TURUN YLIOPISTON JULKAISUJA
ANNALES UNIVERSITATIS TURKUENSIS

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*SARJA - SER. D OSA - TOM. 841*

MEDICA - ODONTOLOGICA

# PERSONAL LIBERTY IN PSYCHIATRIC CARE – TOWARDS SERVICE USER INVOLVEMENT

by

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TURUN YLIOPISTO
Turku 2009

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ISBN 978-951-29-3839-1 (PRINT)
ISBN 978-951-29-3840-7 (PDF)
ISSN 0355-9483
Painosalama Oy – Turku, Finland 2009

**lib-er-ty** (lib'ər·tē) *n. pl.* ·ties **1** The state of being exempt from the domination of others or from restricting circumstances; freedom.

(The New International Webster's Comprehensive Dictionary of the English Language, 1999)

**To Tarja, Siiri and Heta**

Lauri Kuosmanen

**PERSONAL LIBERTY IN PSYCHIATRIC CARE - TOWARDS SERVICE USER INVOLVEMENT**

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# ABSTRACT

This study explores personal liberty in psychiatric care from a service user involvement perspective. The data were collected in four phases during the period 2000-2006 in psychiatric settings in Finland. Firstly, patient satisfaction and factors associated with user involvement were studied (n = 313). Secondly, patients' experiences of deprivation of their liberty were explored (n = 51). Thirdly, an overview on patients' options for lodging complaints was conducted, and all complaints (n = 4645) lodged in Finland from 2000 to 2004 were examined. Fourthly, the effects of different patient education methods on inpatients' experiences of deprivation of liberty were tested (n = 311).

It emerged that patients were quite satisfied, but reported dissatisfaction in restrictions, compulsory care and information dissemination. Patients experienced restrictions on leaving the ward and on communication, confiscation of property and coercive measures as deprivation of liberty. Patients' experienced these interventions to be negative. In Finland, the patient complaint process is complicated and not easily accessible. In general, patient complaints increased considerably in Finland during the study period. In psychiatric care the number of complaints was quite stable and complaints led more seldom to consequences. An Internet-based patient education system was equivalent with traditional education and treatment as usual in supporting personal liberty during hospital care.

This dissertation provides new information about the realization of patients' rights in psychiatric care. In order to improve patients' involvement, systematic methods to increase personal liberty during care need to be developed, the procedures for patients lodging complaints should be simplified, and patients' access to information needs to be ensured using multiple methods.

**Keywords**: personal liberty, service user involvement, patients' perspective, psychiatric nursing, psychiatric care

Lauri Kuosmanen

**HENKILÖKOHTAINEN VAPAUS PSYKIATRISESSA HOIDOSSA - KOHTI PALVELUJEN KÄYTTÄJIEN OSALLISUUTTA**

Hoitotieteen laitos, Lääketieteellinen tiedekunta, Turun yliopisto, Turku

# TIIVISTELMÄ

Tässä tutkimuksessa on tarkasteltu henkilökohtaista vapautta psykiatrisessa hoidossa potilaiden osallisuuden näkökulmasta. Tutkimusaineisto kerättiin neljässä vaiheessa vuosien 2000-2006 aikana suomalaisesta psykiatrisesta hoitojärjestelmästä. Ensimmäisessä vaiheessa selvitettiin potilastyytyväisyyttä ja siihen liittyviä tekijöitä (n = 313). Toisessa vaiheessa tutkittiin potilaiden kokemuksia vapauden rajoittamisesta sairaalahoidon aikana (n = 51). Kolmannessa vaiheessa selvitettiin kirjallisuuskatsauksen avulla psykiatristen potilaiden mahdollisuudet kannella hoidostaan. Tämän lisäksi kaikki vuosina 2000-2004 tehdyt potilaskantelut tutkittiin valtakunnallisen rekisteriaineiston avulla (n = 4645). Neljännessä vaiheessa testattiin eri potilasopetusmenetelmien vaikutuksia potilaiden kokemaan vapauden rajoittamiseen (n = 311).

Tutkimus osoitti, että psykiatriset potilaat olivat melko tyytyväisiä hoitoonsa. Esiin nousi kuitenkin tyytymättömyyttä liittyen tahdonvastaiseen hoitoon ja rajoituksiin sekä tiedonsaantiin. Haastattelujen perusteella potilaat kokivat liikkumisen ja yhteydenpidon rajoittamisen, omaisuuden haltuunoton ja tahdonvastaiset hoitotoimenpiteet vapauden rajoittamiseksi. Potilaiden kokemukset vapauden rajoittamisesta olivat negatiivisia. Tutkimuksen mukaan potilaskanteluiden prosessi on Suomessa monimutkainen ja sellaisen henkilön, jolla on mielenterveyden ongelmia, voi olla vaikea hahmottaa kanteluprosessia. Tutkimusajankohtana kaikkien potilaskanteluiden määrä Suomessa kasvoi merkittävästi. Psykiatrisesta hoidosta tehtyjen kanteluiden määrä ei lisääntynyt yhtä voimakkaasti, ja psykiatristen potilaiden tekemistä kanteluista pienempi osa johti seuraamuksiin. Psykiatristen potilaiden henkilökohtaisen vapauden tukemisessa sairaalahoidon aikana osoittautui tutkimuksen viimeisessä osassa testattu Internet-perustainen potilasopetus yhtä tehokkaaksi kuin perinteinen potilasopetusmenetelmä ja nykykäytännön mukainen hoito.

