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**IMPROVING QUALITY OF LIFE
OF PATIENTS WITH SCHIZOPHRENIA
IN ACUTE PSYCHIATRIC WARDS**

by

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To patients with schizophrenia

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ABSTRACT

The overall goal of this study was to identify means by which the quality of life (QoL) of patients with schizophrenia could be improved in acute psychiatric wards. First, subjective QoL of patients (n=35) was explored. Second, two different QoL instruments (EuroQoL-5D, EQ-5D; Quality of Life Enjoyment and Satisfaction Questionnaire Short Form, Q-LES-Q SF) were examined. Third, patients' (n=35) and nurses' (n=29) perceptions of nursing interventions to support patients' QoL were examined. Fourth, the effect of three different patient education methods on patients' QoL (n=311) was compared. The data were collected during the period 2005-2007.

Patients named health, family, leisure activities, work or study, and social relationships most frequently as their important QoL areas. It emerged that patients' QoL was impaired. Examination of two QoL instruments showed that the EQ-5D has moderate and the Q-LES-Q SF good internal consistency. Moreover, both instruments proved to be reasonably valid and feasible for use with patients with schizophrenia. Altogether six nursing interventions which nurses use to support patients' QoL, and which should be further developed were identified from nurses' descriptions: interventions related to care planning, empowering interventions, social interventions, activating interventions, security interventions, and interventions to support physical health. Evaluation of different patient education methods showed that patients' QoL improved significantly during follow-up. No significant differences between groups were found.

In light of the findings it is recommended to assess QoL of patients with schizophrenia as a basis for care planning and care evaluation in clinical settings. Valid and feasible instruments should be used in this assessment. Moreover, it is recommended that nursing interventions should be further developed to better improve patients' QoL.

Keyword: acute psychiatric ward, assessment, nursing intervention, psychiatric nursing, patient education, quality of life, schizophrenia

Anneli Pitkänen

SKITSOFRENIAA SAIRASTAVIEN POTILAIEN ELÄMÄNLAADUN PARANTAMINEN AKUUTTIPSYKIATRIAN OSASTOILLA

Hoitotieteen laitos, Lääketieteellinen tiedekunta, Turun yliopisto, Turku

TIIVISTELMÄ

Tutkimuksen tavoitteena oli löytää tekijöitä, jotka edesauttavat skitsofreniaa sairastavien potilaiden elämänlaadun parantamista akuuttipsykiatrian osastoilla. Tutkimus toteutettiin neljässä vaiheessa. Ensimmäisessä vaiheessa selvitettiin potilaiden (n=35) näkemystä subjektiivisesta elämänlaadustaan. Toisessa vaiheessa arvioitiin kahden erilaisen elämänlaadun mittarin (EuroQoL-5D, EQ-5D; Quality of Life Enjoyment ja Satisfaction Questionnaire Short Form, Q-LES-Q SF) ominaisuuksia. Kolmannessa vaiheessa kuvattiin potilaiden (n=35) ja hoitajien (n=29) näkemyksiä elämänlaadun tukevista hoitotyön menetelmistä. Neljännessä vaiheessa arvioitiin kolmen erilaisen potilasopetuksen vaikutuksia potilaiden (n=311) elämänlaatuun. Aineisto kerättiin vuosina 2005–2007.

Potilaat nimesivät useimmiten terveyden, perheen, harrastukset, työn tai opiskelun sekä sosiaaliset suhteet tärkeimmiksi elämänlaadun alueikseen. Potilaiden elämänlaadun todettiin olevan heikentynyt. Tutkimustulokset osoittivat EQ-5D:n sisäisen johdonmukaisuuden olevan kohtalaisen ja Q-LES-Q:n hyvän. Molempien elämänlaatumittareiden pätevyys ja käytettävyys osoittautuivat kohtalaisiksi skitsofreniaa sairastavien potilaiden elämänlaadun mittaamiseen. Hoidon suunnitteluun liittyvät, voimaannuttavat, sosiaaliset ja aktivoivat hoitotyön menetelmät sekä turvallisuuteen ja fyysiseen terveyteen liittyvät hoitotyön menetelmät olivat potilaiden ja hoitajien kuvausten mukaan hoitotyön menetelmiä, joilla tuetaan potilaiden elämänlaadun ja joita tulee edelleen kehittää. Eri potilasopetusmenetelmien vaikutuksia arvioitaessa todettiin potilaiden elämänlaadun parantuneen merkitsevästi kaikissa potilasopetusryhmissä. Eri potilasopetusten välillä ei ollut tilastollisesti merkitseviä eroja.

Tutkimustulosten perusteella suositellaan hoidon aikana tapahtuvaa skitsofreniaa sairastavien potilaiden elämänlaadun arviointia niin hoidon suunnittelun kuin hoidon arvioinnin pohjaksi. Elämänlaadun arvioinnissa tulee käyttää luotettavia ja käyttökelpoisia mittareita. Lisäksi suositellaan hoitotyön interventioiden kehittämistä, jotta ne entistä paremmin parantaisivat potilaiden elämänlaadun.

Asiasanat: akuuttipsykiatrian osasto, arviointi, elämänlaatu, hoitotyön menetelmä, potilasopetus, psykiatrinen hoitotyö, skitsofrenia

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ABBREVIATIONS

ANOVA	Analysis of Variance
APA	American Psychiatric Association
CINAHL	Cumulative Index for Nursing and Allied Health Literature
EBHC	Evidence-Based Health Care
EQ-5D	Euroqol-5D
ES	Effect Size
ETENE	The National Advisory Board on Health Care Ethics
GAF	Global Assessment of Functioning
HRQoL	Health Related Quality of Life
ICD-10	International Classification of Diseases, 10th Revision
IT	Information Technology
NICE	National Institute for Health and Clinical Excellence
QALY	Quality-Adjusted Life Year
QoL	Quality of Life
Q-LES-Q	Quality of Life Enjoyment and Satisfaction Questionnaire
Q-LES-Q SF	Quality of Life Enjoyment and Satisfaction Questionnaire Short Form
RANZCP CPG	Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guideline
RCT	Randomized Controlled Trial
SD	Standard Deviation
SDS	Sheehan Disability Scale
SEIQoL	Schedule for Evaluation of Individual Quality of Life
SEIQoL-DW	Schedule for Evaluation of Individual Quality of Life - Direct Weighting
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life Assessment

LIST OF ORIGINAL PUBLICATIONS

The thesis is based on the following papers, which are referred to in the text by their Roman numerals form I-V.

- I Pitkänen A., Hätönen H., Kuosmanen L. & Välimäki M. 2009. Individual quality of life of people with severe mental disorders. *Journal of Psychiatric and Mental Health Nursing* 16, 3-9.
- II Pitkänen A., Välimäki M., Endicott J., Katajisto J., Luukkaala T., Koivunen M., Kuosmanen L. & Hätönen H. Assessing quality of life in patients with schizophrenia in acute psychiatric setting: reliability, validity and feasibility of the EQ-5D and the Q-LES-Q. Resubmitted.
- III Pitkänen A., Hätönen H., Kuosmanen L. & Välimäki M. 2008. Patients' descriptions of nursing actions supporting their quality of life in acute psychiatric wards: A qualitative study. *International Journal of Nursing Studies* 45, 1598-1606.
- IV Pitkänen A., Hätönen H., Kollanen M., Kuosmanen L. & Välimäki M. Nurses' perceptions of nursing interventions supporting quality of life in acute psychiatric wards. *Perspectives in Psychiatric Care*. In press.
- V Pitkänen A., Välimäki M., Katajisto J., Koivunen M., Kuosmanen L., Hätönen H., Patel A. & Knapp M. Patient education methods to support quality of life and functional ability among patients with schizophrenia: a randomised clinical trial. Resubmitted.

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1. INTRODUCTION

Mental health issues are a matter of international concern and have moved up the policy agenda over the past years (European Commission 2005, WHO 2005, European Commission 2008, WHO 2008). In the European Union about 27% (almost 83 million) of adults suffer or have suffered at least one mental disorder (Wittchen & Jakobi 2005). In addition, it has been estimated that the burden of mental disorders will rise significantly over the next decades (WHO 2003). Mental disorders are associated with massive disruption in patients' lives, causing impaired quality of life (QoL) (WHO 2001a), and also burden to families and wider society (WHO 2003).

Schizophrenia, which is one of the most disabling mental disorders (Mueser & McGurk 2004) is found in all geographical areas (Saha et al. 2005), and it is estimated that 24 million people currently suffer from schizophrenia (WHO 2001b). Schizophrenia is associated with relapses with high hospitalization rates (Almond et al. 2004), loss of ability to work, mortality in younger age than a general population (Knapp et al. 2004), and, especially for these reasons, also with remarkable economic costs worldwide (Knapp et al. 2004, Sadock & Sadock 2007, Wahlbeck & Hujanen 2008). Patients with schizophrenia are also stigmatized, which leads to discrimination (Sartorius 1997, Graf et al. 2004, Thornicroft et al. 2009) and thus affects their life opportunities, such as health care services, housing, education, employment and social relationships (Corrigan & Larsson 2008).

The QoL of patients with schizophrenia has been found to be impaired compared to general population (Lehman et al. 1982, Gupta et al. 1998, Bengtsson-Tops & Hansson 1999, Ponizovsky et al. 2003, Bobes & Carcia-Portilla 2006, Evans et al. 2007). Thus, improving the QoL of such patients is emphasized in clinical practice guidelines all over the world (APA 2004, RANZCP CPG team 2005, Finnish Medical Society Duodecim & Psychiatric Association 2008, NICE 2009). To learn about patients' QoL there is a need to find the most appropriate instruments to assess QoL. Although numerous QoL instruments are available (Bowling 2003, Fayers & Machin 2007), there is a gap in the knowledge of how feasible and valid these instruments are for use with patients with schizophrenia (Bobes & Carciá-Portilla 2006, Wisniewski et al. 2007). More research testing these instruments is therefore needed.

In the care of patients with schizophrenia, interventions which only target symptoms are not enough, but a more holistic view is necessary in which patients' QoL is a central concern (Ministry of Social Affairs and Health 2004, Lasalvia et al. 2005, Knapp et al. 2007, WHO 2008). Thus, in psychiatric nursing, too, there is a need to find interventions by which the QoL of these patients is best supported. Clinical practice guidelines for schizophrenia recommend psychosocial treatments in treating patients with schizophrenia (APA 2004, RANZCP CPG team 2005, Finnish Medical Society Duodecim & Psychiatric Association 2008, NICE 2009). One psychosocial intervention, patient education, seems to be promising in promoting the QoL of these patients (Pekkala & Merinder 2002). In the nurse-patient relationship, patient education

is considered to be an important component of nurse's role (Luker & Caress 1989, Coster & Norman 2009). Thus, to systematically implement patient education in the nurse-patient relationship is preferred. One solution to further improve the quality of patient education may be to direct it towards patient education based on information technology (IT) (Rotondi et al. 2005, Jeste 2008).

Although evidence based nursing has been emphasised increasingly, professional judgement and nursing tradition prevail in decision-making (Stuart 2001, Zauszniewski & Suresky 2004). Moreover, most of the nursing research is still descriptive (Stuart 2001, Burckhardt & Hanestad 2003, Montgomery et al. 2009). Thus there is a need for intervention research to ascertain the effectiveness of nursing interventions (Burns & Grove 2005, Polit & Beck 2010) used in psychiatric nursing in order to find the most effective interventions by which the QoL of patients with schizophrenia is best supported.

The present study was concerned with improving the QoL of patients with schizophrenia in acute psychiatric wards. Thus, the purpose was to identify means by which the QoL of these patients could be improved in acute psychiatric wards. The first objective was to examine the subjective QoL of patients with schizophrenia since it has been found to be impaired (Paper I). The second objective was to examine and compare two standardised QoL instruments because there is a need to find the most appropriate instruments to use among patients with schizophrenia in clinical settings and in research (Paper II). The third objective, based on the findings on the first objective related to patients' most important QoL areas, was to examine patients' and nurses' perceptions of nursing interventions improving patients' QoL in acute psychiatric wards (Papers III and IV). Finally, there is a need to find effective ways to implement nursing interventions to best support patients' QoL. Since earlier studies have shown that patient education is one promising nursing intervention to support patients' QoL (Pekkala & Merinder 2002), the effectiveness of three different patient education methods on the QoL of patients with schizophrenia was compared (Paper V). The results of this dissertation generated knowledge for psychiatric nursing practices to develop and implement interventions in acute psychiatric wards to better improve patients QoL.

2. OVERVIEW OF THE LITERATURE

2.1. Quality of life of patients with schizophrenia

2.1.1 *Patients with schizophrenia in psychiatric services*

Schizophrenia has been categorised as one of the most serious and disabling mental disorders (Mueser & McGurk 2004, Picchioni & Murray 2007). The lifetime prevalence of schizophrenia is estimated to be about 1% worldwide (Mueser & McGurk 2004, Austin 2005), and in Finland 0.87% (Perälä et al. 2007). Schizophrenia typically starts in early adulthood or late adolescence (Picchioni & Murray 2007). It is characterised by three broad types of symptoms: psychotic and negative symptoms and cognitive impairment. The psychotic symptoms of schizophrenia are typically hallucinations and delusions. Common negative symptoms include lack of pleasure, reduce quantity or content of speech and lack of motivation. (Mueser & McGurk 2004, Isohanni et al. 2007.)

Cognitive impairment in schizophrenia leads to problems in attention, concentration and memory, as well as in abstract thinking and problem solving (Mueser & McGurk 2004, Isohanni et al. 2007) which affect patients' social skills and activities in daily living (Austin 2005). Patients with schizophrenia suffer from persistent social disability; only 17% of patients have no social disability after 15 years of the onset of illness (Wiersma et al. 2000). Patients' life expectancy is clearly lower than that of general population. In Finland Tiuhonen et al. (2009) found that in 2006 at age 20 years life expectancy for patients with schizophrenia was 37.4 years and for general population 59.9 years. Increased suicide risk among patients with schizophrenia has been reported (Pinikahana et al. 2003, Ponizovsky et al. 2003, Joukamaa et al. 2006), especially during the first years of the disease (Alaräisänen et al. 2009). Moreover, high level of burden in families of patients with schizophrenia is common (Magliano et al. 2005, Noreen & McCain 2005, Chien et al. 2007).

The economic costs of schizophrenia are remarkable (Knapp et al. 2004, Sadock & Sadock 2007, Wahlbeck & Hujanen 2008). Costs are caused, for example by relapses with high hospitalization rates (Almond et al. 2004), loss of ability to work and family burden (Knapp et al. 2004). Because of significant and long-lasting impairments ongoing clinical care, rehabilitation and support services are required (Sadock & Sadock 2007). In Finland, the costs of schizophrenia are estimated to be 700-900 million Euros per year, of which one third is treatment costs (Wahlbeck & Hujanen 2008).

In Finland, treatment of patients with schizophrenia, and indeed the whole delivery of mental health services, have experienced great changes in recent decades. (Nojonen 1990, Nikkonen 1996, Salokangas 2004, Harjajärvi et al. 2006). The deinstitutionalisation process started in Finland later than in most Western countries (Honkonen et al. 1999, Lehtinen 2001), but the decrease of inpatient psychiatric beds

has been huge. In the early 1980s there were about 20,000 beds (Lehtinen et al. 2006) and in 2008 about 4,500 beds (National Institute for Health and Welfare 2010). The National Schizophrenia Project (1981-1987) (National Board of Health 1988), in particular, which aimed to reduce long-stay inpatient care, develop new community services, and enhance patients' QoL, has had a major role in reducing hospitalization rates. During the years 1982-1992 the number of long-stay patients with schizophrenia treated in hospitals decreased by 63%. (Tuori et al. 1998.) Between the years 1996 and 2008 the number of inpatients treated decreased 4% (30,366 vs. 29,047). During the same time the number of psychiatric inpatient periods decreased 5% (44,319 vs. 42,051), whereas the average length of stay decreased 49%, from 67 days to 34 days (National Institute for Health and Welfare 2010). Psychiatric staff resources also decreased drastically in psychiatric hospitals; 29% during the years 1990 to 1993. On the other hand the educational level of staff has risen. (Ministry of Social Affairs and Health 1996.) The latest national plan (Mieli 2009) to develop Finnish mental health and substance abuse work still emphasizes that the need for psychiatric inpatient beds will be 3,000 beds by 2015 if outpatient care is developed according to the plan's recommendations (Ministry of Social Affairs and Health 2009).

Although outpatient care is emphasized as a primary mental health service (Mental Health Act 1990, Ministry of Social Affairs and Health 2001, Finnish Medical Society Duodecim & Psychiatric Association 2008, Ministry of Social Affairs and Health 2009) inpatient care units have remained an important component of psychiatric care. In 2008, over 32,000 patients were admitted to psychiatric hospitals or to the psychiatric units of general hospitals, of which one third came by involuntary referral. The mean age of all inpatients was 42 years (in patients with schizophrenia 45 years) and the average length of stay 34 days (for patients with schizophrenia 55 days). Schizophrenia was the most common diagnosis. Patients with schizophrenia and related disorders had altogether almost 15,626 inpatient periods in 2008. Fifty-five percent of hospital days were used for treating this group of patients. (National Institute for Health and Welfare 2010.) Thus, patients with schizophrenia still use lot of inpatient treatment, especially younger and male patients, and patients without a network of significant others (Salokangas et al. 2009).

The purpose of acute adult inpatient care is to provide humane treatment in a safe and therapeutic setting for patients in the most acute and vulnerable stage of their illness (Department of Health 2002). It should be used when treatment provided in outpatient settings is not sufficient to manage problems caused by mental disorder (Ministry of Social Affairs and Health 2001, Pirkola & Sohlman 2005). Therefore, acute inpatient wards provide high-intensity care for seriously ill patients, for example, patients experiencing severe psychotic relapse and behavioural disturbance or patients with high levels of suicidality (Thornicroft & Tansella 2004). The aims of treatment of patients with schizophrenia are to relieve symptoms and to improve patients' psychosocial functioning and QoL (Finnish Medical Society Duodecim & Psychiatric Association 2008).

In this study, a patient is understood as an individual, who has her or his own perceptions of her or his position in life, and own goals, expectations, standards, and

concerns (See WHOQOL Group 1993). Moreover, a patient in this study is an individual who has schizophrenia or related disorder (WHO 1992), and is treated in an acute psychiatric inpatient ward. As in the guidelines on schizophrenia, this study, too, uses only the term schizophrenia when referring to schizophrenia and related disorders (ICD10, F20-F29; WHO 1992) (RANZCP CPG team 2005, NICE 2009).

