and less than half had experience of compulsory care. In Study III the participants were the next of kin of patients in adult general psychiatric care and selected by the patients. In Study IV most of the participants were women. These limitations must be considered when interpreting the results. However, the interviews were comprehensive in their content

### *The quantitative study (II)*

The development of the instrument QPC followed the three steps recommended by Mishel's (1998, cf. p.12), (1) formulation of a definition of high quality of care from a patient perspective, (2) specific items were constructed and derived from the definition, (3) the instrument was developed with items on a measurable 4-point Likert scale.

With regard to the quantitative study, good psychometric properties are described in terms of validity and reliability (Polit & Beck 2004, Streiner & Norman 2003). QPC-1 was tested in a pilot study for face validity (Bowling 2005) in the following manner. A group of people with earlier experience of in- and out-patient psychiatric care judged the items in three ways. Firstly, they answered the questionnaire at home, to see if there were any problems concerning any of the items. Secondly, they filled in a check-list, also at home, about their understanding of the items, then judged the importance of each item on a rating scale. Thirdly, there were two group discussions where they answered questions from an interview guide about the structure and relevance of the instrument and their general impression of it. The reliability of QPC's six dimensions was tested with reference to homogeneity/internal consistency by investigating whether items in each dimension measured the same characteristic. Sixty-nine items seem to be superfluous in the light of the high internal consistency for QPC-I and QPC-2 (range 0.85-0.95). The optimum Cronbach's alpha coefficient is between 0.70 and 0.90. The value >0.90 is too high and not acceptable, as it indicates that there are similarities among items (Polit & Beck 2004, Streiner & Norman 2003). In addition, the medians of the total dimension for all 69 items in QPC-1 and QPC-2 were high (4 and 3, respectively). The high Cronbach's alpha and median values indicate a need for further development of the instrument. It is now undergoing psychometric testing in another study.

The sample of 116 patients may seem small when it comes to the representativeness of the data and the generalizability of the results, especially as only 27% of the eligible patients completed both OCP-1 and 2, see below. Therefore the large drop-out in the study must be taken into consideration when discussing the result. With regard to the study population, only patients in adult general psychiatric in-patient care were included. The type of ward was chosen because of the expected variation of psychiatric diagnoses on such a ward. In contrast to what has been the case in many earlier studies, the patients represented both voluntary and involuntary care. Patients who have been under compulsory care have seldom been asked about their conceptions (Johansson & Lundman 2002). In addition, more than a half of the respondents were women (69%) and only a small proportion (6%) were over 64, and a sizeable proportion of the respondents were diagnosed with depression (22%) It cannot be ruled out that this might have skewed the results in a positive direction, as Blenkiron & Hammill (2003) found that patients with bipolar depressive disorder rated their degree of satisfaction higher than patients with other diagnoses. Whilst Noble et al. (2001) found in a review study that women and older people have more positive expectations regarding treatment, and patients with severe mental illness less positive expectations. Like other instruments of this type, QPC can only be used with fully-communicating patients.

In this study the staff seemed to experience certain difficulties in administering an instrument in two parts and to be given out on separate occasions. This suggests a limitation of the instrument, especially in view of the relatively low response rate due to there being a lot of drop-outs. One hundred and one patients were unwilling to participate in QPC-1. This may to some extent have been due to illness on days 1–3. In the case of QPC-2, 52 patients did not want to take part, possibly because they felt that too much time was required and/or that it was uninteresting to answer essentially the same questions all over again. Therefore the length of the questionnaire and the design of the data collection must always be kept in mind. An instrument should not be time-consuming and should be easy to fill in for the patients and also easy to administer for both staff and patients (Busch 2002).

However, QPC has its merits. Firstly, it is based on a definition of what constitutes high-quality in psychiatric care as perceived by the patients in study I. Of the patients (n=20), participating in this study, 14 patients came from the in-patient care while six were from out-patient care, four of whom had earlier experience of in-patient care. An important point is that some of the patients were not newly discharged but had time to think about their earlier