Tämän väitöskirja tuottaa uutta tietoa psykiatristen potilaiden oikeuksien toteutumisesta psykiatrisessa hoidossa. Jotta potilaiden osallisuutta omaan hoitoonsa voitaisiin parantaa, on kehitettävä systemaattisia menetelmiä potilaiden henkilökohtaisen vapauden lisäämiseen, yksinkertaistettava potilaiden kantelumahdollisuuksia ja parannettava tiedonsaantia monipuolisia menetelmiä käyttämällä.

**Asiasanat:** henkilökohtainen vapaus, palvelujen käyttäjien osallisuus, potilaiden näkökulma, psykiatrinen hoitotyö, psykiatrinen hoito

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## ABBREVIATIONS

| | |
|---|---|
| ANA | American Nurses Association |
| ANOVA | Analysis of variance |
| CASP | Critical Appraisals Skills Programme |
| CI | Confidence Interval |

| | |
|---|---|
| GAF | Global Assessment of Functioning |
| EPSILON | European Psychiatric Services: Inputs linked to Outcome Domains and Needs |
| ETENE | The National Advisory Board on Health Care Ethics |
| ICD-10 | International Classification of Diseases |
| ICN | International Council of Nurses |
| MANOVA | Multivariate analysis of variance |
| NOMESKO | The Nordic Medico-Statistical Committee |
| PANSS | Positive and Negative Syndrome Scale |
| PSS | Patient Satisfaction Scale |
| PSS-Fin | Patient Satisfaction Scale, Finnish version |
| RR | Risk Ratio |
| SD | Standard Deviation |
| SPRI | Swedish Institute for Health Services Development |
| SPSS | Statistical Package for the Social Sciences |
| TEO | The National Authority for Medicolegal Affairs |
| VAS | Visual Analoque Scale |
| WHO | World Health Organization |

# LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following publications which are referred to in the text by their Roman numerals I - V:

I Kuosmanen L, Hätönen H, Jyrkinen AR, Katajisto J & Välimäki M. 2006. Patient satisfaction with psychiatric inpatient care. Journal of Advanced Nursing 55 (6), 655-663.

II Kuosmanen L, Hätönen H, Malkavaara H, Kylmä J & Välimäki M. 2007. Deprivation of liberty in psychiatric hospital care: the patient's perspective. Nursing Ethics 14 (5), 597-607.

III Välimäki M, Kuosmanen L, Kärkkäinen J & Kjervik D. Patients' rights to complain in Finnish psychiatric care: An overview. International Journal of Law and Psychiatry. In press.

IV Kuosmanen L, Kaltiala-Heino R, Suominen S, Kärkkäinen J, Hätönen H, Ranta S & Välimäki M. 2008. Patient complaints in Finland 2000-2004: a retrospective register study. Journal of Medical Ethics 34 (11), 788-792.

V Kuosmanen L, Välimäki M, Joffe G, Pitkänen A, Hätönen H, Patel A & Knapp M. The effectiveness of technology-based patient education on self-reported deprivation of liberty among people with severe mental illness: a randomised controlled trial. Nordic Journal of Psychiatry. Accepted for publication 2/2009.

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# 1 INTRODUCTION

Personal liberty is a basic human right. It is a central value for all human beings, whether they have mental health problems or not. (United Nations 1948, Council of Europe 2000.) People with mental health problems may have diminished ability to influence their care, and those treated in psychiatric establishments especially have faced difficulties in getting their voice heard and their basic rights are restricted in many ways (WHO 2005a, WHO 2005b). Stigma (Warner 2008), possible cognitive impairments (Medalia & Lim 2004), unbalanced power structures in mental health services (Muir-Cochrane 1996, Sullivan 1998), and the historical use of physical and pharmaceutical control and restraint (Rutter et al. 2004, Schauer et al. 2007), have hampered the realisation of the basic human rights of these people.

At the same time, there has been increasing international interest in using subjective evaluations of health states by the patients or service users (Eurofound 2004, WHO 2005b). The views of service users provide useful information about key aspects of health service delivery (Jenkinson et al. 2002, Picker Institute Europe 2004), but only if their views are applied to health care policy (Dozier et al. 2001). It is essential that service users' needs are taken into account and their voice is heard when designing and operating health services (WHO 1996). This is supported by the idea, that health is something that professionals and patients create together, and patients are described as co-producers of health (Donabedian 1992, Draper et al. 2001). If service users' needs and interests are to be central to services, it follows that their perspectives should be a central focus within the evaluation of service provision (Truman & Raine 2002). Their involvement in decision-making is seen as an indicator of good practice: being involved in decision-making can have therapeutic value in itself (Hickey & Kipping 1998, Robert et al. 2003).

In the area of psychiatric care, the demand for user involvement has been particularly significant, and there is growing interest in promoting realisation of patients' rights among people suffering from mental health problems (Council of Europe 2000, Kingdon et al. 2004, Rutter et al. 2004). The Scandinavian countries especially have undergone a rapid development in legally safeguarding patients' rights (Fallberg 2000). For example, in Denmark (Nys et al. 2007) and in Finland (Act on the Status and Rights of Patients 785/1992), recent legal changes have strengthened the individual's position and rights in the health care system.