2.1.2 Defining the concept of quality of life

There is so far no consensus on the definition of the concept of QoL (Clark 2004, Bowling 2005, Holmes 2005, Moons et al. 2006, Priebe & Fakhoury 2008), although the term has been in use since the 1960s (Haas 1999). The situation has been addressed through the historical development of the concept by many disciplines with their own differing perspectives (Holmes 2005, Cummins & Lau 2006). Generally, QoL is seen as a multidimensional concept and subjective experience (WHOQOL Group 1993, Harrison et al. 1996, Haas 1999, Bowling 2003, Moons et al. 2006), which may change over time (Harrison et al. 1996, Moons et al. 2006). The concept has also been defined as having subjective and objective components (Haas 1999, Bowling 2003). The subjective components directly address life experiences (Murphy & Murphy 2006). Thus, the concepts, for example, of happiness, well-being, and satisfaction are terms which are closely connected to QoL (Megens & van Meijel 2006, Murphy & Murphy 2006). Objective components address the phenomena that have an effect on these experiences (Murphy & Murphy 2006). The objective aspects refer to social functioning and living conditions, such as education, employment, finance, housing and leisure activities. (Barry & Zissi 1997, Haas 1999, Bowling 2005.)

As a subjective experience (WHOQOL Group 1995, Harrison et al. 1996, Haas 1999, Bowling 2003, Moons et al. 2006) QoL is based on the assumption that each individual has their own definition of QoL (Browne et al. 1997, Fayers & Machin 2007). However, research findings have shown that most people define their QoL in terms of “having a positive psychological outlook and emotional well-being, having good physical and mental health and the physical ability to do the things they want to do, having good relationships with friends and family, participating in social activities and recreation, living in a safe neighbourhood with good facilities and services, having enough money and being independent” (Bowling 2005, p. 9). When patients with schizophrenia (n=565) were asked to define QoL, the most frequently mentioned QoL areas were work, health, leisure activities, social contacts, joy of life, family, financial situation, friends, accommodation and independence (Angermeyer et al. 2001).

A more specific term, health-related quality of life (HRQoL), describes the impact of illness on well-being (Danovitch & Endicott 2008). Health, which was defined by the World Health Organization over 60 years ago, as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO 2010), is one aspect of overall QoL (Bowling 2005, Moons et al. 2006). Based on its definition of health the World Health Organization has defined QoL in the context of health as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (WHOQOL Group 1993, p. 153). Both QoL and HRQoL are

used as concepts in health care research. However, it has been argued that focusing on HRQoL may undervalue the effect of nonmedical factors (Moons et al. 2006).

In the nursing literature the definition of QoL has paralleled other disciplines definitions with a focus on the concept's multidimensionality (Padilla et al. 1992). The nursing theorist Peplau (1991), who has been considered to be the mother of psychiatric nursing (Howk 2002), has defined QoL as an all-encompassing theme which includes virtually all aspects of existence. She continues that QoL "is primarily a perception, an idea that individuals form after sensing, observing, or recognizing intuitively the meaning of something that has been experienced. It is not the experience per se, but rather an opinion or judgement that sums up the essence of a situation, a series of events, or a current view about one's life, in part or in whole, during a given period time. Thus quality of life is time-related and situation-dependent." (Peplau 1994, p.10.) Meeberg (1993) argued, on the basis of a literature review, that the critical attributes of QoL are: (a) "a feeling of satisfaction with one's life in general", (b) "the mental capacity to evaluate one's own life as satisfactory or otherwise", (c) "an acceptable state of physical, mental, social and emotional health as determined by the individual referred to", and (d) "an objective assessment by another that the person's living conditions are adequate and not life-threatening".

In the Finnish Medical Subject Headings (FinMeSH) the term QoL is defined as "a generic concept reflecting concern with the modification and enhancement of life attributes, e.g., physical, political, moral and social environment; the overall condition of a human life". The definition is the same as in the PubMed MeSH database maintained by the United States National Library of Medicine. Further, in Finnish nursing terminology (Hoidokki) life command, zest for life, well-being, functionality and safety are placed under the conception of QoL (Finnish Foundation of Nursing Education 2010).

The subject heading, "quality of life", was introduced in the Cumulative Index for Nursing and Allied Health Literature (CINAHL) in 1983 (Padilla et al. 1992). The concept has been used increasingly in nursing research in recent decades (Moons et al. 2006). At present (19th October 2010) a CINAHL search for "quality of life" produces almost 43,000 citations ("All Text"). When the search is restricted to titles, almost 9,800 citations are still produced. When the search terms "quality of life" and psychiatr* or "mental health" are used 6,500 citations are found when searching from "All Text", and over 1,800 when restricting the search to "quality of life" in titles.

In this study, the concept of QoL will be used based on the assumption that QoL is a multidimensional concept and an individual's subjective experience. The interest is in individuals' experiences of their QoL in general and also especially related to their illness. (WHOQOL Group 1993, Harrison et al. 1996, Haas 1999, Bowling 2003, Moons et al. 2006)

2.1.3 Assessing quality of life

Hundreds of QoL instruments are available for use in research and clinical practice because the lack of conceptual clarity has led to variation in measurement of QoL (Bowling 2003, Fayers & Machin 2007). First, assessment has different focuses: emotional well-being, psychological well-being, social well-being, social roles, physical health, and functioning (Bowling 2003). Second, the form of QoL instruments differs. There are single-item scales including a single global question, multi-item scales producing a total single score, and multi-item scales producing a profile of items (Fayers & Machin 2007). QoL instruments used in psychiatric research and clinical settings are most usually multi-item scales and include QoL areas such as physical, psychological and social functioning (Danovitch & Endicott 2008).

Third, there are two strategies to assess QoL; subjective and objective (Dijkers 1999, Priebe 2007). Subjective assessment represents an individual's appraisal of his or her objective life conditions (Priebe 2007). Objective assessment focuses on data that can be gathered without directly surveying the individuals being assessed (Costanza et al. 2008), for example employment, social contacts and independent accommodation (Priebe 2007). The World Health Organization's (WHOQOL Group 1993) definition of QoL puts primary importance on the individual's perception on QoL, and hence it supports the view that the best person to assess is the person whose QoL should be assessed. However, the validity of self-assessment among patients with schizophrenia has been questioned due to the patients' lack of insight into the illness and their cognitive impairment (Atkinson et al. 1997, Doyle et al. 1999, Avad & Voruganti 2000, Bengtsson-Tops et al. 2005, Bobes et al. 2005, Bobes et al. 2007). On the other hand, most psychiatric patients are able to assess their QoL in a credible manner (Voruganti et al. 1998, Naber et al. 2005, Nørholm and Bech 2006), also clinically compliant and stable patients with schizophrenia (Voruganti et al. 1998, Nørholm & Bech 2006). It is recommended to use both subjective and objective assessment methods among patients suffering from a severe mental disorder, especially when using QoL assessment as a framework for care planning (Bengtsson-Tops et al. 2005). To solve the problem of psychiatric patients' capacity to self-assess QoL Wong et al. (2005) developed an instrument (Capacity to Report Quality of Life; CapQOL), to identify patients who are unable to complete subjective QoL instruments due to their cognitive impairments.

Fourth, in the health care sector two types of QoL instruments have been developed; generic and disease specific (Dijkers 1999, Hays 2005, Danovitch & Endicott 2008). Generic instruments are designed for use with any health conditions and also for healthy people. The advantage of generic instruments is that the relative burden of ill health can be compared across different groups of patients. However, due to the generalizability of the instruments they may ignore specific aspects of QoL, which may be important for specific groups of patients. As such they may lack sensitivity to changes arising as a consequence of treatment. Disease-specific instruments are designed to focus on the issues most relevant to a certain patient group, and as such, they have the potential to be more sensitive (Harrison et al. 1996, Robinson et al. 2003, Hays 2005). It is recommended to use both generic and disease-specific instruments in

tandem whenever possible (Bobes et al. 2005, Hays 2005). Both types of these so-called HRQoL instruments have been criticised in the psychiatric sector as they focus directly on disease-related areas of QoL and functional capacity, and do not address social aspects of life (Katschnig 2006).

Fifth, subjective QoL among individuals has mostly been assessed through standardised instruments with a pre-defined set of specific QoL areas (Doyle et al. 1999). In this case it may be that many QoL areas which are prioritised by individuals as important are not included in instruments, while at the same time including other QoL areas that might be of less importance to individuals. (Angermayer et al. 2001). To avoid this concern so-called respondent-generated instruments such as the Schedule for Evaluation of Individual Quality of Life (SEIQoL; Hickey et al. 1996, Browne et al. 1997) have been developed (Macduff 2000, Bowling 2005). When assessing QoL with these instruments, individuals themselves are asked about the most important things in their lives and then asked to weight these most important things (Hickey et al. 1996, Browne et al. 1997). In addition as a research instrument, the respondent-generated instruments are shown to be useful in clinical practice. They provide a systematic base for patient-centred care, facilitate awareness of patients' concerns and support in monitoring patients' QoL (Kettis-Lindblad et al. 2007). Because the respondent-generated instruments are intended for general use, for any health conditions and for healthy people, these instruments are included in the abovementioned generic instruments group (Fayers & Machin 2007)

Finally, there is also a concept called quality-adjusted life year (QALY), which is developed in health economics to evaluate health benefits in both mortality and morbidity. To assess QALY, respondents are asked to make decisions based on a trade-off between the quality and the quantity of life. QALY has deemed important in cost-utility analysis. (Cummins & Lau 2006.) Preference-based generic HRQoL instruments, such as the Euroqol EQ-5D (EQ-5D; Brooks, with the EuroQoL Group (1996) and the 15D Measure of Health-Related Quality of Life (15D, Sintonen 2001), can be used in QALY calculations.

In order to attain an overview of which have been the most often used QoL instruments in research on patients with schizophrenia in recent years, a literature search was performed using the Ovid MEDLINE and CINAHL electronic databases. The search terms for both databases were schizophrenia, quality of life and measurement or assessment or instrument or scale. The search was limited to the period from 2005 to 2009, in English, and adults (18-65 years). Inclusion criteria were: (1) a QoL instrument was used in the study; (2) sample consisted of patients with schizophrenia and/or related disorders (ICD-10 F20-29; WHO 1992) (3) the article described a single empirical study; (4) researchers reported that they used an instrument to examine QoL, life satisfaction, well-being or happiness; (5) a name of a QoL instrument was mentioned in the abstract or in the full article. Exclusion criteria were: (1) no QoL instrument was used in the study; (2) the sample did not include patients with schizophrenia and/or related diagnosis; (3) the study was testing an instrument's psychometric properties; (4) the article did not describe a single empirical study (instead for example editorial, review, meta-analysis); (5) the full article was not

available via Finnish National Electronic Library Interface (Nelli) portal if a name of an QoL instrument was not clearly described in an abstract. The search were conducted in January 2010.

Altogether 515 articles were found by the search strategy; MEDLINE 369 and CINAHL 146. When duplicates were removed between databases the total number of potential articles was 455. Based on the exclusion criteria 172 articles were excluded. The inclusion criteria were fulfilled in 283 articles. (Figure 1.)

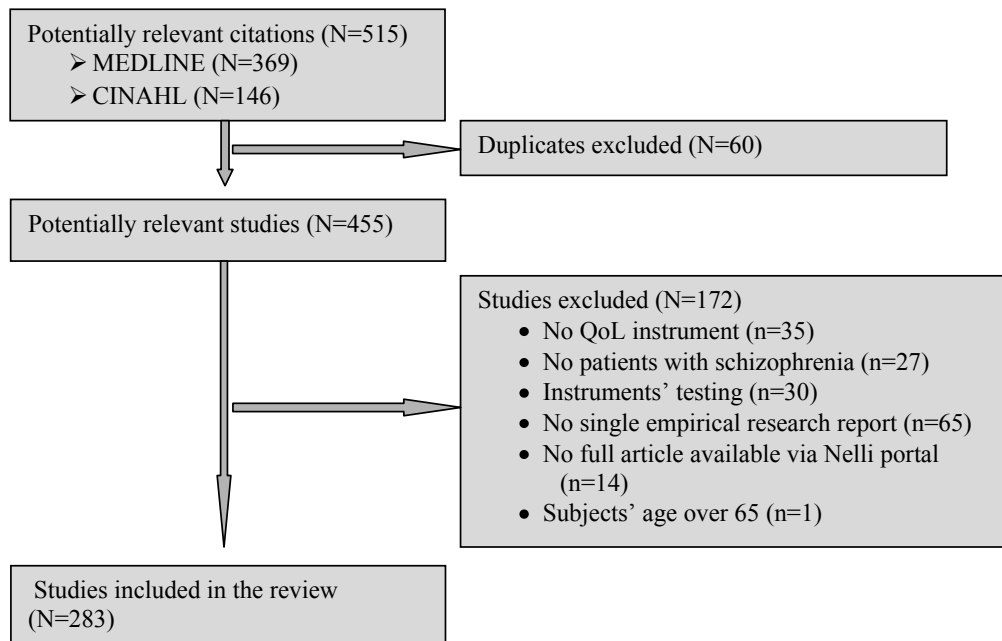


Figure 1. Flowchart of the literature selection process of QoL instruments

In the studies included in the review (N=283) the QoL in patients with schizophrenia was assessed with 29 different QoL instruments (Table 1). The ten most often used QoL instruments are described in Appendix 1.

Table 1. QoL instruments used in research among patients with schizophrenia during the period 2005–2009

	Instruments	Number of articles
1	Quality of Life Scale (QLS, also QOLS); Heinrichs et al., 1984	98
2	The World Health Organization Quality of Life (WHOQOL-100/short form WHOQOL-BREF); WHOQOL Group, 1995	46
3	Medical Outcome Study (MOS) 36-Item Health Survey (SF-36/Short form SF-12); Ware & Sherbourne, 1992	32
4	Lehman Quality of Life Interview (QOLI, also QLI-L); Lehman, 1988	27
5	Manchester Short Assessment of Quality of Life (MANSA); Priebe et al., 1999	19
6	Euroqol EQ-5D (EQ-5D); Brooks with the EuroQoL Group, 1996	12
7	Schizophrenia Quality of Life Scale (SQLS); Wilkinson et al., 2000	12
8	Subjective Wellbeing under Neuroleptic Treatment (SWN/Short form (SWN-K); Naber, 1995	11
9	Lancashire Quality of Life Profile (LQOLP); Oliver et al., 1997	9
10	Quality of Life Enjoyment and Satisfaction Questionnaire Q-LES-Q; Endicott et al., 1993	9
11	Wisconsin Quality of Life Index (W-QLI); Diamond & Becker, 1999	6
12	Satisfaction with Life Domains Scale (SLDS); Baker & Intagliata, 1982	4
13	Quality of Well-Being (QWB); Anderson et al., 1989	3
14	Human Service Scale (HSS); Reagles & Butler, 1976	2
15	Impact of Weight on Quality of Life–Lite Scale (IWQOLLite); Kolotkin et al., 2001	2
16	Menopause-Specific Quality of Life Questionnaire (MENQOL); Hilditch et al., 1996	2
17	Satisfaction with Life Scale (SWLS); Pavot et al., 1991	3
18	15D Measure of Health-Related Quality of Life (15D); Sintonen, 2001	1
19	Affect Balance Scale (ABS); Bradburn, 1969	1
20	Assessment of Quality of Life (AQoL); Hawthorne et al., 1999	1
21	Client’s Assessment of Strengths, Interests, and Goals (CASIG); Wallace et al., 2001	1
22	Happiness (one item); Green et al., 2008	1
23	Quality of Life Index; Ferrans & Powers, 1985	1
24	Quality of Life Scale; Bowie et al., 2007	1
25	Satisfaction with Life Situation (two items); Salokangas et al., 2006	1
26	SCAP-Health Questionnaire (SCAP-HQ); Lehman et al., 2003	1
27	Schedule for Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW); Hickey et al., 1996	1
28	Sheehan Disability Scale (SDS); Leon et al., 1992	1
29	Subjective Quality of Life Profile (SQLP); Gerin et al., 1992	1

As the review shows, numerous instruments have been used to assess QoL in patients with schizophrenia. The instruments differ in the type and form of the instrument. This finding is in line with the study by Montgomery et al. (2009) who reviewed patient health outcomes in psychiatric nursing. They found six RCTs that included six different QoL instruments. Thus, there is no “standard instrument”. In psychiatric nursing, it is important to select the most appropriate QoL instruments from those available. The

instrument should be suitable to the purpose of data collection, and there should be evidence of the instrument's psychometric properties and its feasibility (Awad & Voruganti 2000, Robinson et al. 2003, Priebe 2007, Price et al. 2008, Priebe & Fakhoury 2008). It is notable that in study reports QoL instruments are not described consistently but authors use various names and various abbreviations for the same instrument, which is still one aspect to make literature of QoL assessment more confused.

In this study, consistent with the definition of QoL as a subjective experience, the patients themselves are the best persons to assess their QoL. Further, QoL is assessed with a respondent-generated QoL instrument and with multi-item scales because QoL is a multidimensional concept. (See WHOQOL Group 1993.)

2.1.4 Patients with schizophrenia and quality of life

Since deinstitutionalisation, there has been interest in how patients discharged from hospitals fared in the community (Lehman et al. 1982, Honkonen et al. 1999, Priebe 2007). Thus QoL, too, became a popular outcome in psychiatric research (Fakhoury & Priebe 2002, Katschnig 2006, Bobes et al. 2007, Priebe & Fakhoury 2008). Since then many research findings have confirmed that the presence of schizophrenia is related to poorer subjective QoL (Lehman et al. 1982, Gupta et al., 1998, Bengtsson-Tops & Hansson 1999, Koivumaa-Honkanen et al. 1999, Ponizovsky et al. 2003, Wetherell et al. 2003, Chan & Yu 2004, Thornicroft et al. 2004, Nørholm and Bech 2006, Evans et al. 2007). Several studies have shown that QoL of patients with schizophrenia is poorer than that of the general population (Lehman et al. 1982, Gupta et al. 1998, Bengtsson-Tops & Hansson 1999, Ponizovsky et al. 2003, Bobes & Carcia-Portilla 2006, Evans et al. 2007). Only few studies have compared the impact on QoL on various mental health disorders (Gupta et al. 1998). In Finland, Koivumaa-Honkanen et al. (1999) compared life satisfaction among patients with schizophrenia, major depression and anxiety disorders. The findings showed that patients with schizophrenia rated their life satisfaction most positive although their situation e.g. education, psychosocial functioning, social life and work were poorest when assessed with objective instruments. Moreover, a general population survey concerning the impact of 29 chronic conditions on health-related QoL found that depressive and anxiety disorders have a major impact on QoL than psychosis (Saarni et al. 2006).