experience of in-patient care. Secondly, there has not previously been such an instrument in psychiatric in-patient care (Elbeck & Fecteau 1990, Gigantesco et al. 2003). From the validity point of view, many earlier scales have been criticized for their lack of a theoretical foundation (van Campen et al. 1995, Wilde et al. 1994), and whether the attributes in the scales are the most representative of quality of care from a patient perspective can be called into question (Hansson et al. 1993, Wilde Larsson et al. 2005). Earlier established instruments often have been constructed from the conceptual perspective of the professional, rather than of the patient (Gigantesco et al. 2003, Woodring et al. 2004). Thirdly, the wording of the OPC items was based on patients' interview responses. Fourthly, QPC was constructed to investigate what differences there might be between patients' expectations concerning psychiatric care and their subsequent experience of it, information that also can be used to promote quality improvement in in-patient psychiatric care. Earlier instruments often measured patients' satisfaction or their experiences of the quality of care. This is not enough, because the most important thing when measuring quality of care is the size of the difference between expectation and subsequent experience (Noble et al. 2001, Crow et al. 2002). Fifthly, with regard to face validity, people with their own experience of psychiatric care were involved and they perceived 69 of the 127 items in QPC-1 as easily understood and important within psychiatric in-patient care. Thus the instrument could with advantage be used in conjunction with interviewing of the elderly and of those with a severe mental illness, so as to make their views on the quality of care heard as well.

Many factors outside the care organization can affect the person's perceptions and experiences of the care (Bergman & Klevsjö 2001). Different health-care structures, political, social, economic and cultural characteristics can make it difficult to compare patterns of care in different countries (Beck & Kilian 2006). This is an important reliability question to be taken into consideration if the instrument is used in other countries than Sweden — QPC has been developed in Swedish health-care conditions and on the basis of interviews with Swedish patients.

#### Discussion of the results

*The qualitative studies (I, III and IV)* 

The results of the qualitative interview studies (I, III and IV) generated four descriptive categories or dimensions common to all — Dignity, Participation, Recovery and Environment — and also, in the patient's and next of kin's perspective, the descriptive category Security.

The descriptive categories seem to be in agreement on a general level from all three perspectives, but were more specific for each perspective when comparing individual conceptions. For instance, *Being understood* was a unique facet of Dignity from the patient's perspective while *Closeness in the case of compulsory measures* reflected one facet of the staff's perspective on Dignity. Donabedian (1980) maintains that there are similarities between staff's and patients' views of quality of care on a general level, whilst Brooker & Dinsgshaw (1998) and von Essen & Sjöden (1993) found discrepancies between the different views. The results show substantial variations in all the participants' conceptions of the quality of care in this thesis. This is in accordance with previous research where the concept has been described as being multidimensional (Andersson 1995, Donabedian 1966, Hansson 1989, Wilde *et al.* 1994). The concept was perceived as a positive one, namely as *good* quality of care, and the normative component was striking

It is interesting to note which perspectives the different participants in the present study chose to describe quality of care from. The patients exclusively described it from their own perspective and as a positive concept. The next of kin and the care staff and care associates described it from their own perspective, as well as from a patient perspective. None of the participants was specifically asked from which perspective they would describe quality of care — it was a spontaneous choice. Both staff and next of kin spontaneously included the patients' perspective. Further, it is of interest that the next of kin perceived quality of care in negative as well as positive terms. Their doing so is no doubt attributable to negative past experience of such quality.

Also of interest is that only the care staff mentioned compulsory care in connection with quality of care. There can be different reasons for this. First, staff may experience an ethical dilemma when a trusting relation to the patient is to be built up at the same time as rules of care and treatment have to be followed. Staff sometime attempt to resolve such a dilemma by means of a subtler form of compulsion, for instance appeal or persuasion (Lützen 1998). Second, it may be that the patient and next of kin do not want to talk about compulsory care because they associate it with shame and depreciation. Third, such talk might awaken unpleasant memories for them. Fourth, patients are perhaps not conscious of special rules and rights involved in compulsory care, nor of special needs involved, which may create a certain measure of uncertainty among the staff. Fifth, there may be a lack of knowledge about what both patients and next of kin can expect when it comes to compulsory care. Furthermore, an

interesting and surprising finding is that only next of kin speak of the importance of not forgetting that children of mentally ill parents require particular support. Gross (1989) maintains that these children are at a risk of developing mental illness because of their traumatic situation and therefore need early support, help and preventive measures. Thus care staff must focus more on fulfilling the particular needs of such children.