Recently, user involvement has become an accepted part of policymaking (Rush 2004), and an essential component in the planning, delivery and evaluation of mental health care (Department of Health, UK 1999, Anthony & Crawford 2000, Stickley 2006, Hui & Stickley 2007). So far, the benefits of user participation and involvement in their treatment and decision-making have not been clearly demonstrated (Guadagnoli & Ward 1998, Crawford et al. 2003). There is mixed evidence about how far user involvement is being achieved in mental health care, and whether it is having any impact on service development (Crawford et al. 2003, Weinstein 2006). However, involving users has shown no negative effect on services (Simpson & House 2002). Unbalanced power dynamics between service users and service providers (Hui & Stickley 2007), lack of clarity of users' roles, and fear of unrealistic expectations of users may have kept service user involvement at a tokenistic level (Crawford & Rutter 2004, Weinstein 2006).

In Finland, health care legislation does not distinguish between patient groups, and therefore patients with mental problems are equal before the law. So far, there are no specific recommendations or legislation regarding how persons with mental health problems should be involved in their own treatment. This can diminish service users' opportunities to evaluate and give feedback on the treatment, and may hamper the realisation of the fundamental rights of patients. It is important to increase the general awareness of service users about their rights, and encourage them to challenge some mental health practices, e.g. deprivation of their personal liberty in psychiatric inpatient care (Pierre 2002).

There is a need to protect people with severe mental health problems from discrimination and marginalisation from society, and it is important to support their chances to be actively involved in their own care, to give feedback on services, and to ensure the realisation of their basic rights during treatment (Council of Europe 2000, Ministry of Social Affairs and Health 2001, WHO 2005a). One main goal for service user involvement should be to decrease the burden of mental illness on an individual and on society. Recently, this need has been recognised in the national plan for mental health and substance abuse work (Ministry of Social Affairs and Health 2009) which emphasises that the client's status is reinforced in Finnish mental health care.

The aim of this study is to identify areas where service user involvement could be improved in psychiatric care. In addition, the current situation is described with special reference to psychiatric inpatient care. The contributory goals of this study were to describe patient satisfaction, and deprivation of liberty in psychiatric inpatient care, to explore patient complaints in Finland, and to test the effects of different patient education methods on psychiatric inpatients' experiences of deprivation of liberty. The results of the studies will provide valuable information on how patients and service users have experienced their treatment in various psychiatric settings and especially in psychiatric inpatient care. This will yield important information for the development of recommendations and guidelines supporting service user involvement in Finnish mental health services.

This study was conducted in the area of clinical nursing science. Its main focus is on the perspectives and experiences of persons who have received help from mental health services. Patient (from now on referred to as service users or patients) is understood as an individual who suffers from a mental health problem (see Pirkola & Sohlman 2005), and has been treated either voluntarily or involuntarily (Mental Health Act 1116/1990). The patient is seen holistically through physical, psychological and spiritual dimensions. Central elements of patients' dignity are personal freedom and responsibility (see Grönroos et al. 1994). Patients' status and rights are described in the legislation (Act on the Status and Rights of Patients 785/1992, Constitution of Finland 731/1999).

The study environment is the entire service organisation specialised in the treatment of people with mental health problems. This includes psychiatric hospitals and inpatient units, community care, rehabilitation units and homes, and private mental health services (Ministry of Social Affairs and Health 2004). The environment is explored both at macro and micro level: the study includes nationwide research results and results from individual psychiatric inpatient units. The main focus of the present study, however, is on psychiatric inpatient services.

Health is understood as patients' self-reported mental condition or diagnosis or mental health professionals' evaluation of an individual's state of health. In this study, most of the participants suffer from severe mental health problems such as schizophrenia and related psychoses (WHO 2007). Health in the context of psychiatric inpatient care has to be understood multidimensionally. Professionals have to accept that a patient's estimation of his or her health may differ from that of the professionals due to lack of insight (Kaplan et al. 1994, Schizophrenia: Current Care Guideline 2008).

Nursing in this study is understood as the relationship between individual and nurse in psychiatric settings, mainly in acute psychiatric units. Nursing is carried out on the basis of international (ICN 2006) and national (The Finnish Nurses Association 1996) professional ethical codes. The psychiatric nurse is seen as an advocate of the service users (Negarandeh et al. 2006). The nurse's role can be seen as that of an informant, where the nurse offers relevant information to the patient so that she/he can make decisions. In addition, the nurse encourages the patient to engage in collaboration and active involvement (Brophy et al. 1994). In certain situations nursing can include interventions depriving patients' of their liberty as part of managing disturbed or distressed behaviour or in maintaining the safety of patients and staff in psychiatric settings (Välimäki et al. 2008).