Honkonen et al. (1999) found that in Finland patients with schizophrenia had difficulties in taking responsibility for their own care, managing money and integrating into social life. Salokangas et al. (2001) argued that patients with schizophrenia who were discharged from hospital got too high doses of medication causing them restrictions in social functioning. On the other hand, it has been reported that in Finland patients with schizophrenia are mostly satisfied with their care and quite satisfied on their subjective QoL (Salokangas et al. 2000, Seppälä et al. 2000, Heikkilä et al. 2001, Nordling 2007). Researchers have noted that surprisingly good results related to satisfaction among patients with schizophrenia may be explained by the reduced expectations of these patients (Carr et al. 2003, Hofer et al. 2004, Becker et al. 2005); as a consequence of the process of human adaptation (Becker et al. 2005). Further, it has been argued that patients with poor insight into the presence of their illness, like

patients with schizophrenia (Lincoln et al. 2007), report higher QoL indicating that patients with greater insight realise their restrictions more clearly (Karow et al. 2008).

Much research on QoL of patients with schizophrenia has reported a number of factors, which are potentially related to impaired QoL in patients with schizophrenia. These factors must be kept in mind when planning interventions by which patients' QoL can be enhanced. The factors from the research overview related to decreased QoL will be presented according to the WHOQOL Group's conception of QoL domains: psychological domain, physical domain, level of independence, social relationships, and environment (WHOQOL Group 1993) (Figure 2).

First, research findings have demonstrated that in people with schizophrenia poorer QoL can be attributed to the psychological domain of QoL. The psychological domain includes various kinds of psychiatric symptoms, such as anxiety, depression, and psychosis (Bengtsson-Tops & Hansson 1999, Fahy et al. 1999, Hansson et al. 1999, Bechdolf et al. 2003, Hansson et al. 2003, Reine et al. 2003, Wetherell et al. 2003, Chan & Yu 2004, Hofer et al. 2004, Thornicroft et al. 2004, Braga et al. 2005, Caron et al. 2005, Nørholm & Bech 2006, Salokangas et al. 2006, Eack et al. 2007, Heider et al. 2007, Marwaha et al. 2008) and side effects of medication (Reine et al. 2003, Hofer et al. 2004). Moreover, low self-efficacy (Bechdolf et al. 2003), self-esteem (Hansson et al. 1999, Hansson et al. 2003), and perceived stigma (Graf et al. 2004), as well as negative coping strategies (Bechdolf et al. 2003), poor problem-solving ability (Caron et al. 2005), and a negative attitude toward antipsychotic medication (Hofer et al. 2004) are determinants of the psychological domain of QoL, which may impair QoL of patients with schizophrenia.

Second, reduced QoL among patients with schizophrenia can be attributed to the physical domain of QoL as a weakened physical state (Hansson et al. 1999, Salokangas et al. 2006). Third, impaired QoL is also attributed to level of independence. Patients who have problems in psychosocial functioning (Salokangas et al. 2006), high level of unmet needs (Fahy et al. 1999, Hansson et al. 2003, Eack et al. 2007) and low number of daily activities (Marwaha et al. 2008) have been shown to suffer from impaired QoL. Moreover being admitted to a psychiatric hospital (Gråwe & Løvaas 1994, Kaiser et al. 1997), many previous psychiatric admissions (Chan & Yu 2004) and alcohol abuse of these patients is related to impaired QoL (Thornicroft et al. 2004, Marwaha et al. 2008, Rocca 2009).

Fourth, impaired QoL in patients with schizophrenia may also be associated with social relationships, such as weak social support (Koivumaa-Honkanen et al. 1999, Bechdolf et al. 2003, Caron et al. 2005, Eack et al. 2007), loneliness (Hansson et al. 1999, Hansson et al. 2003, Thornicroft et al. 2004, Salokangas et al. 2006), and unsatisfied amount of contact with family members (Thornicroft et al. 2004, Marwaha et al. 2008). Finally, matters related to patients' environment may impair QoL. It has been shown that being unemployed or dissatisfaction with work situation (Chan & Yu 2004, Thornicroft et al. 2004, Bengtsson-Tops & Hansson 1999, Hansson et al. 1999) and insufficient financial means (Bengtsson-Tops & Hansson 1999, Heider et al. 2007) are related to impaired QoL. Moreover, impaired QoL correlates with meaningless and few

leisure activities (Hansson et al. 1999, Thornicroft et al. 2004), poor personal safety (Hansson et al. 1999), and being a victim of crime (Marwaha et al. 2008).

It is noteworthy that in the literature predictors related to QoL are somewhat contradictory; while some studies have reported negative influence on QoL others have not found any. A summary of the above literature of potential factors related to impaired QoL in patients with schizophrenia is presented in Figure 2 grouped according to the WHOQOL Group's (1993) conception of QoL domains.

In this study, patients with schizophrenia are seen as individuals whose QoL may be impaired for various reasons due to their illness, and thus the main concern in the treatment of these patients should be to enhance their QoL (Ministry of Social Affairs and Health 2004, Lasalvia et al. 2005, Knapp et al. 2007, WHO 2008).

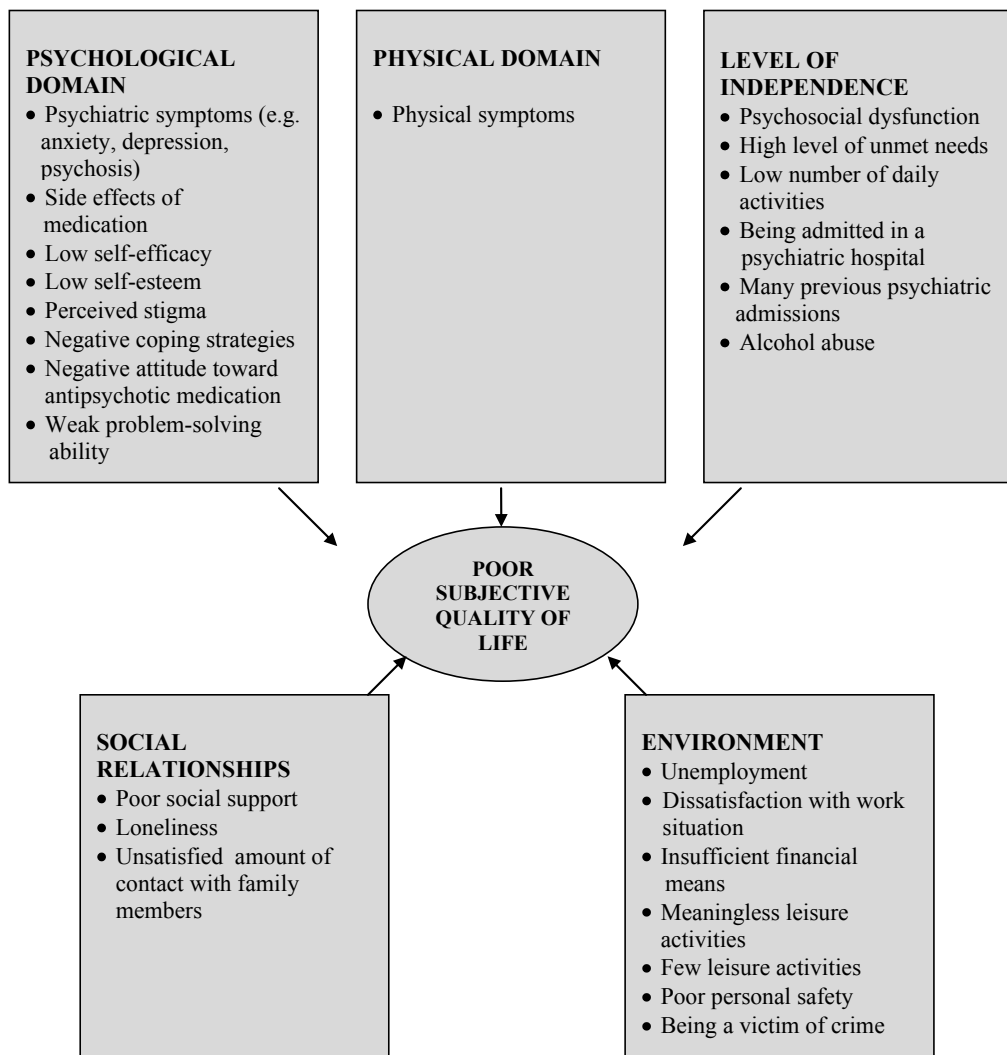


Figure 2. Factors potentially impairing QoL in patients with schizophrenia grouped according to the WHOQOL Group's (1993) conception of QoL domains.

2.1.5 Interventions to improve patients' quality of life in acute psychiatric wards

In Finland there are no national instructions or guidelines specifically regarding psychiatric care in acute psychiatric wards. However, there is legislation (Mental Health Act 1116/1990, Act on the Status and Rights of Patients 785/1992) and quality recommendations for mental health services (Ministry of Social Affairs and Health 2001). According to these guiding principles, patients with schizophrenia in acute psychiatric wards have the right to receive good care, to be treated with respect, to be informed and to make their own decisions. Care should be planned based on appraised individual needs. A patient and his or her close relatives and friends should be able to participate in the planning and assessment of care. All treatment should include elements of rehabilitation which aim to promote patients' coping, functional and working capacity. Moreover, continuity of care should be taken into consideration. The recently published national plan for mental health and substance abuse work also emphasises the strengthening of patients' status (Ministry of Social Affairs and Health 2009). Besides these general principles, there is a clinical guideline regarding schizophrenia (Finnish Medical Society Duodecim & Psychiatric Association 2008), which can be applied when treatment in the acute inpatient ward is planned.

Decreased length of stay (Johnstone & Zolese 1999, Pirkola & Sohlman 2005), increased patients' acuity and safety issues (Bowers et al. 2005, Fourie et al. 2005) as well as patients' diverse care needs (Bowers et al. 2005) are challenges for nursing in acute psychiatric wards (Cleary et al. 2005). These new challenges as well as quality recommendations and guidelines for the treatment of patients with schizophrenia, highlight a need to shift the focus of care towards goals meaningful to patients. Outcomes can no longer be defined only as symptoms but also in terms of psychological well-being, daily functioning, achieving social opportunities and support from the environment (Ministry of Social Affairs and Health 2004). Thus, interventions to manage symptoms are not enough; a more holistic view of interventions is needed in which patients' QoL is the primary concern (Ministry of Social Affairs and Health 2004, Lasalvia et al. 2005, Knapp et al. 2007, WHO 2008).

The holistic view is also an important aspect of mental health recovery (Bradstreet 2006). Recovery has evolved out of service users' movements around the world (Bellack 2006, Scottish Executive 2006), and is nowadays an important concept in many mental health policies and planning documents (Bradstreet 2006). Recovery means that a person is able to live a meaningful and satisfying life, as defined by each individual, in the presence or absence of symptoms (Bradstreet 2006, Scottish Recovery Network 2009). This holistic view of recovery considers all elements of a person's quality of life and the focus is on a person's strengths and a more optimistic approach to mental illness (Bradstreet 2006).

Nursing interventions in psychiatric care can play a pivotal role in this new holistic view of psychiatric care and patients' recovery because nursing emphasizes patients' responses to their illness, their functional adaptation and their holistic needs (Boyd 2005). In psychiatric nursing nurses use broad-based interventions (Peplau 1997, Boyd 2005) aiming to enhance patients' QoL (Nikkonen 1996, Clark 2004, Ministry of

Social Affairs and Health 2004, Tiri 2005). The core element of psychiatric nursing is an interactive process in the nurse-patient relationship (Peplau 1997, Chambers 1998, Fourie 2005, Hewitt & Coffey 2005, Schröder et al. 2006). Because human relationships are important determinants of QoL, patient-nurse relationships are also expected to enhance patients' QoL (Peplau 1994). QoL provides a good and broad view for this interpersonal relationship to discuss the patient's individual perceptions and needs and to let the patient to become a central player in his or her care (Clark 2004).

Clark (2004) interviewed nineteen nurses caring in the community for patients with serious mental illness. The nurses reported that when aiming to enhance patients' QoL they based their nurse-patient relationship on respect, dignity and empowerment, hearing the hopes and dreams of the patients, advocating for and educating them, and helping them to develop their own QoL goals. Meeting patients' basic needs, promoting access to resources and managing symptoms were also important interventions to enhance patients' QoL. On the other hand, in a nurse-patient relationship, depending on the patient's individual needs, nurses can enhance patients' QoL by almost any nursing intervention. (Clark 2004.)

In this study, psychiatric nursing is understood as a therapeutic and educative process, based on an interpersonal relationship between a patient and a nurse (Peplau 1991), where the patient's QoL is the primary concern (Ministry of Social Affairs and Health 2004, Lasalvia et al. 2005, Knapp et al. 2007, WHO 2008).

2.1.6 Effectiveness of patient education interventions to improve quality of life of patients with schizophrenia

Recently the increasing interest in evidence-based health care (EBHC) and further evidence-based nursing (EBN) has called for nurses to apply evidence in practice (Geanellos 2004, van Meijel et al. 2004, Scott & McSherry 2008). EBN has been defined by Scott & McSherry (2008) as a practice which "indicates the use of evidence, theory and expertise in making decisions about optimum care for and with the individual patient". Randomized controlled trials (RCTs) are recognised to be the most powerful research method to find the best evidence about the effectiveness of an intervention (Everitt & Wessely 2008) but have received only slight attention in nursing (van Meijel et al. 2004). Most psychiatric nursing research (Stuart 2001, Montgomery et al. 2009), as well as nursing research in general, is still descriptive (Burckhardt & Hanestad, 2003). A review of the effects of nursing interventions on patients' QoL including 46 studies found that only half were randomized controlled trials (Burckhardt & Hanestad, 2003). Moreover, in a review by Zauszniewski & Suresky (2004) out of 227 studies published in the five most commonly read psychiatric nursing journals only 11% examined nursing interventions. It is therefore unknown if the interventions in psychiatric care actually improve patients' QoL.

Nevertheless, based on best practice clinical guidelines, psychosocial interventions are methods which should be included in the treatment of patients with schizophrenia (APA 2004, RANZCP CPG team 2005, Finnish Medical Society Duodecim &

Psychiatric Association 2008, NICE 2009). These interventions, which aim to improve patients' QoL, functioning and recovery, include various interventions one of which is psychoeducation (Jones & Marder 2008). Psychoeducation is defined as the education of an individual with mental disorder in subject areas that serves the aims of treatment and rehabilitation (Pekkala & Merinder 2002). The terms "patient education", "patient teaching", and "patient instruction" are also terms which have been used as methods to support the information receiving of patients with mental disorders (Dowrick et al. 2008).

Pekkala & Merinder (2002) undertook a Cochrane review of the effectiveness of psychoeducational interventions in patients with schizophrenia. Ten studies were included in the review. The studies included individual and group models of psychoeducation. The authors reported that psychoeducation has benefits compared with standard care. The review concluded that psychoeducation possibly has a positive effect on patients' wellbeing. The conclusion was based on three studies measuring patients' global psychosocial functioning. In their implications for further research they recommended that QoL should be an outcome measure in the examination of psychoeducational interventions.

In order to attain an overview of the literature including QoL as a primary or secondary outcome in patient education research among patients with schizophrenia, and to have an overview of the effectiveness of those interventions on QoL, a literature search was conducted. Electronic databases MEDLINE, CINAHL and PsycINFO over the last twenty years (1990-2009) were searched. The search period was restricted because QoL instruments have been used as outcome in clinical trials in psychiatry research since 1990s (Pinikahana et al. 2002). The search was conducted using the following search terms: (1) quality of life, life satisfaction, well-being or happiness; (2) schizophrenia; (3) randomized controlled trial, controlled clinical trial or clinical trial; and (4) education, teaching, informing, counselling or learning. Searching was restricted to the English language. All searches were conducted in February 2010.

To help to answer the research question and to refine the search strategy the populations, interventions, comparisons and outcomes (PICO) framework for systematic reviewing (Higgins & Green 2009) was used. Inclusion criteria were: (1) adult patients with schizophrenia or related disorders (ICD-10 F20-29; WHO 1992); (2) intervention included patient education; (3) randomized or quasi-randomized trial which compared patient education to standard care or other interventions; (4) primary or secondary outcomes: quality of life, life satisfaction, well-being or happiness.

The search strategy produced 93 potentially relevant citations; MEDLINE 55, CINAHL 28 and PsycINFO 10. When duplicates were removed between databases the total number of potential articles was 81. After the abstracts of potential articles had been examined, 61 articles were excluded based on the exclusion criteria. Twenty studies were examined in more detail. The inclusion criteria were fulfilled in five articles. The reasons for the exclusion of the studies in the final step were: no patients with schizophrenia (n=2); no education intervention (n=10); no intervention research

(n=2); no QoL measure (n=1). A flowchart of the selection process is presented in Figure 3.

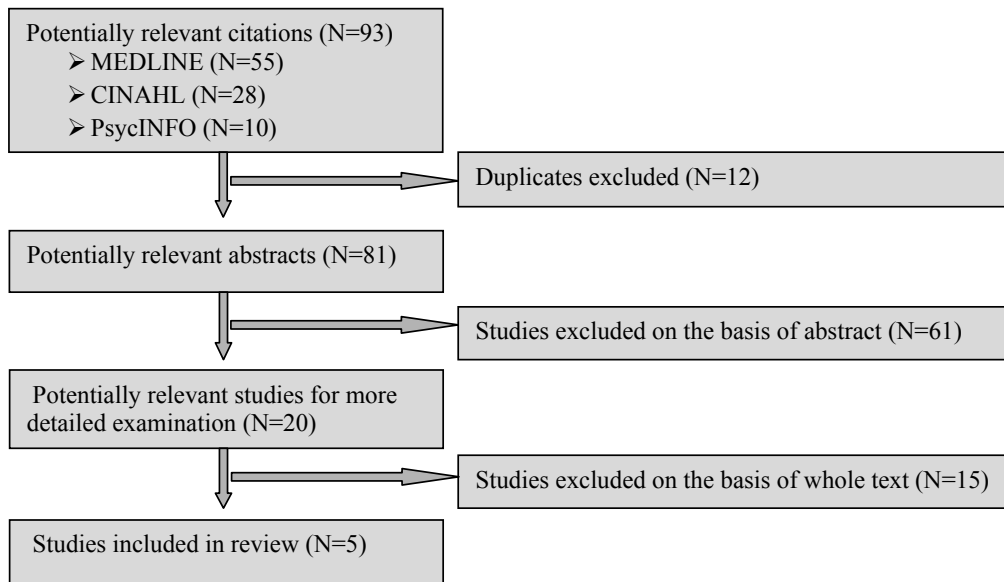


Figure 3. Flowchart of the literature selection process of RCTs related to patient education

The literature search showed that QoL has been used as an outcome measure in some RCTs of patient education among patients with schizophrenia (Table 2). Only two studies in this literature review (Atkinson et al. 1996, Evans et al. 2005) reported significant differences in QoL between study groups. Atkinson et al. (1996), who compared the effects of an education group with a group on a waiting list found significantly greater improvement in QoL after education sessions in the intervention group compared to the waiting list group (68.5 vs. 60.3, $p=0.02$), and this difference persisted at 3-month follow-up (67.9 vs. 58.2, $p=0.01$). In this study, weekly sessions, lasting for 20 weeks, alternated between information sessions including short presentation and discussion, and problem-solving sessions. The sessions included information about matters related to schizophrenia, treatment and rehabilitation. The groups were conducted mainly by a community psychiatric nurse but included also a registrar and an occupational therapist. All group leaders were trained to run groups.