Several researchers maintain that the interpersonal relationship is clearly the most important factor in psychiatric care and treatment (Cleary & Edwards 1999, Längle 2003, Richmond & Roberson 1996), in addition to being the most central aspect of good care (Johansson & Eklund 2003) and quality of care (Campbell 2000, Donabedian 1989, Richmond & Roberson 1996, Shaw 1997). The results of the present thesis are similar: the staff-patient relationship is seen as occupying a central position and as indeed being decisive with regard to the quality of care. In Peplau's (1952) interpersonal relation theory, the essential qualities for staff in the therapeutic nurse-patient relationship are considered to be respect, self-esteem, presence, value clarification, empathy, forgiveness, hope, trust, empowerment, patient-centred objectives and goals, openness, self-disclosure, insight, and self-exploration (Stockmann 2005). This is in line with the general results of the studies in this thesis. In addition, the distinctive feature of psychiatric care is that the interaction between patient and professional has a central therapeutic role (Peplau 1991,1999). Staff should act as therapeutic instruments, as it were, whereby their work will be of a markedly personal character (Hem & Heggen 2003). For patients, staff are both health professionals and fellow human beings. The professionals shall come close to patients at the same time, as they shall be able to find a balance between human closeness and professional distance (Hummelvoll 1997).

Since five descriptive categories or dimensions constituted the core of quality of care in the psychiatric setting (Fig. 2), they will be further discussed in the context of the existing literature below.

Dignity was expressed as the patient's need to be confirmed, respected as a human being, listened to and understood by competent staff who have empathy, self-knowledge, a sense of humour and an attitude that is personal but not intrusive. The importance of such needs in relation to quality of care has been described in several studies. Harvey & Kitson (1996) maintain that quality of care is directly related to how well the patient's needs are listened to in the interaction between patient and professional. Gallagher & Seedhouse (2002) say that

one of the key concepts of dignity from the perspective of patients and relatives in psychiatric care is respect. This would seem to be especially important in that the mentally ill patient's vulnerability can cause a loss of personal dignity. The patient's dignity can easily be infringed when his or her rights (and to some extent obligations too) are taken away through application of the Act on Compulsory Institutional Psychiatric Care or the Act on Forensic Psychiatric Care. Edlund (2002) maintains that the safeguarding of human dignity involves being respectful and supportive in the encounter with, and in one's actions in relation to, other human beings. To confirm a person's dignity is to respect this person and to see him or her as unique, and this care staff can achieve through their actions and general behaviour (von Post 1999), through listening to and believing in the patient's account of his or her situation (Gallagher & Seedhouse 2002, McIntyre et al. 1989) and through interpreting body language and discerning what lies behind psychotic behaviour. Enquist (1996) states that one cannot properly understand other people without having an ability to discern the non-verbal part of what they are communicating. In addition, the Act on Professional Responsibility in the Area of Public Health and Sick Care (SCS 1998:531) states that the patient has the right to expect to encounter professional, knowledgeable and accommodating staff who work in accordance with science and well-tried experience.

In the results appear conceptions that are associated with guilt, shame and stigmatization. This is not new information, as stigmatization because of mental illness is widespread (Lauber *et al.* 2006). What *is* new, however, is the explicit indication of stigmatization in studies on quality of care among staff, patients and next of kin. All three groups state that the patient should be looked upon as like any other person and the next of kin also wanted to be looked upon as like anyone else. This means no judgment on the part of staff and the adoption of a less dramatic attitude to mental illness on the part of staff and society. Stigmatization because of mental illness can influence both quality of life and recovery (Crawford & Brown 2002, Vuokila-Oikkonen *et al.* 2002). In a study carried out in Switzerland, Lauber *et al.* (2006) investigated stigmatizing attitudes to mentally ill people on the part of the general population and psychiatric care professionals. The results showed no significant differences between the two groups: the professionals' attitude towards the mentally ill was not more positive or negative than that of the rest of the population. Significant differences did appear, though, within the group of professional: the psychiatrists had the most negative attitudes, the psychologists the most positive ones. Lauber *et al.* (2006) state that the professionals must

change their attitudes and become aware of what effect their stigmatizing conceptions have on patients. An important goal within psychiatric care is to discover strategies to reduce stigma.

Security was, in this study, perceived by both patients and next of kin as implying a high level of access to both in- and out-patient care. Accessibility of care is the patient's and next of kin's right and is a prerequisite for the provision of good care. One aspect of this is that the cost of care and treatment must not be an obstacle. Earlier studies have shown that accessibility is an important aspect of quality of care (Campbell 2000, Donabedian 1990). A basic requirement concerning good quality of care is patient security, whereby both patient and next of kin are treated with respect and consideration, given proper information and enabled to participate in care that is evidence-based (NBHWCS 2005:12, SCS 1998:531). Evidence based care is define by Rycroft-Malone *et al.* (2004) as a combination of research results, clinical experience and the patient's perceptions.