# 2 OVERVIEW OF THE LITERATURE

## 2.1 Psychiatric services in Finland

In Finland, the municipalities are responsible for arranging mental health services for their inhabitants (Ministry of Social Affairs and Health 2004, Harjajärvi et al. 2006). The right to receive mental health care is guaranteed by the legislation. The relevant Acts state that mental health services should be organized based on the health needs of the residents, and that sufficient treatment should be obtainable (Primary Health Care Act 66/1972, §14, subsection 2a, Act on Specialized Medical Care 1062/1989, §3, Mental Health Act 116/1990, §4). Outpatient care is the preferred form of treatment provided by health centres, mental health offices and psychiatric hospital outpatient departments (Ministry of Social Affairs and Health 2004). In recent years, private and third sectors have become engaged, together with municipalities, in service provision (Harjajärvi et al. 2006). Services should be based on principles of advocacy, promotion, prevention, treatment and rehabilitation (Ministry of Social Affairs and Health 2005).

Finnish mental health services are guided with national programmes and projects. During the last two decades, many development and research programmes in the area of mental health care have been carried out (e.g. The National Schizophrenia Project 1981-1987, The National Suicide Prevention Project 1986-1996, The National Depression Project 1994-1998, The Meaningful Life Programme 1998-2003). Programmes have supported municipalities and mental health professionals in developing and improving their services so that they better meet the needs of population. (Lehtinen & Taipale 2001, Ministry of Social Affairs and Health 2005.)

Psychiatric care underwent an extensive transformation starting at the beginning of the 1990's in Finland. A de-institutionalisation process, the integration of mental health services with other health services, the transfer of the responsibility for organising services from central government to the municipalities all occurred in a short period of time. Alongside with these basically positive administrative and structural changes, Finland underwent the deepest economic regression ever seen in the industrialised countries, resulting in drastic cuts in the mental health budgets and hampering the development of services. (Lehtinen & Taipale 2001, Kärkkäinen 2004, Ministry of Social Affairs and Health 2005, Harjajärvi et al. 2006.) Evaluations made of the process of de-institutionalisation conclude that situation was, however, satisfactory and patients were quite satisfied with the accessibility of the services (Korkeila 1998, Korkeila et al. 1998a-c, Lehtinen & Taipale 2001).

Changes and challenges in the services increased the public discussion about mental health in general, and mental health issues became more prominent in all areas of society. As services today are decentralised and organised at local level, there are major differences between municipalities. Some of them have very small and scattered populations, and there are regional inequalities in the quality and availability of services (Ministry of Social Affairs and Health 2005, Harjajärvi et al. 2006). In addition, the Finnish mental health care system is still too hospital-based, and there is a lack of diverse and flexible community care services (NOMESKO 2007). Other challenges in the provision of mental health services are related to increased incidence of depression, growing extent of psychosocial problems among children and young people, and experiences of stress and burnout among employees (Ministry of Social Affairs and Health 2005).

Psychiatric inpatient care is organised through hospital districts in psychiatric hospitals and inpatient units in general hospitals. In addition, inpatient care is arranged in health centres' psychiatric wards and state mental hospitals. (Ministry of Social Affairs and Health 2005, Stakes 2008.) In 2006, over 32,000 (6.1/1000 inhabitants) patients were treated in psychiatric hospitals and inpatient units, with treatment days exceeding 1.7 million. The average length of hospital stay was 36 days. Of the patients, 50 % were men, and treatment of male patients accounted for 52 % of all treatment days. The most common reasons for psychiatric inpatient care in Finland are severe mental health problems, like psychoses (Pirkola & Sohlman 2005, Stakes 2008), with lifetime prevalence of 3.06 % (Perälä et al. 2007). Schizophrenia, with lifetime prevalence rate of about 1 % (approximately 50 000 patients in Finland) is the single most important psychosis (Schizophrenia: Current Care Guideline 2008). So far, no sign or risk indicator for the prediction of schizophrenia in the general population has been identified (Isohanni et al. 2005). Certain risk factors such as delayed motor or intellectual development, pregnancy and birth complications and diseases of the central nervous system are associated with an increased risk for schizophrenia (Isohanni et al. 2006). In psychiatric inpatient care, the focus of this study, schizophrenia is the most common diagnosis among patients: 20 % of all patients treated in psychiatric hospitals and inpatient units had schizophrenia as their primary diagnosis in 2005. Out of all treatment days, 37 % were used for the treatment of these patients. (Stakes 2006.)

## 2.2 Burden of severe mental health problems

Internationally, mental health problems are the fastest growing burden for health care (WHO 2001, European Parliament 2006). About 14 % of the global burden of disease has been attributed to mental disorders, mostly to depression and other common mental disorders, alcohol abuse, and psychoses, e.g. schizophrenia (Prince et al. 2007). Severe mental health problems, like schizophrenia, are associated with extensive human suffering due to possible cognitive impairments, stigma related to mental illness, and believing that due to their illness these persons are incapable of meaningfully judging the care they receive (WHO 2005b). They have diminished opportunities to have their voice heard in society, and they are a particularly vulnerable group in health care (WHO 2005a).