Moreover, Evans et al. (2005) reported significantly greater improvement (1.4 vs. 0.5, $p=0.047$) in the intervention group when testing the effects of a 3-month individual nutrition education and standard care among patients with olanzapine as medication. In both groups patients received passive nutritional education from the booklet ("Food for the Mind"). In addition to this booklet the intervention group received six individual nutrition education sessions over a 3-month period. An accredited practising dietitian conducted the education lasting one hour. It is noteworthy that in this study 25% of patients had other diagnosis than schizophrenia or related disorder. (Table 2.)

Vreeland et al. (2006) reported the effects of a group based psychoeducational programme (Team Solutions) (n=40) compared with care as usual (n=34). The Team Solutions treatment model is a modular psychoeducational programme that includes the following themes: symptoms of mental illness, medications, relapse prevention, coping strategies, and how to avoid crisis. Education groups were held on two days per week, twice a day, over 24 weeks. Groups were conducted by regular staff who worked in day treatment programmes from which the participants were recruited, or by psychology interns, externs, and postdoctoral fellows. All group leaders received two days' training. No significant changes were found related to QoL from pre- to post intervention in the intervention, except for the self-concept domain in the intervention group (1.9 vs. -0.7, $p < 0.05$). (Table 2.)

In the study by Gray et al. (2006) two different education methods were used. Six elements (assessment, medication problem solving, exploring ambivalence, discussing beliefs and concerns about medication, using medication in the future) formed the core of an adherence therapy group. In an individual health education group the themes included diet and healthy lifestyle. In both groups there were at most eight weekly sessions. Groups were conducted by one of nine therapists representing psychologists, psychiatrists and mental health nurses. No significant changes in QoL were found in either group at 12-month follow up. (Table 2.)

Sibitz et al. (2007) found that a QoL oriented psychoeducational programme with booster sessions is not more effective than a basic psychoeducation programme. In this study, in the first phase, patients (n=103) attended weekly group education meetings for nine weeks. The education included illness related (concept of illness, symptoms and early warning signs, medication, illness related stigma) and QoL related (improving well-being, how to make friends, how to actively plan and manage everyday life, how to create more pleasant environment) themes. After the programme 50% of the education groups were block-randomized to either the groups that continued with booster sessions or with routine clinical care. The booster sessions were held monthly for a further nine months. The booster sessions were based on earlier themes except that a few new topics, e.g. how to manage aggression were integrated to programme. A psychiatrist conducted the groups. (Table 2.)

As the review shows, the findings of RCTs' related to patient education were contradictory. Some studies found significant differences between study groups whereas others did not. It should be noted that the models of patient education, the instruments used and study durations varied. Two studies used individual based and three group based education interventions. Only Atkinson et al. (1996) used a disease-specific QoL instrument. The reports were inadequate to the extent that their quality was uncertain. All studies reported that randomization was done. However, only three described the means of randomization. Blinding was reported in two articles, power calculation was stated only in one article, and drop-out analysis in two articles. Three studies used intention-to-treat analysis. Further, none of the studies were conducted solely on inpatients. (Table 2.) Thus, in light of this literature review, further research is needed to evaluate the impact of patient education on the QoL of patients with schizophrenia.

Table 2. Summary of the RCTs with QoL as an outcome measure related to patient education among patients with schizophrenia.

Author(s) (year), country	Method	Participants	Intervention	QoL instrument	Length of follow up	Effectiveness on QoL
Atkinson et al. (1996), UK	Random allocation, not specified Blinding not specified Power calculation not specified Drop-out analysis not specified Completer analysis	146 outpatients; schizophrenia	Education group (n=73) (ran for 20 weeks, weekly, 1½ hours) vs. waiting list control group (n=73)	Quality of Life Scale (QLS)	3 months after intervention	Significantly greater improvement in the intervention group
Evans et al. (2005), Australia	Random allocation, not specified Blinding not specified Power calculation not specified Drop-out analysis Completer analysis	51 outpatients, of whom 38 patients with schizophrenia, schizoaffective disorder or schizophreniform psychosis	Individual nutrition education (n=29); 6 one hour sessions over a 3-month period vs. standard psychiatric care (n=22) Moreover, all received a booklet on nutrition	Self report one item QoL scale (Subjective view of improvement in QoL)	End of intervention	Significantly greater improvement in the intervention group
Vreeland et al. (2006), USA	A table of random numbers Single-blind Power calculation not specified Drop-out analysis not specified Intention-to treat analysis	71 outpatients; schizophrenia or schizoaffective disorder	Group based psychoeducational programme (Team Solutions groups); 2 days per week, twice a day, over 24 weeks vs. care as usual (n=34)	Psychological General Well-Being Scale (PGWB)	End of intervention	No significant differences between groups, except for the self-concept subscale in the intervention group

Author(s) (year), country	Method	Participants	Intervention	QoL instrument	Length of follow up	Effectiveness on QoL
Gray et al. (2006), Netherlands, Germany, UK, Italy	Block randomization, stratification by an independent clinical trials unit Single-blind Power calculation Drop-out analysis Intention-to-treat analysis	409 in- and outpatients; schizophrenia	Individual adherence therapy (n=165) vs. individual didactic health education (n=184); In both groups: 8 sessions, weekly	Medical Outcome Study 36-item Short Form Health Survey (SF-36)	12 months after randomization	No significant differences between groups
Sibitz et al. (2007), Austria	Block randomization Blinding not specified Power calculation not specified Drop-out analysis Intention-to-treat analysis	103 outpatients; schizophrenia or schizoaffective disorder	Group based psychoeducation (n=55) vs. group based psychoeducation with booster sessions (n=48) In both conditions weekly group meetings over 9 weeks; booster sessions monthly over 9 months	The Quality of Life Index (QLI)	12 months after baseline	No significant differences between groups

2.2. Summary of the literature

Schizophrenia is one of the most serious and disabling mental disorders. Thus, an important aim in treating these patients is to improve their QoL. Although the concept of QoL is widely used in research and clinical settings it has not yet been defined in uniform way. However, based on a growing amount of literature it can be concluded that QoL is a multidimensional concept and subjective experience, which can change over time. Lack of conceptual clarity in QoL has led to a situation where hundreds of QoL instruments have been developed. These instruments have different focuses, forms and assessment strategies. In the health care sector there are both general and disease-specific instruments available. Moreover, so-called respondent-generated instruments have been developed. Further, the concept QALY has been developed for health economic purposes. A literature search over the five last years showed that in research among patients with schizophrenia numerous different QoL instruments are also used. Although no “best instrument” exists, there is a need to find the most appropriate instruments to use in research on schizophrenia. There has been marked interest in the assessment of QoL in patients with schizophrenia. Many research findings have confirmed that patients with schizophrenia suffer from impaired QoL. This impaired QoL can be attributed to five factors: individual’s psychological and physical characteristics, level of independence and social relationships, and also environmental considerations.

According to the best practice clinical guidelines there is a need to shift the focus of care of patients with schizophrenia towards QoL along with symptoms management. Nursing interventions can play a crucial role in this more holistic view of care. In psychiatric nursing the core element is the nurse-patient relationship, in which nurses may use various interventions to enhance patients’ QoL. However, in acute psychiatric wards where length of stay is decreased, patients’ acuity increased and where patients have more diverse needs, it is a challenge to nurses to provide broad-based interventions by which patients’ QoL can be enhanced. Moreover, it has been increasingly recognized that nursing should be evidence based. Still, most psychiatric nursing research is non-experimental. This is also the case when reviewing literature related to patient education to improve QoL of patients with schizophrenia. However, the practice clinical guidelines recommend patient education as an important treatment intervention in the care of patients with schizophrenia. There is therefore a need to find the most appropriate ways to conduct patient education among this group of patients to best improve their QoL.

3. OBJECTIVES OF THE STUDY

The purpose of the present study was to identify means by which QoL of patients with schizophrenia could be improved in acute psychiatric wards. The specific objectives and research questions of the study were:

- 1. To examine subjective QoL of patients with schizophrenia (Paper I)**
 - 1.1. Which are the important areas of QoL for patients with schizophrenia and related disorders?
 - 1.2. How do patients rate their satisfaction in each QoL area they have named?
 - 1.3. What is the relative importance of each QoL area named to patients' overall QoL?

- 2. To examine and compare the psychometric properties and feasibility of QoL instruments among patients with schizophrenia (Paper II)**
 - 2.1. What is the internal consistency of two QoL instruments?
 - 2.2. What is the validity of two QoL instruments?
 - 2.3. What is the feasibility of two QoL instruments?

- 3. To examine patients' and nurses' perceptions of nursing interventions improving patients' QoL in acute psychiatric wards. (Paper III, Paper IV)**
 - 3.1. What do patients perceive as being important nursing interventions for improving their QoL? (Paper III)
 - 3.2. What changes do patients propose to improve their QoL? (Paper III)
 - 3.3. What do nurses report as nursing interventions by which they have supported patients' QoL? (Paper IV)
 - 3.4. What kind of interventions do nurses suggest to further improve patients' QoL? (Paper IV)

- 4. To compare the effectiveness of different patient education methods on QoL of patients with schizophrenia (Paper V)**
 - 4.1. What are the effects of different patient education methods on patients' QoL?
 - 4.2. What are the effects of different patient education methods on patients' functional disability?

The following hypotheses were addressed:

 - a) Systematic patient education is more effective than conventional methods with regard to QoL.
 - b) Systematic patient education is more effective than conventional methods with regard to functional disability.
 - c) Computer based patient education has more beneficial effects on patients' QoL than oral sessions with leaflets or conventional methods.
 - d) Computer based patient education has more beneficial effects on patients' functional disability than oral sessions with leaflets or conventional methods.

The study process is described in Figure 4.



Figure 4. Study process.

4. METHODOLOGY

The present study is concerned with improving QoL of patients with schizophrenia in acute psychiatric wards. To obtain a broader and more complete picture of psychiatric nursing practice mixed methods were used (Burns & Grove 2005, Flemming 2007, Johnson et al. 2007).

4.1. Design, setting and sample

In **phase I**, an explorative descriptive study design was used. The data were collected in seven acute psychiatric wards of two general hospitals in southern Finland. The inclusion criteria were: diagnosis schizophrenia, schizotypal or delusional disorders (F20-29) according to the ICD-10 criteria (WHO 1992), symptomatically stable condition evaluated by the personnel on the study wards, age 18-65, able to speak Finnish and competent to give written informed consent. The study sample consisted of 35 patients. (Paper I.)

In **phase II**, a cross-sectional descriptive study design was used. The data used were baseline data in a multi-centre project (Mieli.Net Project, Academy of Finland, TERTTU 2004-2007) where an interactive web-based patient education system (Mieli.net; Mental.net) was developed (Välimäki et al. 2008). The data collection took place on nine acute psychiatric wards of two psychiatric hospitals in southern Finland. The inclusion criteria for patients were: age 18-65, diagnosis schizophrenia, schizotypal or delusional disorder (F20-29, according to the ICD-10 criteria; WHO 1992), ability to speak and write Finnish, and competent to give written informed consent. Out of 2,793 patients screened, a total of 829 patients met the inclusion criteria and 38% (n=311) were willing to participate. (Paper II.)

In **phase III**, an explorative descriptive study design was used. The data were collected on the same seven acute psychiatric wards as in phase I. This phase was conducted in two parts. In the first part, the sample consisted of the same patients (n=35) as in phase I (see phase I). (Paper III.) In the second part, purposive sampling was used in order to reach nurses who had experience of acute psychiatric inpatient nursing and were willing to share and discuss their views (Burns & Grove 2005, Parahoo 2006). The sample consisted of 29 nurses. (Paper IV.)

In **phase IV**, a randomized three-arm longitudinal controlled trial design was undertaken in the Mieli.Net project. Patients were randomly assigned to three treatment groups: a computerised patient education group (IT education group; intervention group; Mieli.Net portal), an education group with oral sessions and written material (conventional education group; comparison group), and an education group with standard treatment (standard care group; control group). The content of the education material developed in the intervention group as well as in the comparison group covered five areas: illness, treatment, well-being, support and patients' rights. In

addition, in the intervention group there was a channel for peer support, eSupport tool for counselling and links to web-pages including public services. In both groups one information session and five education sessions based on five information areas were held during inpatient care. In the control group education was given according to ward standards.

The study inclusion criteria and the study sample were identified in phase II. The sample size was estimated on the basis of earlier research findings with the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q; Danovitch & Endicott 2008), the primary outcome measure of this study. It was estimated that to achieve a difference of seven points on the scale between group means (within group SD =10) for global Q-LES-Q index to be statistically significant at the 0.05 level with 90% power, group size should be at least 53 participants. The study design is described in Figure 5. (Paper V.)

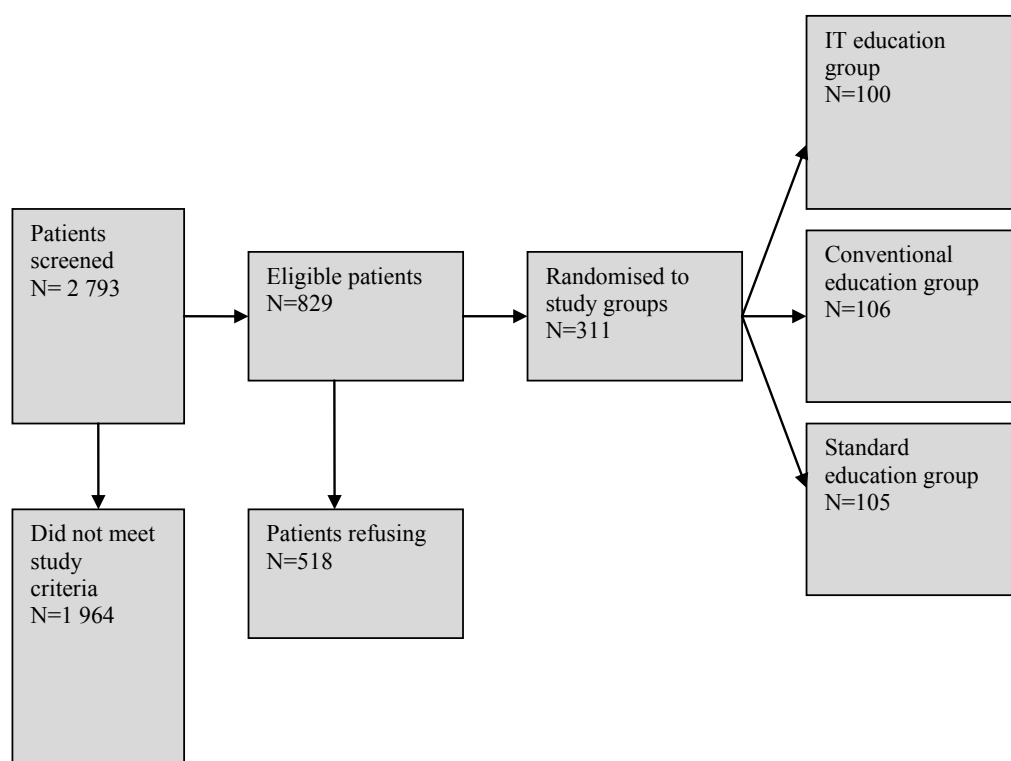


Figure 5. Study design comparing the effectiveness of different patient education methods.

4.2. Instruments

In **phase I**, QoL was assessed with a patient-generated measure the Schedule for Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW; Hickey et al. 1996, Browne et al. 1997). The SEIQoL-DW is a simplified version of the Schedule for Evaluation of Individual Quality of Life (SEIQoL), which was developed in Ireland

based on a phenomenological approach that QoL is individual and the measurement should offer the unique individual perspective on QoL. As such, it is a generic QoL instrument and may be used among various groups of patients and among healthy people as well. (O'Boyle et al. 1993.) The SEIQoL-DW is a semi-structured interview with three steps. First, patients select the five most important areas of their lives. Second, patients determine the current level of satisfaction in each selected QoL area. Finally, patients judge the relative importance of each QoL area by using a direct weighting disk. An overall score (SEIQoL Index) representing overall subjective QoL is then calculated (Hickey et al. 1996, Browne et al. 1997.) Time to complete the instrument takes 5 to 15 minutes (Patel et al. 2003). The Finnish version of the instrument used in this study was translated and back-translated according to standard procedures (Burns & Grove 2005). (Paper I.)

Over the past few years the SEIQoL-DW has been increasingly used, both in clinical practice and research (Wettergren et al. 2009). It has also been used among patients with severe mental disorders (Hantikainen et al. 2001, Prince & Gerber 2001, Mahone 2008) and the acceptance of the instrument has been good (Hantikainen et al. 2001, Prince & Gerber 2001). Wettergren et al. (2009) reviewed 39 articles using the SEIQoL-DW. They found that convergent validity ranged mostly from moderate ($r=0.30-0.49$) to high ($r >.49$). Discriminant validity, which was measured by correlations between the SEIQoL Index score and self-reported instruments of health and functional status, appeared to be acceptable. Four studies reported moderate ($r=0.30-0.49$) and eight weak ($r<.30$) discriminant validity. (Wettergren et al. 2009.) The study among patients with serious mental illness reported high convergent validity ($r >.49$) of the SEIQoL Index score with the Quality of Life Inventory (QOLI) and Satisfaction with Life Scale (SWLS) (Prince & Gerber 2001). (Paper I.)