Participation and Recovery were other important features of good quality of care, whereby the importance of empowerment in psychiatric care emerged. The results indicate that knowledge about the mental illness can provide a sense of control over everyday life and can support coping with the symptoms. With knowledge about the mental illness, patients can participate in discussion and co-operate in the treatment planning. This is in accordance with the results of a study by Kilkku et al. (2003) concerning patients with first-time psychosis that shows that patients' own understanding and acceptance of the mental illness affects their experience of receiving information and care. Kilkku et al. (2003) state that information given to patients should be adapted to the patient's unique life situation and previous experiences of care. The finding in this thesis is also in agreement with how Hansson & Björkman (2005) view the concept of empowerment. They state (p. 32) that two dimensions of the concept are shared in several approaches: "one psychological dimension which is concerned with selfesteem, self-trust and self-efficacy and one social action-oriented dimension comprising factors such as power, involvement and control over the own life situation and care and support." According to Lindhorst et al. (2002), the health care organization can promote empowerment in many ways. One way to promote empowerment in psychiatric care is for management to see that staff has time to involve patients and next of kin (if the patient wants) in the treatment planning and present a range of treatment options (Lindhorst et al. 2002). In Sweden this is in fact a statutory measure (SCS 1982:763): the law states that care and treatment should be given in co-operation with patients as soon as possible, and should be accompanied by respect for the patient's self-determination. Next of kin have a right to information and participation in the care (provided this does not infringe privacy and secrecy legislation) and should be shown consideration and respect (SCS 1980:100).

Environment emerged as being of great importance with regard both to the patient's recovery and to the next of kin's motivation to come and see the patient. What was asked for was a calm and attractive environment with small units where the patients had similar diagnoses. The importance of the ward milieu for the patient's recovery has been brought out in several studies (Middelboe et al. 2001, Rossberg & Friis 2004, Schjødt et al. 2003) and it is far from being a new discovery: it was pointed out long ago by Florence Nightingale (1859). Environment has also been presented as one of four meta-paradigms in nursing theory (Meleis 2005). Earlier studies in psychiatric care have demonstrated the importance of the care and treatment environment for in-patients (Middelboe et al. 2001, Schjødt et al. 2003) and the importance of the ward atmosphere for satisfaction with the treatment (Rossberg & Friis 2004). The environment is affected by the composition of the patient group with regard to age and diagnosis (Friis et al. 1982) and by size of unit (Valgum et al. 1985). It is the institution's responsibility to see that the psychiatric ward constitutes a protective environment (Teising 2000) and it is the staff's responsibility to create a good environment for the patients. The ward milieus are often organized on the basis of the staff's perceptions and ideas, not the patients' (Schjødt et al. 2003). Yet patients, staff and also next of kin are in the ward milieu for different reasons and have different needs with regard to this environment. Schjødt et al. (2003) investigated patients' and staff's perceptions of the social climate in a ward milieu and found that there was overall agreement. That is in line with the finding of this thesis that patients, staff and next of kin generally have similar perceptions regarding the environment. In spite of the broad similarity between how patients perceived quality of care and how next of kin perceived it, management and staff should not neglect the need to be sensitive to the differences, which did appear. It is essential to bear such differences in mind when seeking to improve the quality of care.

### *The quantitative study (II)*

An instrument (QPC) to measure patients' expectations regarding quality of care (QPC-1) and their subsequent experience of it (QPC-2) was developed and used empirically in this thesis. The theoretical basis of the instrument is patients' conceptions of quality of care from Study I in this thesis. The patients had described quality of care as something normative (how the care

ought to be), which in the instrument is represented by patients' expectations. The extent to which these expectations were fulfilled is represented by the patients' experiences (how the care is). This is in accordance with Donabedian's (1980) opinion that quality of care involves two components, a normative one and an empirical one, the latter component being central to the measurement of quality in health care. The degree of each is determined by the extent to which the care fulfils the established criteria of good care (Donabedian 1988). In this thesis it is the patients who have established the criteria of high quality. The instrument was also developed to promote quality improvement in in-patient psychiatric care. Therefore it was constructed in such a way as to be able to investigate what differences there might be between patients' expectations concerning psychiatric care and their subsequent experience of it. Such differences can be described in terms of negatively/positively disconfirmed expectations (Crow et al. 2002). In this thesis has the term "patient satisfaction" assessed to describe the quality of care too restrictive.