The burden of severe mental health problems is extensive. For example, schizophrenia causes huge direct and indirect costs to society due to disability, degree of dependency, loss of productivity through impairment, and reduced life expectancy (Rössler et al. 2005, Wittchen & Jacobi 2005). It often presents at young age, in acute phases requires often hospitalisation, and the spells of illness are long (Lönnqvist 2006, Perälä et al. 2007). The treatment of schizophrenia is based on a long-term and trusted relationship with mental health professionals and on a individually made care plan. The main evidence-based elements of treatment are antipsychotic medication, different forms of therapies (cognitive-behavioural psychotherapy, group therapy, creative therapies), psychoeducation, family interventions, practising of daily and social skills, and supported occupational rehabilitation. (Schizophrenia: Current Care Guideline 2008.) In addition, it is important to support patients' independence (Nikkonen 1995) and possibilities to participate working life after hospital care (Nikkonen 1996). So far, the outcome of schizophrenia is not good enough and more effective treatment and rehabilitation methods are needed (Lauronen 2007).

Schizophrenia is associated with poor quality of life (Wetherell et al. 2003, Nørholm & Bech 2006), and is listed as the eighth leading cause of disability-adjusted life years worldwide in the age group 15–44 years (WHO 2001). The economic costs of schizophrenia vary between nations and studies, but it is estimated that schizophrenia causes nearly 2 % of all health care costs in each country (Hu 2006). In Finland, the costs of schizophrenia were estimated to be 2.5 billion Finnish Marks in 1987 and 700-900 million Euros in 2008 (Academy of Finland 1987, Wahlbeck & Hujanen 2008).

## 2.3 Personal liberty in psychiatric care

Liberty refers to the state of being exempt from the domination of others or from restricting circumstances (The New International Webster's Comprehensive Dictionary of the English Language 1999). Personal liberty is a basic right for all human beings. The United Nations Declaration of Human Rights states in article 1 that all human beings are born free and equal in dignity and rights. The right to liberty and equality is man's birthright and cannot be alienated. (United Nations 1948.) In Finland, the Constitution of Finland (1999) ensures the personal liberty of people. In the area of psychiatric care, there are exceptions to these basic rights and in certain situations patients can be treated against or without their will (Mental Health Act 1116/1991).

Historically, some forms of deprivation of patients' liberty have occurred in psychiatric care since the first asylums and mental hospitals were established in the 18th and 19th centuries and individuals with mental illnesses were isolated from other citizens. However, there have been physicians who have defended psychiatric patients' personal liberty already in the early days of psychiatry. For example, the work and ideas of Philippe Pinel (1745-1826), Vincenzo Chiarugi (1759 - 1820) and Jean-Etienne Esquirol (1772-1840) introduced reforms to psychiatric hospital care, and exerted considerable influence in the development of approach called moral treatment in the 18th century Europe. (Shorter 2005.)

The moral treatment movement influenced the reform of the inhumane asylum system in Europe and USA in the early 19th century (Shorter 2005). Moral treatment regarded humanity, reasoning, group living, protestant ethics and patients' re-education essential in the treatment of people with mental health problems. In hospitals, coercion was avoided and programmed work was an essential part of patients' every day life. The principles of moral treatment formed the basis for the idea of the therapeutic community, an ideology and treatment model emphasising reciprocal interaction with patients, support for the patients' autonomy and opportunities to influence their environment. (Isohanni 1983.) Unfortunately, in the late 19th century, due to industrialization and population growth, psychiatric hospitals turned into large institutions with inadequate staff and resources (Shorter 2005). This development hampered the development of the idea of therapeutic community and more human treatment of mentally ill patients (Isohanni 1983, Tuohimäki 2007).

After the Second World War progress of psychoanalysis, group therapy and social sciences fostered the movement towards more humane psychiatric care and ideas of therapeutic community expanded in the USA and UK (Isohanni 1983). Large institutions, however, formed the basis of psychiatric care in many countries until the 1970's and 1980's, and in Finland until the changes in the early 1990's (Lehtinen & Taipale 2001). In the 1960's, the antipsychiatric movement attempted to make radical changes in institutionalised care. The most radical changes were seen in Italy, where the 1978 reform closed traditional mental hospitals and patients' care was transformed into communities (Camuccio 2008). Although there is a lack of reliable information about the results of the reform (Barbui & Tansella 2008), the changes made in Italy increased the public discussion in the following decades and highlighted many important aspects related to psychiatric patients' personal liberty.

Today, in health care personal liberty is a core right of a patient. The right to self-determination and free choice are emphasised both in international and national guidelines and legislations. (Act on the Status and Rights of Patients 785/1992, European Charter of Patients' Rights 2002.) In Finland, a person can be committed for treatment in psychiatric hospital against his or her own will only if that person is diagnosed as mentally ill, if the person needs treatment for mental illness which, if not treated, would become considerably worse or severely endanger the person's health or safety or the health or safety of others, and if all other mental health services are inapplicable or inadequate (Mental Health Act 1116/1991). Patients' legal protection has to be realised and patients' self-determination can be restricted only based on legislation and in the best interests of the patient. Further, it is important that the psychiatric patient's right to adequate treatment is secured, and the primary health care physician is obligated to arrange treatment, even involuntary, for those with severe mental health problems. (Heikkinen at al. 2007, Therapia Fennica 2008.)