Gender, age, marital status and employment status were investigated as sociodemographic variables. Diagnosis, number of previous admissions to psychiatric inpatient care and average length of current hospitalization were medical history variables. (Paper I.)

In **phase II**, QoL was assessed by two QoL instruments: the Quality of Life Enjoyment and Satisfaction Questionnaire Short Form (Q-LES-Q SF; Danovitch & Endicott 2008) and the EuroQoL (EQ-5D; Brooks 2003, EuroQoL Group 2010). The Q-LES-Q was developed in the USA in the early 1990s for use in depressive patients to assess respondents' degree of enjoyment and satisfaction in different areas of daily life (Endicott et al. 1993). It is a self-administered instrument. The long version of the Q-LES-Q includes 60 items with 33 additional optional items. The Q-LES-Q SF, which is identical to the General Activities subscale of the longer version of the Q-LES-Q instrument, includes 16 items. Each item is scored on a 5-point scale from "very poor" to "very good". The global QoL index can be summed of the first 14 items. Two last items deal with medication and overall life satisfaction. It takes about five minutes to complete the Q-LES-Q SF scale. (Danovitch & Endicott 2008.) The Finnish version of the Q-LES-Q SF was translated and back-translated according to standard procedures (Burns & Grove 2005). The Q-LES-Q has been used with psychiatric patients (Bishop et al. 1999, Ritsner et al. 2002, Ritsner 2003, Demyttenaere et al. 2008) and also

among patients with schizophrenia in clinical trials (Kingsep et al. 2003, Ritsner & Gibel 2006). The Q-LES-Q scale demonstrated high internal consistency (Cronbach's α 0.82-0.94) and test-retest reliability (0.90) in this group of patients (Ritsner et al. 2005.) Wisniewski et al. (2007) compared the Q-LES-Q SF with the SF-12 in a depressed population and found a significant correlation between the Q-LES-Q SF total score with the SF-12 Mental Function ($r=0.399$) and with Physical Function item ($r=0.332$). (Paper II.)

The EQ-5D was developed in the late 1980s by the EuroQoL Group, with group members from various European countries. The instrument was designed to describe and evaluate health-related QoL. (Brooks, with the EuroQoL Group 1996). It is a generic, self-report instrument which consists of a descriptive part and a visual analog scale (EQ-VAS). The descriptive part includes five items divided into three degrees of severity: no, moderate and major problems. By combining one level from each of the five items a total of 243 different health conditions can be defined, which can be converted into a single index score (EQ-I) by using different weighting methods (in this study Ohinmaa and Sintonen 1995). (Brooks 2003, EuroQoL Group 2010.) The EQ-5D descriptive scale was used in this study. The EQ-5D has been used to measure outcomes in a variety of patients (EuroQoL Group 2010), including patients with severe mental illness (Prieto et al. 2003, König et al. 2007). The EQ-5D has shown acceptable construct validity with the WHOQOL-BREF ($r_s=0.32-0.62$) and with the GAF (Global Assessment of Functioning) ($r_s=0.46$) among patients with schizophrenia (König et al. 2007). (Paper II.)

Demographic information included gender, age, marital status, employment status, occupational education, diagnosis and overall functioning (Global Assessment of Functioning, GAF; Williams 2008). The GAF scale consists of ten behavioural descriptions ranging from 1-10 ('Persistent danger of severely hurting self or others, or persistent inability to maintain minimal personal hygiene, or serious suicidal act with clear expectation of death') to 91-100 ('superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his or her many positive qualities. No symptoms.'). The GAF has been used in a number of studies among patients with schizophrenia (Price et al. 2008). (Paper II.)

In **phase III**, a semi-structured face-to-face interview method was used to examine patients' and nurses' perceptions of nursing interventions improving patients' QoL. In the first part of phase III, the data were collected from the patients in individual interviews by asking them to describe in their own words 1) how nurses had supported their five most important QoL areas (see phase I) and 2) how these QoL areas should be supported by nurses to better enhance patients' QoL. Gender, age, marital and employment status, previous admissions to psychiatric hospitals, and length of current inpatient care at the time of the interview were gathered as demographic information. (Paper III.)

In the second part of phase III, based on patients' descriptions of their most important QoL areas (see phase I) a focus group interview guide including five themes (health

and mental health, family and family life, social relationships, leisure activities, work and study) was developed. According to the five themes the nurses were asked to describe in their own words 1) what kind of nursing interventions they have to support patients' QoL areas during inpatient care and 2) what development suggestions they have to further improve patients' QoL during inpatient care. Demographic information consisted of nurses' gender, age, job description, experience of psychiatric nursing, and experience in acute psychiatric ward. (Paper IV.)

In phase IV, two instruments were used to compare the effectiveness of different patient education methods. First, QoL was assessed by the Quality of Life Enjoyment and Satisfaction Questionnaire Short Form (Q-LES-Q SF; Danovitch & Endicott 2008) described in phase II. Second, functional disability was assessed using the Sheehan Disability Scale (SDS; Leon et al. 1992, Sheehan & Sheehan 2008, Williams 2008). The instrument was developed in the USA in 1981 to measure impairment in functioning in outcome studies in psychiatric care. It is a self-report instrument which uses visual, numerical and verbal descriptive anchors to assess three areas of functioning: work, social life and family. Each item is assessed on a 10-point visual analogue scale (0=no disability, 10=extreme disability). Completing the scale takes one to two minutes. (Sheehan & Sheehan 2008, Williams 2008.) The SDS has been used in studies among patients with schizophrenia (McQuaid et al. 2000, Bellino et al. 2004, Braga et al. 2005). The SDS has been shown to be valid, reliable and sensitive to treatment effects (Sheehan & Sheehan 2008, Arbuckle et al. 2009). The Finnish version of the SDS was translated and back-translated according to standard procedures for the purposes of this study (Burns & Grove 2005). (Paper V.)

Gender, age, education, occupation and number of previous inpatient treatments were included in the demographic information. Moreover, severity of psychiatric symptoms was assessed by trained nurses with the Positive and Negative Syndrome Scales (PANSS) (Kay et al. 1987) (Paper V.)

The study instruments related to QoL are presented in Table 3.

Table 3. Study instruments related to QoL

Phase Instrument	Type of the instrument	Scale	Range of the possible scores
Phase I SEIQoL	Generic, Respondent-generated, A semi-structured interview	Most important areas of QoL	0-10 level of satisfaction on QoL 0-100 relative importance of QoL area
Phase II Q-LES-Q SF	Disease-specific, Self-rated	Physical health, feelings, work, household duties, social relations, family relations, leisure activities, daily functioning, sexual drive/performance, economic status, living or housing arrangements, mobility, vision, overall well-being, overall life satisfaction	1-5
EQ-5D (descriptive scale)	Generic, Self-rated	Mobility, self-care, usual activities, pain or discomfort and anxiety or depression	1-3
Phase III The semi-structured interview schedule	Semi-structured interview	How nurses have supported the patients' most important QoL areas How patients' most important QoL areas should be supported by nurses to better enhance patients' QoL	
Phase IV Q-LES-Q	Disease-specific, Self-rated	Physical health, feelings, work et al. (See above.)	1-5

4.3. Data collection

In **phase I**, the data collection period was from November 2005 to May 2006. The nurses on the study wards evaluated whether the patient fulfilled the inclusion criteria or not and asked the patient's willingness to participate into the study interviews. The tape-recorded interviews were conducted on the hospital wards. At the beginning of the interviews the participants received oral and written explanation of the details of the study. The average duration of the interviews was 24 minutes (range 10-54 minutes). The demographic data and medical history of patients were collected from the patient records. (Paper I.)

Phase II was carried out from March 2005 to October 2006. The recruitment process of patients was organised by the nurses on the study wards. A protocol researcher

informed patients about the study and asked their willingness to participate. The patients completed the instruments independently after having been informed about the instruments by the protocol researcher who was further available if patients had any questions about the instruments. The nurses on the study wards collected information on patient characteristics from the patient records. (Paper II.)

In **phase III**, the data from the patients were collected from November 2005 to May 2006 in the interviews carried out in phase I. For this data collection patients were asked to describe how the nurses had supported and how they should support their selected five most important QoL areas (see Paper I). The average length of this part of the interviews was 25 minutes (range 10-49 minutes). Information on patients' characteristics was collected from the patient records by the nurses on the study wards. (Paper III.)

The data on the nurses was collected between July and December 2006 by means of focus-group (n=7) interviews (Parahoo 2006, Curtis & Redmond 2007). The focus group interviews were conducted by two researchers in each focus group. The interviews were tape recorded. At the beginning of the interviews the nurses received information about the details of the study and completed the background information forms. Seven interviews took place on the hospitals' wards; the average length was one hour thirty-four minutes (range 81-105 minutes). (Paper IV.)

In **phase IV**, the data were collected between March 2005 and October 2007. The data collection protocol is as described in phase II except that in this phase data were gathered at five points; baseline (phase II), and one, three, six, and twelve months later. (Paper V.)

4.4. Data analysis

In **phase I**, the data from patients' semi-structured interviews related to their descriptions of the most important areas of life were analysed by inductive content analysis, which provided a systematic approach to analyse qualitative data (Polit et al. 2001, Silverman 2005, Elo & Kyngäs 2007). The tape-recorded interviews were transcribed and read through several times to become familiar with the data. Next, every QoL area described by patients was labelled and subcategories were identified from the labelled QoL areas. Finally, by grouping together subcategories, main categories were established. (Denzin & Lincoln 2000, Polit et al. 2001.) Traditional manual methods were used in analysing the data (Polit et al. 2001). The quantitative data were analysed with descriptive statistics (frequencies and percentage values). The statistical analysis was performed using the Statistical Package for Social Sciences (SPSS), version 11.0. (Paper I.)

In **phase II**, three steps were taken to analyse the data. First, internal consistency was examined by Cronbach's alpha coefficient values for the total sample and sub-samples. Further, the internal consistency of the instruments was evaluated using a corrected item to total correlation coefficient and an inter-item correlation matrix. Second, the

validity of the instruments was evaluated by three methods. To determine the correlations between observed variables and underlying latent variables principal component analysis was performed. To test for statistically significant differences in contrasted groups higher overall functional status (GAF scores ≤ 50 vs. >50) and schizophrenia vs. other diagnoses a Mann-Whitney U-test was used. Spearman's correlation coefficient analysis was used to investigate the relationship between the overall index of instruments. Third, missing value analysis was performed to evaluate the difficulty of items. Statistical analyses were performed with the Statistical Package for Social Sciences (SPSS), version 18.0.0. Statistical tests were conducted at 5% level of significance. (Paper II.)

In **phase III**, both data from the patients' interviews and data from the nurses' focus-group interviews were analysed using inductive content analysis. At the beginning of the analysis the tape-recorded interviews were transcribed verbatim and read through several times, asking the research questions to become familiar with the whole data. Next the transcribed texts were divided into meaning units which could be a word, a sentence or part of a sentence. The units were then abstracted and labelled with a code. The subcategories were identified from the labelled units in order to identify differences and similarities. Main categories were created by grouping together subcategories with similar meanings. (Latvala & Vanhanen-Nuutinen 2001, Graneheim & Lundman 2004, Polit & Beck 2010.) The data were analysed by traditional manual methods (Polit et al. 2001). (Paper III, Paper IV.)

In **phase IV**, when analysing background characteristics between groups at baseline, Pearson's Chi-Square test in the categorical variables and one-way analysis of variance (ANOVA) in the continuous variables were used. To compare background characteristics between dropouts and completers Pearson's Chi-Square test in the categorical variables and the independent sample t-test in the continuous variables were used. One-way ANOVA was used to compare groups for the Q-LES-Q SF total score (items 1-14) and the SDS items at baseline, 1 month, 3, 6, and 12 months. Repeated measures ANOVA was used to assess the changes of Q-LES-Q SF total score and the SDS items during follow-up. Lastly, all items of the Q-LES-Q SF were analysed using Friedman's test between baseline and 12 months to obtain a more detailed picture of possible differences in QoL areas between groups. Post hoc analysis was made by Wilcoxon's test. The data analysis was performed on an intention-to-treat basis (Bowers et al. 2006, Everitt & Wessely 2008). The LOCF ("Last Observation Carried Forward") method was used (Hollis & Campbell 1999, Bowers et al. 2006). Moreover, effect size analysis was carried out by dividing the group difference or between measurement difference in mean scores by the pooled-within-group standard deviation. P-values lower than 0.05 were considered statistically significant. Analyses were performed using the Statistical Package for Social Sciences (SPSS for Windows, version 18.0.0; SPSS Inc., Chicago, IL, USA). (Paper V.)

4.5. Ethical questions

Patients with schizophrenia are regarded as vulnerable individuals who may be incapable of giving fully informed consent to participate in a study (Usher & Holmes 1997, Burns & Grove 2005, Polit & Beck 2010). Thus particular attention was paid to ethical questions. Ethical decision-making was supported by the law (Medical Research Act 1999) and ethical guidelines on research ethics (ETENE 2001, Academy of Finland 2003, European Commission 2007, World Medical Association 2008).

In **phase I**, approval for the study protocol was obtained from the local ethics committee (Dnro A12/05; Medical Research Act 1999) and permission to carry out the study was requested from the directors of the respective organizations. The ward personnel evaluated whether or not an individual patient was competent enough to participate in the interview (Latvala et al. 1998, Carpenter et al. 2000). In the first stage, the nurses gave patients information related to the voluntary nature, purpose and protocol of the study, and ascertained patients' preliminary willingness to participate. The participants were further informed by the researcher in oral and written form about the purpose, nature and process of the study including the content of the coming interview, as well as the risks and benefits related to the study. The patients were also informed that they could withdraw from the study at any point without prejudice to their treatment. (Medical Research Act 1999.) Moreover, the researcher gave the patients an opportunity to pose additional questions. After the patients had received the information the researcher ensured verbally that the patients had understood the information about the study, the voluntary nature of the study, and the meaning of the written consent form (Burns & Grove 2005). After this, informed consent was requested by written consent form. Permission for tape-recording was requested at the beginning of the interview. The study interview situations were kept unhurried. The interviewer tried to help the patients by posing extra supportive questions. At the end of the interviews the researcher reminded patients of the possibility to contact the interviewer afterwards if the interview had raised questions (Polit & Beck 2010). Permission to use the SEIQoL-DW instrument was granted by the Mieli.Net Project. The collected data were kept safe and only the researcher had access to it. The results were reported so that no individual could be identified. (Burns & Grove 2005, Polit & Beck 2010.) (Paper I.)

In **phase II**, the study protocol was evaluated by the local ethics committee (Dnro ETL R01181, ETL R04028H, ETL R03138H; Medical Research Act 1999) and permission to collect data was obtained from the directors of the respective organisations. The decision on whether or not the patients were competent enough to participate in the study was made by ward staff in collaboration with the research assistants (Latvala et al. 1998, Carpenter et al. 2000). The research assistants were trained to carry out the study process including e.g. informed consent protocol and instructions related to study instruments (Medical Research Act 1999). The research assistant gave patients written and oral information about the purpose of the study, the procedures, as well as the risks and benefits. They were also told that participation was voluntary and that they could withdraw from the study at any time. Moreover, patients were informed that refusal or

withdrawal would not affect their care. (Medical Research Act 1999.) If the patients were uncertain about participation they had an opportunity to meet the research assistant again the next day (Polit & Beck 2010). Patients' willingness to participate in the study was ascertained by written consent form. Permission to use the study instruments was obtained by the Mieli.Net Project. The data were stored appropriately and handled anonymously. (Burns & Grove 2005, Polit & Beck 2010.) (Paper II.)

In phase III, the patients' data had been collected in the same interviews as data in phase I. Therefore, in this section only nurses' data collection is discussed. Because this study did not focus on patients, no statement from the ethics committee was needed according to Finnish law (Medical Research Act 1999, ETENE 2001). The study had permission for data collection from the directors of the respective organizations. The researcher attended an information meeting for all wards taking part in the study to describe the purpose, methods and voluntary nature of the study. Moreover, it was announced that focus group interviews would last approximately one and a half hour. Written information was also available so that all nurses had access to the same information. In the following days ward managers asked nurses to participate in the study. At the beginning of the focus group interviews the researcher again gave information in written form of the study purpose, methods and voluntary nature of interviews. (Medical Research Act 1999.) After this the nurses gave written consent. Before starting the interviews permission for tape-recording was requested. The interview situations were kept unhurried to encourage participants to describe their conceptions. The data were kept confidential and handled anonymously (Burns & Grove 2005, Polit & Beck 2010). (Papers III and IV.)

In phase IV, where a randomized clinical trial design was used, treatment differed between groups only in relation to patient education and there was no placebo group, but the control group received patient education as usual (ETENE 2001). Because data were collected from the same sample as in phase II, other ethical questions concerning phase IV are discussed in phase II. In this RCT, there was no placebo group; all patients received treatment as usual. (Paper V.)

5. RESULTS

The results are reported according to the four phases of the study. The first section describes subjective QoL of patients with schizophrenia. The second section describes the results of the internal consistency, validity and feasibility of two instruments. The third section describes patients' and nurses' perceptions of nursing interventions used to support patients' QoL and their suggestions for the development of QoL enhancement. The fourth section describes the results of an RCT comparing the effectiveness of three different patient education methods on the QoL of patients with schizophrenia.

5.1. Quality of life of patients with schizophrenia

The objective was to examine the QoL of patients with schizophrenia (n=35). One hundred and seventy-five QoL areas described by the patients were reduced to 14 categories. Health was named as one of the most important QoL areas by almost 80 % of patients (n=27). The next most named areas were family (60%), leisure activities (57%), work or study (49%) and social relationships (49%). The other QoL areas named by patients were: accommodation, finance, spirituality, positive feelings, pets, freedom, security, dreams and nature. Mean satisfaction for the most frequently reported QoL areas were quite low (range 49 and 69; scale 0-100). The overall mean QoL score of patients was 61.5 (range 24.6 - 89.6, SD 17.4) suggesting that patients' QoL was impaired. (Paper I.)

When rating the relative importance of QoL areas, 12 out of those 27 patients who had named health, judged it as the most important QoL area. Twenty-one had named family and nine of these patients judged family the most important QoL area. Eight patients named spirituality and four of them judged it the most important QoL area. Further, leisure activities, social relationships, positive feelings, and freedom were also judged the most important QoL area. Patients' satisfaction with the most important QoL area ranged between 24 and 59 (scale 0-100), and proved to be lower than mean satisfaction with all QoL areas. (Paper I.)