The empirical use of QPC among in-patients with different mental illnesses and on eight wards shows that the ratings of expectations and experiences were in general very high in both parts of the instrument, which implies a skewed distribution of the answers without variation and with the subsequent unsatisfactory reliability in the form of exceedingly high levels of Cronbach's alpha. However, the patients' ratings in QPC-2 were in general somewhat lower than their ratings in QPC-1. This result of high ratings of quality of care is rather similar to the results of other studies among in-patients both national (Svensson & Hansson 1994) and international (Greenwood et al. 1999, Kuosmanen et al. 2006). Nevertheless, the result indicate high rating of quality in QPC-1 in the dimension Dignity, which contained the most items regarding interpersonal relationship. Dignity has been pointed out by several researchers as being the most important factor in psychiatric treatment from the patient's perspective (Clearly & Edwards 1999, Längle et al. 2003, Richmond & Roberson 1996). Gigantesco et al. (2002) found that the highest level of satisfaction was with regard to staff kindness and availability, staff competence and helpfulness during hospitalisation, which is similar to the conceptions contained in the staff perspective in this thesis. In QPC-2 high rating of quality was in the dimension Security, containing items to do with accessibility, continuity and trust.

The lowest score with regard to quality of care was information about treatment alternatives. Among the five dimensions, the patients' experience in comparison with their expectations involved negatively disconfirmed items in the category Recovery, especially with respect to the items "Treatment leads to getting better" and "Information about treatment". This is rather similar to what has been found in other studies among in-patients. For example in the study by Gigantesco *et al.* (2002) the lowest levels of quality of care were found with regard to information about treatment and involvement in the treatment programme. Howard *et al.* (2003) showed that patients were dissatisfied with treatment planning and the degree of medication education (corresponding in the present study to their experiencing a low quality of care).

Despite the ratings of high quality of care, there are still areas where patients' expectations are disconfirmed in a negative way. Experienced quality of care was lower than expected in the case of 64 of 69 items, significantly so in the case of 30. These negatively disconfirmed items can be discussed as an area for improvement. However, such differences would never have been detected if QPC had only measured patients' experiences of the care. This is interesting and speaks for the need for an instrument in two parts, measuring both expectations and experiences. Noble *et al.* (2001) maintain in a review study that the best-known measuring instrument is the SERVQUAL, which systematically compares consumers' expectations and experiences. This instrument is used mostly in the service industries but has also been used in health care.

The current study shows, regarding the background variables, that only 40% of the participants know their diagnosis and that 58% do not know if the care during the treatment episode has changed from voluntary to involuntary or vice versa. Regarding the patients' characteristics, i.e. sex, age, education and diagnosis, no significant differences were found in this study. This is in line with certain previous studies (Leavey *et al.* 1997, Lebow 1983b,c). Other researchers have found that men (Greenwood *et al.* 1999, Hansson 1989) and older people (Barker *et al.* 1996, Blenkiron & Hammill 2003, Gigantesco 2002) were more satisfied with their care. Some studies have shown a significant relationship between patients' education and their ratings of quality of care (Leavey *et al.* 1997, Lebow 1983a). A relationship has also been found between diagnosis and lower level of satisfaction or quality of care, especially the diagnosis of schizophrenia or other psychosis (Lebow 1982, Perreault *et al.* 1996), though in other studies no such relationship has been found (Greenwood *et al.* 1999, Lebow 1983b). Nor in the present study was any relationship found between quality of care and diagnosis. Only two background variables showed significant differences in two

dimensions in this study. Patients who felt that the time of discharge was consistent with the stage of their illness had significantly higher ratings of quality of care in the dimension Recovery. Patients who perceived that their mental health at discharge was good also had higher ratings in the dimension Recovery, as well as in the dimension Participation. It seems to be the patient's psychiatric health at discharge rather than diagnosis that predicts ratings of quality of care in these two dimensions. This is in line with two other studies in Sweden (Hansson 1989). However, the research in psychiatric care regarding patients' background characteristics and quality of care or satisfaction is uncertain and contradictory and more studies are needed in this respect.

To sum up, the result of this thesis shows the importance of the interpersonal relationship. This is not new knowledge as several researchers have found the same result in both in-and out patient (cf. Björkman *et al.* 1995, Hansson *et al.* 1993). This result in this thesis is also in line with Donabedian (1980) and Wilde *et al.* (1993), who maintain that quality of care has closely interrelated aspects, such as interpersonal relationships, technical care and amenities in the care environment.

The new knowledge gained from this research concerns the meaning of the concept quality of care in psychiatric care, which was mapped out from three different perspectives (study I, III and IV). Also a new instrument (QPC) was developed for in-patient care. The researchers used the patient's own conceptions regarding the meaning of quality of care when constructing the instrument and its items. These items make it possible to identify which aspects of care are related to higher or lower quality. Furthermore, the instrument is in two parts where the patient's experiences of the quality of care can be distinguished from his/her expectations of care.