If the patient refuses a certain treatment or measure, he or she has to be cared for in another medically acceptable way, if available, and in mutual understanding with him/her (Act on the Status and Rights of Patients 785/1992). If patients' personal liberty or other basic rights has to be restricted, it should occur only if required due to the treatment of illness, the patient's safety or to ensure the protection of other interests. All procedures must be performed as safely as possible and with respect for the patient's human dignity. (The Amendment of Mental Health Act 1423/2001, European Charter of Patients' Rights 2002.) On the other hand, deprivation of patients' liberty in psychiatric hospitals may in many instances be justifiable for maintaining patient and staff safety (APA 1984, Fisher 1994).

In general, involuntary treatment and deprivation of liberty in psychiatric care are motivated by the good of the patient and by the good of others (Kaltiala-Heino 1996). E.g. the use of seclusion and restraint are interventions used in the treatment and management of disruptive and violent behaviour in psychiatric settings (Sailas 1999). In western societies the criteria for deprivation of liberty in psychiatric care are roughly divided into three categories: dangerousness to others, dangerous to self, and need for treatment. The first concerns mainly the social control of the patient, and the latter two refer to the patient's best interests. (Isohanni et al. 1991, Kaltiala-Heino 1996, Pylkkänen 2007.) This raises questions whether others can know better than the patient what is in her/his best interests and when overriding patient's wishes in names of her/his own best (paternalism) turns to coercion or use of power (Kaltiala-Heino & Välimäki 1999).

Based on the WHO (2005a) deprivation of patients' liberty in psychiatric establishments should be exceptions and occur only in very specific circumstances. From the individual patient's perspective deprivation of liberty can be harmful and traumatic (Nijman et al. 2005). In addition, personal liberties, such as free walking, are important curative factors during hospital care (Vartiainen et al. 1995) and respect of patients' self-determination can have positive effects on the therapeutic environment of psychiatric wards and inpatient units (Isohanni 1992). Thus, the promotion of voluntary treatment should form the basis of mental health services.

A variety of methods are being used in psychiatric hospitals to restrict patients' liberty. Involuntary admission and detention, seclusion and restraint (Välimäki et al. 2001, Tuohimäki 2007), restrictions on leaving the ward (Muralidharan & Fenton 2006), forced medication (Poulsen 2002, Steinert et al. 2007), restrictions on communication or leaving the ward, and confiscation of patients' personal property are reality in psychiatric units worldwide, although there is a lack of evidence on their clinical effectiveness (Sailas & Fenton 2001, Nelstrop et al. 2006).

In Europe, the rates of involuntary placements in psychiatric care vary remarkably. Finland, with a rate of 218 / 100 000 population, is one of the countries that use above average involuntary placement (Salize & Dressing 2004), and other forms of deprivation of liberty (Tuohimäki 2007). In 2006, out of 29,648 patients treated in psychiatric inpatient care, 10,363 (35 %) had experienced involuntary treatment at some stage of their treatment, 2,090 (7.2 %) had been secluded in a room, 1253 (4.3 %) had been mechanically restrained, 764 (2.6 %) had been forcibly medicated and 488 (1.7 %) had been physically restrained. The numbers of involuntary treatments, use of the seclusion room, mechanical restraints, forced medication and physical holding have not decreased in recent years. (Stakes 2008.)

## 2.4 Service user involvement in psychiatric care

Over the last two decades many industrialised economies have sought to encourage patients or service users to play a more active role in the planning and delivery of health care (Crawford et al. 2003, Rutter et al. 2004) since service user involvement has become a popular catchphrase in health policies and it is recognised as a concept relevant to all aspects of health care (Hui & Stickley 2007). Service user is a generic term to describe persons who receive, have received or are eligible for health and social care services, particularly on a longer-term basis (Beresford 2005). Service users are experts, with in-depth knowledge of health services, and they can provide new information that prompts professionals to re-evaluate their work, challenges traditional assumptions and highlights key priorities (Robert et al. 2003). Service user involvement is perceived as service users' or patients' options to affect the content and quality of public service (Heikkilä & Julkunen 2003), and to participate in decisions regarding treatment, service development, and evaluation (Department of Health, UK 2003, Tritter & McCallum 2006).

The aim of user involvement is to make services more responsive to people's needs, and to build an approach that treats the whole person rather than a collection of symptoms and that puts patients in control (Department of Health, UK 2003). Emphasis on user involvement has arisen from a variety of factors: perceived remoteness and unresponsiveness of services to the needs and wishes of users, a diverse and discerning public, the desire to increase accountability throughout the health service, and the demands of consumerist principles and the patient choice in health care (Hickey & Kipping 1998, Lester et al. 2006).

In Finland, there is no specific legislation on how patients or users should be involved in their own treatment. Health care legislation does not distinguish between patient groups, and therefore patients with mental problems are equal before the law. The Act on the Status and Rights of Patients (785/1992) lists the basic rights of patients, and principles on how patients' opinions are to be taken into account. Based on the Act, patients have to be cared for in mutual understanding with him or her (Chapter 2, Section 4a). In addition, patients' options to complain are described (Chapter 3, Section 10). Based on the Mental Health Act (1116/1990) and the Amendment of the Mental Health Act (1423/2001) a patient's opinion needs to be taken into account when deciding on involuntary treatment and other restrictions on basic rights. In addition, the legislation describes the different options to complain in situations were patient's basic rights are restricted. The Proposal for a National Framework for Mental Health Services of year 2001 does not make any recommendations related to user involvement in mental health care. It states that as responsibility for the activity rests with the decision-makers and professionals, proposals are mainly directed at these (Ministry of Social Affairs and Health 2001). However, the requirement from the Ministry of Social Affairs and Health to the most recent effort to steer Finnish mental health and substance abuse treatment, the Mieli 2009 working group, emphasises that the service user perspective needs to be taken into account (Ministry of Social Affairs and Health 2009). It is estimated that in Finland user involvement has mostly been passive, and limited to participation in working groups to tackle specific issues (Tritter & McCallum 2006).