5.2. A comparison of two instruments assessing quality of life of patients with schizophrenia

The objective was to examine and compare two QoL instruments; the EQ-5D (Brooks 2003, EuroQoL Group 2010) and the Q-LES-Q SF (Danovitch & Endicott 2008). For the EQ-5D descriptive scale, internal consistency (Cronbach's' alpha 0.63) proved to be under the level of adequacy 0.70 (Burns & Grove 2005). It should be noted that internal consistency is related to number of items (Ferketich 1991) and in the EQ-5D there are only five items. For the Q-LES-Q SF scale internal consistency was good

(Cronbach's' alpha 0.89). There was no improvement in Cronbach's alpha when any item of the scales was deleted. The average inter-item correlation coefficient for the EQ-5D was 0.26 and demonstrated to be slightly under criterion level which is between 0.30 and 0.70 (Ferketich 1991). For the Q-LES-Q SF the average inter-item correlation was in acceptable level (0.36). For the EQ-5D scale, the Cronbach's alpha value for the patients with better functioning was higher (0.66) than for the patients with lower functioning (0.61). For the EQ-5D alpha value was higher (0.65) for patients with schizophrenia than for those with other diagnoses (0.62). For the Q-LES-Q SF the alpha value for the patients with better functioning and poorer functioning were very similar (0.88 vs. 0.89). The Cronbach's alpha value for the Q-LES-Q SF for patients diagnosed with schizophrenia was excellent (0.90) vs. patients in other diagnostic groups good (0.87). (Paper II.)

One-component solution in principal component analysis for the both instruments explained 41% of total variance for the EQ-5D and 56% for the Q-LES-Q SF. All items of both instruments demonstrated factor loadings over the commonly used cut-off 0.40. When construct validity was assessed by Mann-Whitney test the instruments revealed no statistically significant differences (EQ-5D, $U=3785$, $p=0.350$; Q-LES-Q SF, $U=4275$, $p=0.354$) between diagnosis subgroups. However, poorer functioning indicated poorer QoL measured with the EQ-5D ($U=3098$, $p<0.001$) or the Q-LES-Q ($U=3357$, $p<0.001$). The Spearman's correlation coefficient showed moderate correlation ($r = 0.445$; $p < 0.001$) between these two quality of life instruments when the overall index of QoL instrument was used. (Paper II.)

Missing values range proved to be lower on the EQ-5D descriptive scale (5% to 6%) than on the Q-LES-Q scale (6% to 31%). Thirty-one percent of the responses were missing in the Q-LES-Q when patients were asked to evaluate their satisfaction with their work. Missing values had some differences between subgroups in both instruments. (Paper II.)

5.3. Patients' and nurses' perceptions of nursing interventions improving patients' quality of life in acute psychiatric wards

The objective was to examine patients' and nurses' perceptions of nursing interventions in enhancing patients' QoL. Five main categories of nursing interventions (empowering interventions, social interventions, activating interventions, security interventions and interventions to support physical health) were identified from the patients' descriptions of interventions that nurses use to support patients' QoL. Empowering interventions were described as actions where nurses show interest in patients, discuss with patients, encourage patients, give patients information and opportunities to exercise self-determination. Social interventions were described as actions where nurses meet patients' family members, give patients opportunities for social contacts, and give opportunities to visit home during inpatient care. Activating interventions were described as actions using occupational or creative therapies or physical activities as well as actions where nurses give patients chances for recreational

events or to continue a hobby. Actions where nurses took care of patients' safety and privacy were identified as security interventions. Further, interventions simproving physical health were described as actions where nurses take care of medication, monitor patients' somatic well-being, and give patients opportunities to rest. (Paper III.)

From the nurses' descriptions of nursing interventions which they use to support patients' QoL five main categories (empowering interventions, social interventions, activating interventions, security interventions and interventions related to care planning) were identified. Empowering interventions, by which nurses support patients' QoL, were described as actions where the nurses show interest, discuss, encourage, give information, maintain hope, and motivate. Actions where nurses support patients' family members, give patients opportunities for social contacts or to continue studies, and arrange social support were understood as social interventions. Activating interventions, by which nurses support patients' QoL were described as actions where nurses do activities together with patients, arrange activities, give patients opportunities for participating in activities, and guide patients to activities. Security interventions were described as actions where nurses take care of the basic needs of patients, take care of ward safety, and impose restrictions on patients. Interventions related to care planning were described as actions where nurses appraise patients' needs for care, collect information, and plan an individual patient's care. (Paper IV.)

Patients' and nurses' perceptions of nursing interventions by which nurses support patients' QoL in acute psychiatric wards is presented in Table 4.

Table 4. Patients' and nurses' perceptions of nursing interventions by which nurses improve patients' QoL in acute psychiatric wards

Patients' perceptions	Main category	Nurses' perceptions
Showing interest Discussing Encouraging Giving information Giving opportunities to exercise self-determination	Empowering interventions	Showing interest Discussing Encouraging Giving information Maintaining hope Motivating
Meeting family members Giving opportunities for social contacts Giving opportunities for visit home	Social interventions	Supporting family members Giving opportunities for social contacts Giving opportunities for continue studies Arranging social support
Using occupational therapies Using creative therapies Using physical activities Giving opportunities for recreational events Giving opportunities for continued hobby	Activating interventions	Doing activities together with patients Arranging activities Giving opportunities for participating in activities Guiding to activities
Taking care of patients' safety Taking care of patients' privacy	Security interventions	Taking care of basic needs Taking care of ward's safety Setting restrictions to patients
Taking care of medication Monitoring somatic well-being Giving opportunities to rest	Interventions supporting physical health	
	Interventions related care planning	Appraising patients' needs for care Collecting information Planning individual patient's care

Patients' suggestions for the development of QoL enhancement were reduced to five categories: empowering interventions, social interventions, activating interventions, security interventions and interventions to support physical health. Actions where nurses show interest in patients, discuss with patients, encourage patients, give patients information, give patients opportunities to exercise self-determination, pay attention to patient's individual needs, and show respect and empathy to patients were understood as empowering interventions, which should be developed. Social interventions which

patients suggested to be further developed were described as actions where nurses meet patients' family members, give patients opportunities for social contacts and to visit home during inpatient care. Activating interventions were understood as actions where nurses use physical activities or give patients opportunities for recreational events or to continue regular hobbies. Security interventions, for suggestions to develop nurses' interventions to better enhance patients' QoL, were described as actions where nurses take care of patients' safety and privacy. The fifth category, interventions supporting physical health, included only one action to be developed, taking care of medication. (Paper III.)

Nurses' suggestions for changes in nursing interventions to further improve patients' QoL were reduced to four categories. Empowering interventions which need to be developed were described as actions where nurses show interest, discuss, encourage, give information, and motivate patients. Social interventions include actions where nurses arrange social support and support patients' family members. Activating interventions to be further developed are actions where nurses do activities together with patients, arrange activities, and give patients opportunities to participate in activities. Interventions related to care planning were actions where nurses appraise patients' needs for care and collect information. (Paper IV.)

Patients' and nurses' suggestions for developing nursing interventions to better improve patients' QoL in acute psychiatric wards is presented in Table 5.

Table 5. Patients' and nurses' suggestions for developing nursing interventions to better support patients' QoL in acute psychiatric wards

Patients' suggestions	Main category	Nurses' suggestions
Showing interest Discussing Encouraging Giving information Giving opportunities to exercise self-determination Paying attention to individual needs Showing respect Showing empathy	Empowering interventions	Showing interest Discussing Encouraging Giving information Motivating
Meeting family members Giving opportunities for social contacts Giving opportunities for visit home	Social interventions	Arranging social support Supporting family members
Using physical activities Giving opportunities for recreational events Giving opportunities for continued hobby	Activating interventions	Doing activities together with patients Arranging activities Giving opportunities for participating in activities
Taking care of patients' safety Taking care of patients' privacy	Security interventions	
Taking care of medication	Interventions supporting physical health	
	Interventions related care planning	Appraising patients' needs for care Collecting information

5.4. Effectiveness of different patient education methods on quality of life of patients with schizophrenia

The objective was to compare the effectiveness of different patient education methods on the QoL of patients with schizophrenia. In general, in the whole study population, patients' mean global QoL index (Q-LES-Q SF) increased in the follow-up period from 41.6 (SD 10.5) to 48.2 (SD 10.4) (scale 14-70). No significant differences were found between groups at any time point. The increase in the mean global QoL index was significant in all study groups during the 12 months follow up time ($p < 0.001$).

However, no significant differences between groups were found. In the analysis of all 16 Q-LES-Q SF items at baseline and at 12 months, significant changes were found in every education group; most in the standard treatment group and least in the computer based education group. Effect sizes in items “work” and “leisure activities” in the conventional education group and in the item “physical health” in the standard treatment group were moderate. (Paper V.)

For functional disability measured by the Sheehan Disability Scale (SDS) significant differences were found at all time-points; at baseline in all three areas (work/study, social life, family life/home responsibilities). Only in baseline in the item “social life” effect size was moderate (ES=0.54). During the 12-month follow-up time there were significant increases ($p < 0.001$) in patients’ social ability in all areas in each group (-0.9 to -2.1; scale 1-10) but no significant differences ($p > 0.05$) were found between groups. (Paper V.)

5.5. Summary of the results

In the findings of this study, health, family, leisure time activities, work or study, and social relationships were named the most important QoL areas (Paper I). Assessing the patients’ QoL revealed that their QoL was impaired (Paper I, Paper V). The EQ-5D proved to have moderate and the Q-LES-Q SF good internal consistency. Moreover, both instruments proved to be reasonably valid and feasible for use with patients with schizophrenia. (Paper II). Altogether six nursing interventions which nurses use to support patients’ QoL and which should be further improved were identified when the patients and the nurses were asked to describe how the nurses had supported and how they should better support patients’ most important QoL areas. These interventions were empowering interventions, social interventions, activating interventions, security interventions, interventions to support physical health and those related to care planning. (Paper III, Paper IV.) When the effect of three education groups (computer assisted patient education, education with leaflets, and standard care) on QoL was tested, the patients’ QoL improved significantly over the follow-up time in all groups. No significant differences were found between the groups. (Paper V.)

6. DISCUSSION

This section begins by discussing the ethical questions of this study. Second, the validity and reliability of the research process and findings are discussed. Third, the main findings are discussed and compared with the literature in accordance with the research questions. These are followed by implications for improving patients' QoL in acute psychiatric wards, and finally suggestions for future research are presented.

6.1. Discussion of ethical questions

In this study, inpatients with schizophrenia in acute psychiatric wards were the target population. Because of patients' possibly impaired decision-making capacity, it was essential that patients were not informed about the study or asked for their consent before the observation period, which may last for a maximum of 4 days (Mental Health Act 1990), was over, and before the ward staff having evaluated a patient to be in stable enough condition related to their symptoms (Carpenter et al. 2000). Earlier studies have shown that patients who give informed consent may be ignorant of the basic elements of the research because of the inadequacy of the informed consent process (Cohn & Larson 2007). Thus, in this study, the consent information was planned carefully and given in written and verbal form in one-to-one interaction by a person familiar with the study process. Patients were also given an opportunity to receive answers to their questions about the informed consent. Nevertheless, it is not possible to show that the consent was based on the patients' free, independent opinion (Välimäki & Lehtonen 2002). Because of the cognitive demands of an informed consent process, the patients may have had difficulties in comprehending information and weighing up the benefits and risks of the study, and thus had deficient ability to free decision-making (Carpenter et al. 2000). Assessment of capacity to consent to research (Palmer et al. 2005), and further a brief educational session to enhance decisional capacity would perhaps been a good method to enhance patients' capacity to give informed consent (Carpenter et al. 2000, Palmer et al. 2005).

On the other hand, regardless of how comprehensive patients' information is, it may be that some patients wanted to please the staff or they feared that refusing would affect their care, and thus signed the consent with this in mind (Latvala et al. 1998, Burns & Grove 2005). This concern is especially important among these patients who may have low self-esteem because of their illness (Hansson et al. 1999, Hansson et al. 2003), and who, moreover, were recruited during their psychiatric inpatient care.

The research requirement process was described in detail and it guided recruitment. Based on this recruitment guide, the personnel on the study wards evaluated patients' ability to participate in the study (Carpenter et al. 2000). It may be that participants were assessed in such a way that not all competent patients were allowed to make a decision on their participation. Not offering a chance for participation can in itself be

seen as a violation of the right to self-determination for these patients. However, to assess, whether a patient with schizophrenia is competent to be a potential participant may not have been an easy task for the staff. Moreover, there is a probability that this caused selection bias (Burns & Grove 2005) where only the most stable patients are presented in the sample and the voices of patients in a more severe stage of their illness, are not heard in the study findings.

In phases I and III, patients were interviewed face-to-face. Most of them seemed very willing to discuss their perceptions. Moreover, many of them stated that they appreciate that patients' opinions were elicited in developing nursing practice. It is important to note that these psychiatric patients' perspectives may often be neglected in research (Wood & Pistrang 2004). From an ethical point of view it is doubtful to restrict these patients as research participants because of their severe mental illness since only patients with schizophrenia can describe their subjective QoL and how their QoL is best supported by nursing interventions. Thus, if we consider it important to base the development of psychiatric nursing on patients' needs, research that aims to provide knowledge from the patients' point of view is essential.

In phase IV, the RCT was conducted. The trial was designed as part of an extensive research project (Mieli.Net project) with careful planning which is important for an ethical RCT (Everitt & Wessely 2008). There was no placebo group in this RCT. Thus all patients were able to receive patient education also ensuring the ethics of the study (Everitt & Wessely 2008). Two recently developed patient education models, education with leaflets and computer based education, were tested. Patients with schizophrenia especially can benefit from education that uses multiple channels because of their attention and memory deficits (Ahmed et al. 1997). Moreover, to use computer based education methods in patient education is important in this group of patients because psychiatric patients are among the most marginalized persons in society (Sayze & Curran 2007), and may be further marginalized in the information society. In that respect this study represents therapeutic nursing research where participants may have the potential to benefit from the research interventions (Burns & Grove 2005). However, new methods, especially computer based patient education, may have caused participants emotional burden because of their cognitive deficits (Sadock & Sadock 2007) and functional disability (Mueser & McGurk 2004). On the other hand, in this study, interventions were conducted in a nurse-patient relationship where all the nurses had professional training in facing emotional distress. Further, in light of earlier studies, it seems that computer based patient education has been accepted among patients with schizophrenia (Jones et al. 2001, Rotondi et al. 2005). Finally, from an ethical point of view, it can be argued that it is ethical to conduct RCTs (Everitt & Wessely 2008). By comparing different nursing interventions in an RCT it is possible to find the most effective nursing interventions by which patients' QoL can be best enhanced.

In this study the nurses were informants in the focus group interviews in phase III. Based on the research principle related to respect of human dignity (Usher & Holmes 1997, Burns & Grove 2005, Polit & Beck 2010) nurses' willingness to participate in the study was also ascertained by written consent form. This was important because the

ward managers asked the nurses to participate in the study. Nevertheless, it may be that nurses still felt obliged to be informants (Elo & Isola 2008). On the other hand, in all focus groups all the nurses seemed to be active in participating in the discussions which supports the view that they were willing to share their perceptions on the nursing interventions carried out in their own wards. In this study, the nurses also had important roles as research assistants. In phase IV especially where the nurses educated patients according to the study protocol it may be that nurses have experienced some anxiety since the educational interventions used were different from their usual educational methods. For example, in the IT education group some nurses' poor IT skills (Koivunen et al. 2008) may have caused emotional distress. Moreover, burden may be caused by low staff resources. Although the new ways to conduct patient education took time there were no extra staff resources in the wards during the study period. With this possible burden in mind, there was a protocol researcher in both study hospitals who gave both practical and emotional support to staff to lighten their burden.

6.2. Discussion of validity and reliability

Validity and reliability are the most important criteria in evaluating the quality of a study. Validity refers to the degree to which the inferences made are accurate and well-founded. It also refers to whether an instrument accurately measures what it is intended to measure. When evaluating the validity of a quantitative study four aspects are important: statistical conclusion validity, internal validity, construct validity and external validity. Reliability refers to the degree of consistency or dependability with which a measurement technique measures a concept under investigation. Three aspects of reliability are of interest when testing reliability: internal consistency, equivalence and stability. (Burns & Grove 2005, Polit & Beck 2010.) When discussing qualitative part of the study, the concepts of reliability and validity are replaced by a concept of trustworthiness which is considered by means of credibility, dependability, confirmability and transferability (Holloway & Wheeler 2002, Graneheim & Lundman 2004, Tobin & Begley 2004, Polit & Beck 2010).

In this study, consolidated standards of reporting studies applying qualitative interviews (Tong et al. 2007) and RCTs in general (Altman et al. 2001), as well as RCTs of nonpharmacologic treatments (Boutron et al. 2008) were the guiding principles to conduct a valid study.

In phase I, the data were collected in individual semi-structured interviews using the SEIQoL-DW (Hickey et al. 1996, Browne et al. 1997) and analysed by inductive content analysis and descriptive statistics. The interviews were carried out according to SEIQoL manual (O'Boyle et al. 1993).

Credibility, which refers to confidence in the truth of the data, how well the data and data analysis process address the intended focus (Polit et al. 2001, Graneheim & Lundman 2004, Polit & Beck 2010), was taken into consideration when sampling was conducted. The participants had personal experience of diagnoses of schizophrenia. It should be noted that the nurses on the study wards recruited the patients, which may

have caused a selection bias (Burns & Grove 2005). Patients who did not participate may have differed in some important way from the patients included in the study. One aspect of credibility is researcher credibility (Polit et al. 2001). In this study all interviews were conducted and analysed by one researcher who had experience of interviews, a long history in psychiatric nursing, as well as training and experience in the inductive content analysis process. The researcher had long experience as a nurse and as a nursing director in psychiatric hospitals as well as the patient-centred framework for psychiatric nursing. She was conscious that this history and framework might possibly affect her pre-understanding of the topic of interest, and thus tried to minimize the influence when analysing the data (Polit & Beck 2010). Moreover, regarding credibility, the interview situation was kept unhurried and the interviewer helped the patients to describe their perceptions by supportive questions. Interviewing the patients more than once would perhaps have increased credibility (Tobin & Begley 2004). However, this was not possible for practical reasons. To ensure that the categories formed reflect the subject of the study and cover the data in a reliable manner (Graneheim & Lundman 2004, Elo & Kyngäs 2007) at least three papers were reanalysed after each break, the deviant cases were kept in mind until they could be accounted for, and the analysis process continued until all cases of the data were incorporated into the analysis (Silverman 2005). (Paper I.)