### CONCLUSIONS

There are few interview studies concerning the concept quality of care in the psychiatric setting from different perspective. Therefore in this thesis three qualitative interview studies were carried out where patients (I), next of kin (III) and care staff and care associates (IV) were involved, all three groups being closely concerned with the quality and outcome of care. This thesis has shown that:

- The concept was described mainly as good quality of care and as normative.
- The participants described quality of care similarly on a general level. But on a more specific level there were differences between their conceptions of quality of care.
- Quality of care can be expressed in the descriptive categories Dignity, Participation, Recovery and Environment, and also, in the patient's and next of kin's perspective, Security.
- Good relations and communication between, staff, patient and next of kin were central
  factors with regard to the quality of care. The patients and next of kin asked for
  information about mental illnesses in order to be able to handle their life-situation and
  to take part in the planning of the care.
- The next of kin highlighted the importance of not forgetting that the children of mentally ill parents required particular support, help and preventive measures.
- It was very important that mental illness should be de-dramatized for both patient and next of kin through staff's being understanding and non-judgemental.
- Experienced quality in care was lower than expected in the case of 64 (93%) of 69 items, *significantly* lower in the case of 30 of the 64. The items that are disconfirmed could be discussed as an area for improvement of quality of care in psychiatric setting.
- This new instrument needs to be further tested before the psychometric properties can
  be established. Thereafter it could hopefully be used in in-patient psychiatric care to
  improve the care and in prioritizing resources within care.
- The results in the qualitative studies on the three different perspectives indicate that
  the QPC instrument may be able to measure overall quality of care in psychiatric
  settings. However, additional questions for out-patients, next of kin and care staff are
  needed in order to also achieve a high level of reliability when applied in the
  respective groups.

### **IMPLICATIONS**

- Clinical practice can be improved by guidelines and instruments developed on the basis of this thesis. In spite of the many similarities in the views of quality of care, staff should not neglect the need to be sensitive to differences between how patients and next of kin perceived this quality. It is essential to have knowledge of the differences from one perspective to another, as both management and other staff have an important role in deciding how the different perspectives can be used in the improvement of the quality of care.
- Quality of care as measured by QPC can be used as a tool to motivate care staff to continually improve the care provided.
- Knowledge about patients' and next of kin's feelings of shame, guilt and stigmatization could be a part of all basic and advanced nursing education and could be useful in furthering the understanding of patients' and next of kin's distress. It could also be used in-patient and next-of-kin education for the purpose of reducing the sense of shame and guilt arising from being mentally ill or being the next of kin of a mentally ill person. In addition, the mass media could with advantage use such knowledge to contribute to reducing the social stigmatization of mentally ill persons and their next of kin.
- After psychometric testing and validation, the new instrument QPC can be routinely
  used as a self-rating instrument for the purpose of improving psychiatric in-patient
  care. Since there are few published instruments for measuring quality of care in the inpatient settings, this instrument may contribute to the development in this field.

This thesis will end with a note on the current state of mental health care in several European countries; recently there have been quite a few exposing stories in the media concerning the inadequate care received. These concerns have also been identified in this thesis in the form of particular conceptions contained in the descriptive categories, as well as in the items of the instrument (QPC). Therefore, the results and the knowledge gained from this thesis can prove to be useful in the continuing efforts to raise the quality of care in the psychiatric setting in Europe.

# SAMMANFATTNING PÅ SVENSKA (SUMMARY IN SWEDISH)

Den psykiatriska vården har under de senaste decennierna undergått genomgripande förändringar mot allt öppnare vårdformer, minskat antal vårdplatser (dygnet runt) och kortade vårdtider. Parallellt med detta har också vårdens syn på såväl patienter som deras anhöriga förändrats, liksom deras kunskaper om och förväntningar på den vård som erbjuds. Det har dock riktats liten uppmärksamhet åt patienters utvärdering av den egna vården både i Sverige och i andra länder. Det har inte heller funnits något större intresse av att undersöka hur patienter, närstående, vårdpersonal och psykiatrins vårdgrannar uppfattar begreppet vårdkvalitet i en psykiatrisk kontext. Dessutom har lite uppmärksamhet ägnats åt att utveckla instrument för att mäta vårdkvalitet ur ett patientperspektiv som avser psykiatrisk slutenvård. Patientens perspektiv är viktigt att ha med från allra första början i utvecklingen av ett instrument, eftersom det är endast patienten som kan beskriva sina förväntningar på och bedöma sina upplevelser av vårdens kvalitet.