Hickey & Kipping (1998) introduced two approaches, presented in Table 1, to take user involvement into account in mental health care: the consumerist approach and the democratisation approach. Both approaches introduce the implications for the extent to which users can be involved in decisions about their care. The consumerist approach argues that public services are best planned and delivered when the views of service users, professionals, the general public and government are taken into account. This approach accepts inequalities in power between parties as the reality, and the elected officials make final decisions. Service users are invited to participate, but on the terms laid down by the policymakers and the professionals. (Hickey & Kipping 1998, Rush 2004.) Examples of ways to assess the views of service users are to undertake satisfaction surveys or introduce complaints procedures (Hickey & Kipping 1998, Svensson & Hansson 2006).

The democratisation approach is concerned with how citizens are treated, based on a belief that everyone should have a greater say and more control over state funded organisations. This approach should in addition include decision-making between staff working in organisations providing a service and users receiving the service. The basic difference between these approaches is that in the consumerist approach consumer accepts the service ideology so that his or her role is merely in evaluating the outcomes, while in the democratisation approach the citizen actually decides on the content of service. In reality there are constraints, especially in psychiatric care, which may inhibit the redistribution of power between professionals and service users. However, approaches can be used as a framework informing practice of user involvement and evaluating current practices. (Hickey & Kipping 1998, Rush 2004.)

**Table 1.** Consumerist and democratisation approaches to user involvement in mental health care

| Approach | Aim | Methods | User role |
|---|---|---|---|
| Consumerist approach | To increase the responsiveness of the service to the user | Users' access to information<br>Satisfaction surveys<br>Complaints | Accepting service ideology<br>Evaluating the services |
| Democratisation approach | To involve users in the decision-making | Negotiations between service users and providers | Participating in the decision-making<br>Deciding the content of service |

Source: Hickey & Kipping (1998)

## 2.5 Previous research concerning personal liberty and service user involvement in psychiatric care

Satisfaction surveys give patients a chance to evaluate how the basic principles of patients' rights, such as personal liberty, are realised in treatment. Surveys can also be seen as one form of realisation of personal liberty in psychiatric care. (European Charter of Patients' Rights 2002.) This is especially important in situations where patients' personal liberty is restricted. There are, however, situations when psychiatric patients' personal liberty has to be curtailed. When a patient is disturbed, distressed or aggressive, the health care organisation has to protect the safety of other patients and staff (Fisher 1994). It is also important to remember that psychiatric patients have the right to receive treatment, although in some situations this has to be arranged against their will (The Mental Health Act 1116/1990, The Act on the Status and Rights of Patients 785/1992). In addition to patient satisfaction, one basic element of user involvement and personal liberty in health care is the right to complain if the patient is not pleased with his/her treatment (Council of European Commission 2006). In psychiatric care, it is estimated that patients have fewer options to have their voice heard and complain if not pleased with treatment (Sullivan 1998). Restrictions on personal liberty are one of the most important reasons for complaints made in the area of psychiatric care (Holi 2001, 2002, 2003, 2004, 2005). So far, there is a lack of interventions to minimise the amount of deprivation of liberty occurring during psychiatric hospital care. It is important that staff support patients' autonomy as much as possible, even in ostensibly minor matters (Hoekstra et al. 2004). Most of all, there is a need for systematic programmes decreasing deprivation of patients' liberty in hospital care (WHO 2005a). Programmes need to be implemented in collaboration with patients and nursing personnel and they should support patients' possibilities to be involved in their own treatment.

### *2.5.1 Patient satisfaction with psychiatric care*

Patient satisfaction can be seen as an important, although not as a sole, indicator of the quality of health care services (Leino-Kilpi & Vuorenheimo 1992, Gray et al. 2005, Suhonen et al. 2007). There is often a positive association between patient satisfaction and service outcomes (Carlson & Gabriel 2001), and also individual patients' treatment outcomes (Bjorngaard et al. 2007). Patient satisfaction is an important predictor of future use of services (Svensson & Hansson 1994, Eriksson & Westrin 1995) and treatment compliance (Renzi et al. 2002). In general, patients treated in psychiatric or mental health services are quite satisfied with their treatment (Svensson & Hansson 1994, Korkeila 1998, Muller et al. 2002, Siponen & Välimäki 2003).

In psychiatric care, patients have reported high satisfaction with the health care personnel (Howard et al. 2003), anticipatory guidance concerning planned care and treatment, opportunities to discuss stressful incidents, and personnel's good understanding of the patient's mental disorder (Beech & Norman 1995, Allen et al. 2003). On the other hand, failures in information transfer to patients concerning treatment and illness are a frequent source of patient dissatisfaction (Alexius et al. 2000, Becker et al. 2002, Allen et al. 2003, Picker Institute Europe 2003). Coercive measures, e.g. seclusion, restraint and restrictions on leaving the ward may also impair patient satisfaction in psychiatric inpatient care (Meehan et al. 2000, Middleboe et al. 2001, Olofsson & Norberg 2001, Iversen et al. 2007).