Dependability is concerned with data stability over time and over conditions (Polit et al. 2001, Graneheim & Lundman 2004, Polit & Beck 2010). In this study the researcher was an integral component of the study process and thus the researcher's own actions and decisions inevitably impacted upon the study findings (Horsburg 2003). Although the researcher's role as a research instrument makes it impossible to replicate this study, it is possible to repeat it (Holloway & Wheeler 2002). The whole research process was described so that readers can follow the research path. Moreover, to enhance the dependability of the study the coding process and categories used were discussed with a group of doctoral students (Holloway & Wheeler 2002, Graneheim & Lundman 2004, Silverman 2005). (Paper I.)

Confirmability deals with the objectivity and neutrality of the data (Polit et al. 2001, Graneheim & Lundman 2004, Polit & Beck 2010). Therefore the data was not collected from the hospital where the researcher is employed. Moreover, confirmability was increased by describing the analysis process in detail. In the categorization process, patients' original utterances and expressions were used as far as possible. Further, seven randomly chosen interviews (20%) were reanalysed by another nursing researcher. Agreement between the original and the reanalysed coding was 90%, which indicates good confirmability (Latvala & Vanhanen-Nuutinen 2001). Finally, an example of the analysis process and quotations from the original data were used in reporting (Elo & Kyngäs 2007). Participants' recognition of the findings would be one aspect to improve confirmability (Graneheim & Lundman 2004). However, for practical reasons it was not used. (Paper I.)

Transferability, which is concerned with the extent to which the findings from the data can be transferred to other groups or settings (Polit et al. 2001, Graneheim & Lundman 2004, Polit & Beck 2010), was strengthened by giving a description of the study

context, setting and selection of participants and their characteristics (Horsburg 2003). The main problem limiting the transferability of the findings is the small number of participants included (Polit et al. 2001, Polit & Beck 2010). However, the findings may lend credibility to the notion that individual assessment of QoL in psychiatric nursing is important. Moreover, the findings had already been used in formulating interview themes into this study in phase III. (Paper I.)

Reliability and validity are major criteria for assessing an instrument's quality (Polit et al. 2001, Burns & Grove 2005, Polit & Beck 2010). According to a review by Wettergren et al. (2009) the SEIQoL-DW seems to have moderately to high convergent and discriminant validity demonstrating that it measures the QoL construct (Burns & Grove 2005). The SEIQoL-DW has earlier shown fairly good convergent validity in a study among outpatients with serious mental disorders (Satisfaction with Life Scale, SWLS; correlation 0.582, $p < 0.01$ and Quality of Life Inventory, QOLI; correlation 0.696, $p < 0.01$). Moreover, the SEIQoL-DW has earlier been well accepted by this group of patients. (Prince & Gerber 2001.) (Paper I.)

In phase II, the baseline data for phase IV was used to test the validity, reliability and feasibility of the two QoL instruments.

Statistical conclusion validity concerns that relationship and differences drawn from statistical analysis are on accurate reflection of reality (Burns & Grove 2005). In this study the sample size was quite large ($n=311$) and selection of statistical tests was confirmed by a statistician, which increases the statistical conclusion validity. (Burns & Grove 2005, Polit & Beck 2010.) (Paper II.)

External validity, which concerns the degree to which the study results can be generalized to other samples or settings (Burns & Grove 2005, Polit & Beck 2010), is threatened because out of 829 eligible patients 62% refused to participate (Bowers et al. 2006). The participants were chosen by ward staff because of their psychiatric condition, and thus the participants selected for the study may differ in some important way from those not selected, which means that selection bias may be a threat to internal validity (Burns & Grove 2005). Moreover, the data were collected from patients in acute inpatient wards at the beginning of their hospital period. Thus they might be fairly unstable compared with patients who have been hospitalized longer or who are outpatients. Thus the characteristics of the sample may not be representative of all patients with schizophrenia. (Paper II.)

In phase III the data were collected from the patients ($n=35$) in individual semi-structured interviews and from the nurses ($n=29$) in semi-structured focus group interviews ($n=7$). The data were analysed by inductive content analysis (Polit et al. 2001, Silverman 2005, Elo & Kyngäs 2007).

The interviews with patients were conducted with the same sample and the same interviews as in phase I. Moreover, although new data was collected from the patients, the analysis was conducted as in phase I. Thus, issues related to trustworthiness of the recruitment process, the interviews and the data analysis were already discussed in the phase I with some exceptions. In this phase the patients described their perceptions of

nursing interventions to support their QoL. Over half of the participants had been in psychiatric inpatient care more than three times and they represented patients from seven wards in two hospitals. This wide experience with nursing interventions increases the *credibility* of the study (Graneheim & Lundman 2004). Further, related to *confirmability*, reanalysis of data was not conducted by another researcher for practical reasons. In the following paragraphs, credibility, dependability, confirmability and transferability will be discussed with reference to the data generated from the focus group interviews with the nurses. (Paper III.)

The *credibility* of the study concerning the nurses' perceptions of nursing interventions to support QoL was strengthened through inclusion criteria by requiring that nurses were professional nurses with at least three months' experience of working in an acute psychiatric inpatient ward (Graneheim & Lundman 2004, Tobin & Beckley 2004). Moreover, the experience in the study sample varied from one year to 37 years. The sample consisted of nurses who were willing to participate, which may have caused bias (Burns & Grove 2005). It is not possible to know if other nurses would have had different views. However, the nurses' willingness to share information and various experiences made it possible to discuss the phenomena under study from a variety of aspects and thus produce richer data (Graneheim & Lundman 2004). Because of resources in the study wards the time to conduct interviews was limited to approximately one and a half hours. It may be that interviewing the participants for longer or again at some other time would have increased credibility (Tobin & Begley 2004). The interviews were carried out by interviewers with long experience in psychiatric nursing who were trained to conduct nursing research, which strengthens the credibility of the study (Polit et al. 2001, Polit & Beck 2010). In the analysis process, after each break, at least three papers were reanalysed, the deviant cases were kept in mind until they could be accounted for, and the process continued until all cases were incorporated into the analysis (Silverman 2005). Finally, the credibility of the findings was supported by their consistency with findings from patients' data. (Paper IV.)

Dependability was strengthened by the interview guide, which was applied in all interviews to ensure that the interviews were conducted in the same way (Graneheim & Lundman 2004). Discussing the analysis process and the categories formed among co-researchers were also used to increase dependability (Holloway & Wheeler 2002, Graneheim & Lundman 2004, Silverman 2005). Moreover, the whole study process was described in detail and as clearly as possible (Holloway & Wheeler 2002). (Paper IV.)

Confirmability was increased by the interviewers, who were outsiders to the study organisations, and by describing the analysis process in detail, and as clearly as possible to show a relationship between the data and the categories (Polit et al. 2001, Polit & Beck 2010). Further, examples of the analysis process of the nurses' data and authentic citations of the data were used to enable a reader to assess the credibility of the study (Elo & Kyngäs 2007). For practical reasons it was not possible to use participants' recognition of the findings (Graneheim & Lundman 2004). (Paper IV.)

Transferability in this qualitative study was not the main goal since the nurses' interviews were conducted in only seven wards in two psychiatric hospitals. However, a description of the study contexts, settings, as well as the selection and characteristics of participants was reported clearly to enable a reader to decide whether or not the findings are transferable to another context (Graneheim & Lundman 2004). (Paper IV.)

In phase IV, the RCT to evaluate the effectiveness of three methods of patient education was conducted. The RCT is nowadays generally regarded as the best way to assess treatment interventions for particular conditions (Bowers et al. 2006, Everitt & Wessely 2008).

Internal validity refers the degree to which it can be inferred that the effects detected in the study are a true reflection of reality (Burns & Grove 2005, Polit & Beck 2010). It is related to randomisation (Polit & Beck 2010). In this study, participants were randomly allocated to the different study groups using simple randomization. In this sampling method each intervention assignment is totally unpredictable, which increases internal validity by avoiding selection bias (Burns & Grove 2005, Everitt & Wessely 2008). No differences between groups in baseline in demographic characteristics, symptom severity or main outcome, QoL were found. However, in the item "social life" related to functional disability a significant difference ($p=0.002$) between study groups was found at baseline, which should be born in mind when findings are interpreted. Drop-out analysis showed that there were no statistically significant differences between completers and dropouts in demographic characteristics or symptom severity, except that men in the standard group were more likely to drop out of the study ($p=0.049$). Although the nurses were trained to carry out computer based education, they differed in their IT skills, as well as in motivation and attitudes toward IT (Koivunen et al. 2008), which might have had an effect on the application of the IT based intervention. Moreover, internal validity is threatened because blinding was not possible in the clinical situation. The risk of contamination between patients and also between nurses must be taken into account. (Everitt & Wessely 2008.) (Paper. V.)

Statistical conclusion validity refers to statistical power, since low statistical power increases the probability of type II error (Burns & Grove 2005). In this study, it was estimated that to obtain a difference of seven points on the scale between group means (within group SD =10) for the global Q-LES-Q SF index to be statistically significant at the 0.05 level with 90% power, group size should be at least 53 participants. This sample size was achieved. Statistical conclusion validity also refers to the construction of the independent variable. In this study, three very different types of treatments in patient education were developed. However, in everyday practice the differences were not as big as planned because the education may not have been provided the same way each time or as planned to be administered. If this is the case, it may have weakened to detect outcome effects that actually exist (Burns & Grove 2005, Polit & Beck 2010). In this study, the objective was to assess the real-world effectiveness of patient education methods. Thus, the data were analysed on an intention-to-treat basis (Hollis & Campbell 1999, Bowers et al. 2006, Everitt & Wessely 2008). The last observed method (LOCF), which is widely used in clinical trials, was applied in data imputation

(Hollis & Campbell 1999, Everitt & Wessely 2008). On the other hand, some authors do not recommend it because it may lead to a systematic underestimation of variability (Everitt & Wessely 2008). Further, statistical conclusion validity is related to selection of statistical tests (Burns & Grove 2005). In this study all statistical tests were confirmed by a statistician (Paper V.)

External validity concerns how representative the results are (Polit et al. 2001). Thus the CONSORT guidelines recommend the provision of a flow diagram of participants (Altman et al. 2001, Boutron et al. 2008). The flow of the patients will be reported elsewhere by the research consortium of the Mieli.Net project. Sixty-two percent of eligible patients refused to participate. Moreover, drop-out rate was high (28%). This is not surprising since the sample consisted of patients with schizophrenia among whom high refusal and drop out rates are common (Jones et al. 2001), perhaps related to their difficulties to commit to treatment (Atkinson et al. 1996). Further, the study was conducted in only two Finnish psychiatric hospitals which decreases the external validity (Polit et al. 2001). (Paper V.)

Validity and reliability of measuring instruments are essential to detect true differences between study interventions (Burns & Grove 2005, Polit & Beck 2010). Because validity varies from one sample to another (Burns & Grove 2005), the validity of the primary outcome measure, the Q-LES-Q SF, was tested in phase II. Construct validity was found to be acceptable, internal consistency high, and feasibility fairly good (for details see Paper II.) Further, an earlier study among outpatients with schizophrenia demonstrated good test-retest reliability (0.90) for the Q-LES-Q (Ritsner et al. 2005). According to the study findings among patients with generalized anxiety disorder the Q-LES-Q SF seems to be sensitive to changes (Wyrwich et al. 2009). The secondary outcome measure SDS showed high internal consistency (Cronbach's alpha 0.83) considering that the scale includes only three items (Ferketich 1991). Deleting any item on the scale did not increase the alpha coefficient. Internal consistency of the SDS seemed to be quite acceptable, also when inter-item correlation ($r=0.51-0.71$) and corrected item to total correlation ($r=0.63-0.76$) were examined, although relation over 0.70 might be an excessively high correlation (Ferketich 1991). In earlier studies the SDS has also shown acceptable reliability (Cronbach's alpha 0.56-0.86) (Leon et al. 1992) and moreover sensitivity to treatment effects (Sheehan & Sheehan 2008). (Paper V.)

6.3. Discussion of results

The overall purpose of this study was to identify means by which QoL of patients with schizophrenia could be improved in acute psychiatric wards. To achieve this subjective QoL of patients, assessment of QoL, nursing interventions to improve QoL, and effectiveness of patient education methods were examined. The results of the study are next discussed in light of the objectives of the study.

The first objective was to examine patients' subjective QoL. (Paper I.) The study found that QoL is a multidimensional concept (WHOQOL Group 1995, Harrison et al. 1996,

Haas 1999, Moons et al. 2006). Almost one hundred different definitions of important QoL areas were reported by 35 patients. The findings are consistent with those of earlier studies among psychiatric patients in which patients named various QoL areas (Angermeyer et al. 2001, Hantikainen et al. 2001, Prince & Gerber 2001, Corring & Cook 2007). Further, the patients' most often named QoL areas, health, family, leisure activities, work and social relationships, are same as those mentioned by most people when defining QoL (Bowling 2005). However, there were various other areas of QoL that the patients mentioned like freedom, security, dreams, pets and nature. This concurs with a general view that QoL is a subjective experience (WHOQOL Group 1995, Harrison et al. 1996, Haas 1999, Bowling 2003, Moons et al. 2006). As Peplau (1991) argued, QoL can be seen as an all-encompassing theme which includes virtually all aspects of existence.

The patients in this study considered health and mental health very important for their QoL. Compared to findings with healthy subjects (Moons et al. 2005) patients named health much more often as the important QoL area. This is not surprising, since schizophrenia is one of the most serious and disabling mental disorders (Mueser & McGurk 2004, Picchioni & Murray 2007). Moreover, patients were interviewed in acute psychiatric inpatient wards, where patients are in their most acute state of the illness (Department of Health 2002). Patients' satisfaction regarding health varied surprisingly widely. Some patients rated themselves as healthy individuals (Moons et al. 2005). An explanation for the surprisingly high QoL rates may be that many patients with schizophrenia have poor insight into the presence of their illness (Lincoln et al. 2007, Picchioni & Murray 2007), and thus do not realise consequences of their mental illness for restrictions in daily living (Karow et al. 2008). Another explanation for research findings related to satisfaction with QoL is that patients have adapted their standards of QoL downwards (Becker et al. 2005, Katschnig 2006).

On the other hand, some patients rated their satisfaction regarding health very weak indicating that these patients perhaps experienced their health to be a huge threat to their QoL. Altogether, patients' satisfaction regarding health was clearly lower than healthy subjects (Moons et al. 2005). The findings support the view that schizophrenia impairs subjective QoL (Lehman et al. 1982, Gupta et al., 1998, Bengtsson-Tops & Hansson 1999, Koivumaa-Honkanen et al. 1999, Ponizovsky et al. 2003, Wetherell et al. 2003, Chan & Yu 2004, Thornicroft et al. 2004, Nørholm & Bech 2006, Evans et al. 2007). From the nursing point of view, in improving patients' QoL it is essential for nurses to understand that satisfaction with health is a major factor related to patients' QoL (Hansson et al. 1999, Salokangas et al. 2006).

In phase I the majority (69%) of the study sample were single or divorced, which is typical in this group of patients (Hansson et al. 2003, Salokangas et al. 2009). In spite of this, many patients (60%) named family as an important QoL area, but satisfaction with family as a QoL area was clearly lower than that of healthy individuals (Moons et al. 2005). For many patients family members may be the only persons to give the support and security that patients miss (Salokangas et al. 2006). Moreover, patients with schizophrenia experience loneliness (Hansson et al. 1999, Hansson et al. 2003, Thornicroft et al. 2004, Salokangas et al. 2006). For these reasons, in treating these

patients the family should be part of the care process, as is recommended in the clinical practice guidelines (QoL (APA 2004, RANZCP CPG team 2005, Finnish Medical Society Duodecim & Psychiatric Association 2008, NICE 2009).

Unemployment (Thornicroft et al. 2004, Mubarak 2005) and insufficient financial means (Heider et al. 2007) are related to impaired QoL in patients with schizophrenia. Although only 19% of the study sample were employed, only a minority of patients named financial means as an important QoL area, whereas in healthy samples almost half of the participants named financial means (Hickey et al. 1996, Moons et al. 2005). A long period of lack of work and poor financial situation over the years may have accustomed patients to the situation and served to lower their expectations (Carr et al. 2003). However, those patients who named financial matters as an important area of their QoL were clearly more dissatisfied with their financial means than healthy subjects in an international sample (Moons et al. 2005). Although it is not unproblematic to compare findings from different cultures it may be that the findings from this study indicate that financial matters among patients with schizophrenia should be a concern in psychiatric nursing.

The second objective was to examine and compare two standardised QoL instruments. (Paper II.) As shown earlier in the review of the literature, numerous QoL instruments have been used to assess QoL in patients with schizophrenia (See p. 20). Only a few of them have properly demonstrated psychometric properties (Bobes & Carciá-Portilla 2006). However, it is important to use instruments with evidence of psychometric properties and feasibility (Awad & Voruganti 2000, Robinson et al. 2003, Priebe 2007, Price et al. 2008, Priebe & Fakhoury 2008). Thus, instruments must be tested in different patient groups. In this study, the EQ-5D and the Q-LES-Q SF were tested among patients with schizophrenia. (See Table 3, Appendix 1.)

Internal consistency of the Q-LES-Q SF was demonstrably high. This is in line with values detected in earlier studies among patients with schizophrenia (Bishop et al. 1999, Ritsner et al. 2002, Ritsner et al. 2005). For the EQ-5D the finding indicated moderate internal consistency given the small number of items (Ferketich 1991). On the other hand, it should be noted that the alpha value is clearly lower than in general population as found in a study by Kontodimopoulos et al. (2008). Deleting any item on the scales did not increase the alpha coefficient. Further, the high inter-item correlations supports the homogeneity of the Q-LES-Q, whereas only 20% of the inter-item correlations of EQ-5D were at a criterion level between 0.30 and 0.70 (Ferketich 1991).

The findings showed that the patients with deficits in functioning had significantly poorer QoL than those with better functioning with both instruments. Since deficits in functioning are associated with impaired QoL in patients with schizophrenia (Salokangas et al. 2006) the findings support the acceptable construct validity of both instruments. The acceptable construct validity of the EQ-5D is supported by earlier findings among patients with schizophrenia (Prieto et al. 2004). Moreover, both the EQ-5D index and the Q-LES-Q total score showed moderate correlation indicating that the instruments only partly measure the same construct, which is not surprising. The Q-

LES-Q represents the QoL construct more widely (See Table 3.). However, the cause of the weak correlation may also be that the EQ-5D assesses degree of severity and the Q-LES-Q satisfaction (Wisniewski et al. 2007).