Vården skall planeras och genomföras i nära samarbete med patienter. Mot bakgrund av detta är det nödvändigt att allt kvalitetsarbete inom psykiatrin tar sin utgångspunkt just i patienternas uppfattning av vad som ligger i begreppet vårdkvalitet. Därutöver är det också viktigt att veta vad andra intressenter av vårdens kvalitet, d.v.s. närstående och professionen, lägger för innebörd i begreppet för att kunna jämföra vårdkvalitet ur flera perspektiv.

Det övergripande syftet med denna avhandling var att beskriva vårdkvalitet utifrån olika perspektiv i psykiatrisk vård och att utveckla ett instrument för vårdkvalitet från ett patientperspektiv, samt använda instrumentet empiriskt. En deskriptiv kvalitativ design med en fenomenografisk analys användes i studie I, III och IV. I studie II användes en deskriptiv och komparativ design med statistiska analyser. I de kvalitativa studierna (I, III och IV) fick samtliga intervju personer samma ingångsfråga: Hur uppfattar du begreppet vårdkvalitet inom psykiatrisk vård? Vidare ställdes följdfrågor, dess innehåll och antal varierade beroende på hur fylliga intervjusvaren var. Studie I bygger på uppfattningar från 20 intervjuer med patienter inom allmänpsykiatrisk vård. I Studie II besvarade 116 patienter inom 8 allmänpsykiatriska avdelningar instrumentet "Kvalitet i Psykiatrisk Vård" (KPV). Studie III bygger på uppfattningar från 12 intervjuer med närstående till patienter som ingick i studie (I). Slutligen studie IV grundar sig på uppfattningar från totalt 20 intervjuer med vårdpersonal

inom psykiatrisk vård och personal som representerade psykiatrins vårdgrannar. Totalt inkluderades 168 deltagare i avhandlingens olika studier.

Resultatet i studie I visade att vårdkvalitet uppfattades som ett positivt begrepp, d.v.s. som något gott och normativt. Fyra beskrivningskategorier framträdde i resultatet; "Värdigheten respekteras", "Känsla av trygghet i vården", "Delaktighet i vården", "Tillfrisknande" och "Vårdmiljö". Två uppfattningar framkom som inte tidigare framträtt explicit i tidigare studier om vårdkvalitet; "Bli hjälpt med att reducera skammen" och "Bli sedd som vem som helst".

I studie II utvecklades en definition av hög vårdkvalitet utifrån patientens perspektiv med en teoretisk grund i studie I. Definitionen operationaliserades till påståenden i instrumentet KPV som omfattar två delar. Den ena delen mäter patientens förväntningar på den kommande vården (KPV-1) och fylls i vid ankomsten till avdelningen och den andra delen (KPV-2) mäter patientens upplevelser av den givna vården och fylls i vid utskrivning. Varje del omfattar 69 identiska frågor som skiljer sig åt i tempus. Instrumentet användes empiriskt vid åtta allmänpsykiatriska avdelningar i två län under maj - december 2005. Undersökningen visade att patienterna skattade vårdkvalitet generellt högt. I en jämförelse mellan förväntningar och upplevelser i de påståenden patienten besvarat att de *inte* instämde i, visade att patienternas upplevelser av vårdkvalitet var lägre än deras förväntningar i 64 av 69 påståenden (93%) och signifikant lägre i 30 av 64 påståenden. Den största skillnaden var i fråga om behandling. Där svarade 13 % att de inte förväntade sig att behandlingen skulle leda till att de skulle må bättre, medan 47 % upplevde att behandlingen inte lett till att de mådde bättre, en differens på 34%.

I studie III beskrev närstående vårdkvalitet i huvudsak utifrån sitt eget perspektiv, men även från patientens perspektiv. Fem beskrivningskategorier framkom i resultatet; "Värdighet", "Trygghet", "Delaktighet", "Tillfrisknande" och "Hälsofrämjande omgivning". Goda relationer och kommunikation mellan personal, patient och närstående framkom som centrala faktorer beträffande vårdkvalitet. Närstående frågade efter information om psykiska sjukdomar och ville samarbeta och bli delaktiga i vården.

I resultatet av studie IV beskrev vårdpersonal och vårdgrannar vårdkvalitet utifrån patientens perspektiv, men implicit även utifrån ett professionellt perspektiv. De uppfattade begreppet som positivt och beskrev att vårdkvalitet har stor betydelse för patientens hälsa och

livssituation. Fyra beskrivningskategorier framkom som beskrivning av vårdkvalitet; "Patientens värdighet är respekterad", "Patientens delaktighet i vården", "Patientens tillfrisknande" och "Patientens vårdmiljö".