Feasibility was tested by analysing missing values. The analysis suggests that the patients found the EQ-5D easier to use, since there were more missing values in the Q-LES-Q. On the other hand, it should be noted that the patients assessing their QoL were inpatients and thus assessing the items “work”, “household duties” and “sexual drive/performance” may be irrelevant from the patients’ point of view. In addition, the simple explanation for missing values for the item “work” could be that employment rate is low among patients with schizophrenia (Marwaha & Johnson 2004, Thornicroft et al. 2004). In analysing missing values differences were found in both instruments related to overall functioning which may indicate that the patients with low functioning found the instruments more difficult to use.

The EQ-5D is designed to assess QoL in various conditions. Only one item refers to mental health, focusing on depression and anxiety. When reflecting the EQ-5D against the patients’ descriptions of their most important QoL areas (See Paper I), it can be argued that the EQ-5D is too narrow to assess the QoL in this group of patients. Only three QoL areas (health, family, work) of 14 named by patients can be assessed by the EQ-5D. By contrast, with the Q-LES-Q SF the seven most often named QoL areas (health, family, leisure activities, work, social relationships, accommodation, finance) can be assessed. Thus, the Q-LES-Q SF is a better choice to measure subjective QoL of patients with schizophrenia, while the EQ-5D is an acceptable instrument to briefly assess patients’ QoL problems related to health status. Van de Willige et al. (2005) found that the EQ-5D is able to detect changes related to the dimensions but that the EQ-5D index was less sensitive to changes in patients with schizophrenia. The sensitivity of the Q-LES-Q SF to changes in this group of patients should be examined. In all, the literature comparing QoL instruments among psychiatric patients is not extensive (Wisniewski et al. 2007). More research on these two QoL instruments and the psychometric properties and feasibility of other QoL instruments is needed (Bobes & Carciá-Portilla 2006, Wisniewski et al. 2007).

In this study, both respondent-generated (Paper I) and standardised (Paper II, Paper IV) instruments were used to assess patients’ QoL. The patients’ QoL was found to be decidedly low in both assessments in the acute psychiatric inpatient wards. At 12-month follow-up QoL was still clearly impaired compared to that of healthy subjects (Schechter et al. 2007) These fairly low QoL findings seem to be inconsistent with the results from earlier studies among patients with schizophrenia in Finland (Salokangas et al. 2000, Seppälä et al. 2000, Heikkilä et al. 2001, Nordling 2007) reporting that patients are quite satisfied with their subjective QoL. Samples in earlier studies may have included more patients with a longer history of illness and who for that reason have adapted to their situation by reducing their expectations (Carr et al. 2003, Hofer et al. 2004, Becker et al. 2005). Be that as it may, there should be a concern in Finnish society about how these individuals currently manage in their lives. Greater effort needs to be made to improve mental health service delivery and treatment interventions to better enhance the QoL of these individuals and their families (Knapp et al. 2007).

The third objective of this study was to examine patients' and nurses' perceptions of nursing interventions improving patients' QoL in acute psychiatric wards. (Papers III and IV.) According to the findings of this study, nurses in acute psychiatric wards seem to take advantage of their opportunities to support positive changes on patients' QoL by using many kinds of interventions. It could be assumed that when grouping together the patients' and the nurses' descriptions of the interventions it is possible to obtain a quite good picture of the interventions by which nurses can improve patients' QoL in acute psychiatric wards.

The nurse-patient relationship, which has been argued to be the most essential part of psychiatric nursing (Peplau 1997, Chambers 1998, Fourie et al. 2005, Schröder et al. 2006), enables nurses to enhance patients' QoL (Clark 2004, Megens & van Meijel 2006). This was also noted in this study. Especially when the participants described empowering interventions the relationship with the primary nurse was discussed. Both patients and nurses reported that discussing, showing interest, encouraging and giving information are actions by which nurses already now enhance patients' QoL. Moreover, the nurses reported that they maintained hope and motivated patients. This is important, since hopelessness has been shown to be a significant indicator of poor QoL (Haatainen 2004). A hopeful and optimistic attitude is fundamental, especially in treating patients with schizophrenia (RANZCP CPG team 2005, NICE 2009), since the recovery of patients is related to hope and optimism for the future (Resnick et al. 2005).

As seen in the findings in phase I (Paper I) and earlier studies (Angermeyer et al. 2001, Bowling 2005), most patients value family as an important area of QoL. This is not surprising since schizophrenia is characterized by impaired functioning in daily living and loss of social relationships (Mueser & McGurk 2004). To manage in their lives, many patients need a lot of practical help and emotional support from their family members. Family and patients' other close relationships are nowadays highlighted as important participants in the treatment of patients with schizophrenia (APA 2004, RANZCP CPG team 2005, Finnish Medical Society Duodecim & Psychiatric Association 2008, NICE 2009). One goal is to decrease family burden caused by patient's illness (Magliano et al. 2005, Noreen & McCain 2005, Chien et al. 2007). However, the findings of this study and others indicate that there is still a need to develop this part of psychiatric nursing (Vuokila-Oikkonen 2002, Kaas et al. 2003, Fourie et al. 2005, Kilkku 2008, van de Bovenkamp & Trappenburg 2009). Family members expect information and support in order to cope with the situation (van de Bovenkamp & Trappenburg 2009). It can be assumed that when the burden of family members decreases they are more empowered to support patients, which in turn has a positive effect on patients' QoL. Moreover, to enhance patients' QoL related to family matters, it is important to support patients with children in their parental responsibility (Korhonen et al. 2010).

Patients treated in acute psychiatric wards experience many kinds of restrictions (Johansson et al. 2006, Kuosmanen 2009). It has been argued that the atmosphere in acute psychiatric inpatient wards is overshadowed by control, where local routines and law have an important role (Johansson et al. 2006). In this study, patients valued their

opportunity to exercise self-determination in decision-making. However, they still considered that to better enhance QoL, nurses should use less force and restrictions. More attention should be paid to patients' opportunities to exercise self-determination, which is restricted when staff exercise power (Schröder et al. 2006). Nurses in these wards work in high pressure environments where safety issues because of adverse incidents, such as violence, self-harm and absconding, are a matter of concern (Cleary et al. 2005, Fourie et al. 2005, Bowers et al. 2007). Such safety issues may at least partly explain the need for the extensive use of restrictions. Although it is nowadays a challenge in psychiatric acute wards to create a safe and humane ward atmosphere with minimal restrictions, this should be a goal, since patients treated in these settings are in the most vulnerable stage of their illness (Department of Health 2002). Moreover, these patients experience stigma and discrimination in society (Graf et al. 2004, Thornicroft et al. 2009, van Zelst 2009) which should also be born in mind when restricting the self-determination of these patients. Further, it should be noted that the patients suggested that to better support their QoL nurses should show more respect and empathy. Such hopes are likely related to those situations where patients self-determination has been restricted.

Patient-centred care, in which patients' needs and preferences are in the most important value, is widely recommended as a basic principle in modern treatment settings (WHO 2001a, WHO 2005, Ministry of Social Affairs and Health 2009). According to the findings of this and earlier studies (Latvala & Janhonen 1998, Vuokila-Oikkonen 2002, Koivisto et al. 2004, Kilkku 2008, Kuosmanen 2009), it seems that in Finland psychiatric nursing is still only on its way towards patient-centred care. In this study, the nurses discussed patient-centred care by suggesting that they should develop systems by which to collect information to assess patients' needs for care. One way to assess patients' needs for care is provided by QoL view by taking QoL assessment as a starting point when planning nursing interventions (Kettis-Lindblad et al. 2007). Especially in the nurse-patient relationship a nurse has a good opportunity to individually assess a patient's QoL, discuss the patient's individual experiences and goals related to QoL, and, based on assessment and discussions, plan nursing interventions to be used in the patient's care together with the patient and his or her family members. Moreover, as has been shown (Angermeyer et al. 2001, Paper I) patients with schizophrenia define their QoL in various ways. In this case respondent-generated QoL assessment might give professionals a new, more holistic outlook on living with schizophrenia. In general, there is an obvious need to develop means to support patient-centred care and to influence attitudes of ward staff to become more appreciative of patients' needs and preferences as a basic element in care (Lammers & Happell 2003).

The fourth objective was to examine the effectiveness of three different patient education methods on the QoL of patients with schizophrenia. (Paper V.) Patient education is recommended in clinical practice guidelines (APA 2004, RANZCP CPG team 2005, Finnish Medical Society Duodecim & Psychiatric Association 2008, NICE 2009). However, in earlier studies, patients have expressed their dissatisfaction with information received in Finnish psychiatric settings (Hotti 2004, Kilkku 2008, Hätönen 2010). In this study, too, the patients suggested that nurses should provide more

information, especially related to illness, medication, and other treatment options (Paper III). There is therefore a need to develop patient education methods in Finnish psychiatric care (Hätönen 2010). This is also essential from the QoL point of view because it seems that by educating patients their well-being can be enhanced (Pekkala & Merinder 2002). As seen in the literature review related to patient education, using QoL as an outcome instrument in RCTs is still fairly rare (See p. 29).

In this study two recently developed patient education methods, computerised patient education and education with leaflets, as well as treatment as usual were tested in an RCT using QoL as an outcome. The findings showed that all study groups made a significant improvement in QoL and in functional ability. This is not the case in many studies using psychosocial interventions among patients with schizophrenia (Priebe & Fakhoury 2008), nor in the already mentioned studies related to patient education (Gray et al. 2006, Vreeland et al. 2006). (See Table 2.) However, the hypothesis that systematic patient education methods are more effective than care as usual with regard to QoL and functional disability had to be rejected, likewise the hypothesis that computer based systematic patient education would be more likely to increase patients' QoL and alleviate functional disability.

Atkinson et al. (1996), who compared a waiting list group with education group sessions over 20 weeks with one session in each week, and Evans et al. (2005), who compared standard psychiatric care with six individual education sessions over three months, succeeded in finding significantly greater improvement in the intervention groups. (See Table 2.) In this study five sessions over a short time period during acute inpatient care may have limited the likelihood of observing any significant group differences in outcomes. Another explanation may be contamination between groups since blinding in clinical settings was not possible. Moreover, the average age of participants in this study was 38 years. Implementing this study with younger subjects might have identified more significant differences between groups. These younger individuals may also have been more disposed to use IT based patient education during the follow up-time in home environments, which was the idea when the programme (Mieli.Net) was developed. In this study sample, only about one third of the patients in the IT based patient education group used computer based education independently in their home environments. Moreover, Koivunen et al. (2008) found that nurses differ in their skills and motivation to IT, which may have affected the patients' opportunities to receive optimal IT based patient education.

This study suggest that there is no evidence to support any particular education method. The method to be used should be tailored to the patient's individual needs (Hätönen 2010). However, this study showed that IT based patient education was no less effective than the two other methods, and it was implemented successfully in acute psychiatric wards among patients with schizophrenia. Nevertheless, a face-to-face relationship between a patient and a nurse, which is a core element in psychiatric nursing (Peplau 1997, Chambers 1998, Fourie et al. 2005, Schröder et al. 2006), may be the best situation to give individualized patient education. Patients moreover value information received through discussions with nurses (Hätönen 2010). On the other hand, in practice it may be too demanding to give all relevant information since

patients' individual information needs are various. IT based education, with its ability to include huge amount of information to be tailored to individual needs may therefore offer a supplement which can be used in nurse-patient interaction in acute psychiatric wards, in outpatient settings, as well as independently by patients and their families in their day-to-day living settings. Moreover, it is noteworthy that patients with schizophrenia are stigmatized, which leads to discrimination (Sartorius 1997, Graf et al. 2004, Thornicroft et al. 2009, van Zelst 2009). The IT based patient education programme on the Internet offers patients a way to participate in society as active citizens and thereby also to enhance their QoL.

6.4. Implications for improving patients' quality of life in acute psychiatric wards

The overall purpose of this study was to identify areas by which the QoL of patients with schizophrenia could be better improved in acute psychiatric wards. The study identified areas to be developed from the perspectives of nursing practice, nursing management, and nursing education. The implications will be presented in light of the four study phases logically, step by step.

Quality of life of patients with schizophrenia

1. Nurses should be aware that QoL is a multidimensional concept of which patients have their individual definition.
2. Nurses' knowledge of the effect of schizophrenia on patients' QoL should be ensured.
3. Nurses should be aware that patients with schizophrenia suffer from impaired QoL. Thus patients' individual QoL should be assessed at the beginning of care and assessment should be a continuing process.

Assessment of quality of life of patients with schizophrenia

1. QoL instruments to be used in clinical settings should be respondent-generating or sufficient multidimensional covering QoL areas important to most patients with schizophrenia.
2. The Q-LES-Q is a better choice to measure the subjective QoL of patients with schizophrenia, while the EQ-5D is an acceptable instrument to briefly assess patients' QoL problems related to health status.
3. Instructions on how routine QoL assessment in clinical settings can be successfully implemented should be developed.
4. Nurses should be trained to assess patients' QoL.

Nursing interventions improving patients' quality of life in acute psychiatric wards

1. In nurse-patient relationships nurses should discuss the patient's individual experiences and goals related to QoL.

2. Based on the assessment of QoL and discussions with a patient and his or her family members an individually tailored nursing interventions should be planned together with the patient.
3. The interventions described in this study, such as
 - use empowering interventions, such as showing interest, respect, and empathy, as well as maintaining hope and encouraging
 - give patients opportunities to exercise self-determination as far as possible
 - give patients information based on their information needs
 - collaborate with family members according to patients' and family members' needs
 - secure patients' important social contacts
 - concern themselves with the patients' financial situation
 - make it possible for patients to engage in various kinds of activities
 - take care of patients' safety and privacy
 - take care of patients' physical health and medicationcan be used as a base for individually tailored interventions to improve patients' QoL.
4. Nurses should have time-resources to conduct interventions which improve patients QoL.
5. Greater effort needs to be invested in the development of nursing interventions to better improve patients' QoL.
6. Nurses' knowledge and skills in providing nursing interventions by which patients' QoL is best improved should be ensured.

Effectiveness of patient education methods on quality of life of patients with schizophrenia

1. Different educational methods should be available to patients.
2. IT based patient education should be one option in educating patients.

6.5. Suggestions for future research

Further research related to improving QoL of patients with schizophrenia is needed. To gather more evidence on this field, suggestions for future research ideas have arisen on the basis of this study:

1. The QoL assessment as a framework for planning nursing interventions for patients with schizophrenia in acute psychiatric wards needs to be studied.
2. Patients' and family members' evaluation of nursing interventions to support patients' QoL should be explored.
3. A systematic literature review is needed of interventions improving patients' QoL in acute psychiatric wards.
4. Effectiveness of different nursing interventions to support patients' QoL should be tested.
5. More research is needed on the psychometric properties and feasibility of QoL instruments used in patients with schizophrenia in acute psychiatric wards.

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Table. Ten most often used QoL instruments in research with patients with schizophrenia

APPENDIX.

Instrument	Authors (Year)	Type of the instrument	Domains	Format
Quality of Life Scale (QLS or QOLS)	Heinrichs et al. (1984)	Disease-specific (schizophrenia)	Intrapsychic foundation (e.g. motivation, empathy), interpersonal relations (e.g. household, social network), instrumental role (e.g. occupational role, work satisfaction), common objects and activities	Semi-structured interview; 21 items; Completed within 45 minutes
The World Health Organization Quality of Life (WHOQOL-100/WHOQOL-BREF) ¹⁾	The WHOQOL group (1995)	Generic	Physical, psychological, level of independence, social relationships, environment, spirituality	Self-administered or interviewer-administered; 100/26 items; Self-administered completed within 10-20 / 5 minutes; Interviewer administered completed within 60/15-20 minutes
Medical Outcome Study (MOS) 36-Item Health Survey (SF-36/ SF-12[short form of the SF-36]) ²⁾	Ware & Sherbourne (1992)	Generic	Physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role-limitations due to emotional problems, mental health	Structured questionnaire; Self-administered or interviewer-administered; 36 items/12 items; Completed within 10/2 minutes Preference-Based
Lehman Quality of Life Interview – (QOLI or QLI-L) ¹⁾	Lehman (1988)	Disease-specific (severe mental illness)	Living situation, daily activities and functioning, family relations, social relations, finances, work and school, legal and safety issues, health	Interviewer administered; Full version 158 items, brief version 78 items; Both objective and subjective questions; Completed within 45 /16 minutes
Manchester Short Assessment of Quality of Life (MANSA)	Priebe et al. (1999)	Disease-specific (severe mental illness)	Job, financial situation, friendships, leisure activities, accommodation, safety, people that patients live with, sex life, relationship with family, physical health, mental health	Interviewer-administered; 16 items; Both objective and subjective questions; Completed within 10-15 minutes

Instrument	Authors (Year)	Type of the instrument	Domains	Format
Euroqol EQ-5D (EQ-5D) ³⁾	Brooks, with the EuroQoL Group (1996)	Generic	Mobility, self-care, usual activities, pain or discomfort and anxiety or depression	Self-administered; 5 items; Completed within 1-2 minutes Preference-Based
Schizophrenia Quality of Life Scale (SQLS)	Wilkinson et al. (2000)	Disease-specific (schizophrenia)	Psychosocial (e.g. worries, loneliness), motivation and energy (e.g. daily activities, cope), symptoms and side-effects (e.g. sleep, vision)	Self-administered; 30 items; Completed within 5-10 minutes
Subjective Well-being under Neuroleptic Treatment (SWN)/Short Form (SWN-K) ⁴⁾	Naber (1995)	Disease-specific (schizophrenia)	Emotional regulation, mental functioning, self control, social integration, physical functioning	Self-administered; 38/20 items; Completed within 10-15 minutes
Lancashire Quality of Life Profile (LQOLP)	Oliver et al. (1997)	Disease-specific (severe mental illness)	Living situation, family, social relationships, leisure activities, work/education, finances, personal safety, health, religion	Interviewer-administered; 105 items; Both objective and subjective questions; Completed approximately within 35 minutes
Quality of Life and Satisfaction Questionnaire (Q-LES-Q)/Short Form (Q-LES-Q SF) ¹⁾	Endicott et al. (1993)	Generic for psychiatry	Physical health, subjective feelings, leisure time activities, social relationships, general activities; Optional domains: work, school, household duties	Self-administered; 60+33 optional items/16 items; Completed within 15/5 minutes

Additional references: ¹⁾ Danovitch & Endicott 2008, ²⁾ Ware et al. 1996, ³⁾ EuroQoL Group 2010, ⁴⁾ Naber et al. 2001.

* RAND-36 includes the same set of items as SF-36. Only scoring of the general health and pain scales is different (Aalto et al. 1999).