Sammanfattningsvis framkom i denna avhandling att vårdkvalitet inom psykiatrisk vård är ett normativt och multidimensionellt begrepp som visar på "hur vården ska vara". Generellt uppfattades också vårdkvaliteten som något gott d.v.s. god vårdkvalitet. Den interpersonella relationen visade sig ha en stor betydelse för vårdens kvalitet när det gäller patienter och närstående. Skuld, skam och stigmatisering framkom som viktiga områden att beakta i vårdkvalitet. Resultatet pekade på att det fanns många likheter i de olika perspektivens uppfattningar av vårdkvalitet på en generell nivå, men också olikheter på en specifik nivå. Fem centrala dimensionen framkom; Värdighet, Trygghet, Delaktighet, Tillfriskande och Vårdmiljö, som tillsammans innehåller 13 olika uppfattningar, som oavsett perspektiv utgör kärnan av vårdkvalitet inom psykiatrisk vård. Den empiriska undersökningen av instrumentet KPV visade att patienterna skattade vårdkvalitet i allmänhet högt vilket innebär att vården ansågs vara av hög kvalitet. Det fanns dock skillnader i patienternas förväntningar och upplevelser, och just dessa skillnader ger värdefull information om vilka aspekter av vården som behöver ägnas särskild uppmärksamhet i ett fortsatt kvalitetsarbete.

Denna avhandling bidrar till en ökad förståelse för innebörden av begreppet vårdkvalitet inom psykiatrisk vård. Denna kunskap kan användas som ett underlag i förbättringsarbeten i vården, i undervisning inom grundutbildningar i vårdyrken och i fortbildningsinsatser samt i patient- och närstående utbildningar. Fördelen med instrumentet KPV är att det består av specifika frågor utifrån patientens perspektiv, som gör det möjligt att identifiera högre och lägre kvalitet. Instrumentet kan förhoppningsvis efter psykometrisk prövning användas som ett självskattningsinstrument i det dagliga rutinarbetet inom den psykiatriska vården.

### **ACKNOWLEDGEMENTS**

This thesis was carried out at the Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences, Linköping University, Linköping, Sweden, and I gratefully acknowledge having been given such an opportunity. I would also like to express my warm and sincere gratitude to everyone who has supported me and contributed to this thesis in different ways. Especially I want to thank:

The patients, next of kin, care staff and care associates who kindly participated in the studies.

The care staff involved in the data collection

Professor Gerd Ahlström, my main supervisor, for excellent guidance, constructive criticism and perspicacity. Thank you for being available, encouraging, supporting and inspiring me in the work on this thesis. I am deeply impressed by the breadth and depth of your knowledge in the field of scientific research and also by your energy.

Professor Bodil Wilde Larsson, my co-supervisor, for sharing your great knowledge of quality in care and scientific research. Thank you for guidance, constructive criticism, encouragement, support and, not least, friendship.

Professor Anna-Christina Ek, for accepting me as a doctoral student, for your generosity and for sharing your deep scientific knowledge during seminars.

Professor Ingemar Engström, head of the Psychiatric Research Centre, Örebro County Council, for believing in me from the very beginning, introducing me to the world of research and giving me creative freedom in a fruitful and pleasant research environment.

Anita Ericsson, for you careful work as co-estimator in two of the qualitative studies.

Malcolm Forbes, for your excellent revision of my English.

Stig Wenneberg, for valuable comments on parts in this thesis.

My doctoral colleagues at the Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences, Linköpings University for your friendship, constructive discussion and support during seminars.

My doctoral colleagues and friends at the Psychiatric Research Centre, Örebro County Council, for support, stimulating discussion and friendship during the writing of this thesis. Particular thanks to Anna Wadefjord, for your kindness, support and ability to make the impossible possible on the computer. Lars Kjellin, for always taking time for discussion. Tabita Björk, for introducing me to the SPSS.

All staff at the Medical Library, Örebro University Hospital, for excellent service.

Erika Lindén, Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences, Linköpings University, for being helpful and service-minded.

My father Wide, who is no longer with us, who followed the writing of this thesis with great interest and expectations; and my mother Ingrid, also no longer with us, who always supported me.

Johnny, my beloved husband, for encouraginging me when things did not go my way and for sharing my joy when they did — and for so much more...

Last but not least, I want to thank the following for financial support: Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences, Linköping University; Psychiatric Research Centre, Örebro County Council; Swedish Research Council; Research Committee of Örebro County Council; Psychiatry Foundation; Swedish Society of Nursing.

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