There are several factors associated with psychiatric patients' level of satisfaction. Studies have focused mainly on the connections between satisfaction, sociodemographic factors and diagnosis. Studies reveal that patients with severe mental disorder, drug abuse or suicidal behaviour (Kelstrup et al.1993, Svensson & Hansson 1994, Rosenheck et al. 1997) are in general less satisfied with their care. Age, gender, income and formal education have shown no clear connection with the patient satisfaction (Kelstrup et al. 1993, Leavy et al. 1997, Middleboe et al. 2001). In the EPSILON Study schizophrenia patients' lower service satisfaction correlated with being retired or unemployed, having a high number of hospital admissions, a large level of psychopathological impairment, a large number of unmet needs and poor quality of life (Becker et al. 2002).

A number of methodological problems have arisen in patient satisfaction studies: the wide variety of instruments used (Suhonen et al. 2007), poor reporting of response rates

(Sitzia & Wood 1998, Gray et al. 2005), insufficient utilisation of the results in clinical work (Suhonen & Välimäki 2003), and organisations' poor commitment to act on results (Draper et al. 2001). It is essential that information emerging from patient satisfaction surveys can be fed back to individual health professionals and organisations, ensuring continuous quality development (WHO 1996). As patients consistently report a high level of satisfaction with the care, it is possible that patient satisfaction questionnaires may be biased toward the perspective of professionals (Svensson & Hansson 2006). This is supported by a finding, that when users or other patients interviewed patients, more dissatisfaction emerged (Clark et al. 1999). In addition, there is a need for methodological development in satisfaction studies (Svensson & Hansson 2006). For example, including an option to enter a narrative response on surveys to identify specific issues that contributed to dissatisfaction in a general area. From the user involvement perspective, satisfaction studies are one important method of exploring patients' expectations of health services and to increase the responsiveness of the service, and thus important as such (Hickey & Kipping 1998).

### *2.5.2 Patients' experiences of deprivation of liberty in psychiatric care*

From the mental health service users' point of view, personal liberty can be seen as a basic right, of which they can be deprived only in exceptional situations. Based on the existing literature, patients' perceptions of being deprived of their liberty in psychiatric services are mainly negative, and patients have reported traumatic and harmful experiences (Morrall & Muir-Cochrane 2002, Frueh et al. 2005, Nijman et al. 2005). Patients have reported coercion as the main barrier to the formation of a therapeutic relationship (Gilburt et al. 2008). Deprivation of liberty and coercion during inpatient psychiatric care are associated with treatment dissatisfaction (Olofsson & Nordberg 2001), less insight (Bindman et al. 2005), and possibly negative outcomes of care (Houston & Maritto 2001, Bonsack & Borgeat 2005). On the other hand, in a study by Steinert et al. (2007) the outcome measures, the Positive and Negative Syndrome Scale (PANSS) and the Global Assessment of Functioning (GAF) (see Sajatovic & Ramirez 2006) were not significantly related to the voluntariness of patients' participation.

In psychiatric settings it is argued that patients give priority to personal rights related to treatment, whereas the staff endorses the right to object to treatment but not the right to refuse it (Appelbaum & Gutheil 1999). On the other hand, staff working in psychiatric settings have to balance between the dilemma posed by caring for patients and at the same time protecting them and society from harm (Samele et al. 2007). Situations where a patient in need for treatment refuses the care provided, often lead to some form of deprivation of liberty. In these situations, the risks and benefits of various treatments, the risk associated with no intervention, and patients' clinical condition need to be considered. (Roe et al. 2002.) In general, deprivation of patients' liberty should be used as a last resort when all alternative methods have failed (Kingdon et al. 2004, WHO 2005a, European Parliament 2006). Unfortunately in many countries means of giving the patient appropriate care that is least restrictive are not sufficiently available (WHO 2000).

### *2.5.3 Patient complaints in psychiatric care*

The right to complain is a central element of health care service users' rights (Council of European Commission 2006). Patients' options to lodge complaints are ensured by various pieces of legislation for example in Denmark (Nys & Dierickx 2007), the Netherlands (Abbing 2006) and Sweden (Nordlund & Edegren 1999). The right to complain is one of the fourteen basic patient rights introduced in the European Charter of Patients' Rights (2002). From the health care services' point of view, complaints are a complementary source of information on patient safety (Council of European Commission 2006, Holi 2007), and the monitoring of patient complaints in health services is a part of quality assurance (WHO 1996). Therefore, all information related to patients' complaints needs to be utilized in the governance and planning of health care organisations by learning from mistakes and adverse events (Kassim 2007).

In Finland, based on memoranda made by the National Authority for Medicolegal Affairs (TEO), the number of complaints has increased in Finland in recent years (Holi 2001, 2002, 2003, 2004, 2005). It is estimated that in the future, as Finnish people become more aware of their rights as patients, and as more patients are treated with modern medical technology, more complaints will be lodged (Holi 2007). The Act on the Status and Rights of Patients (785/1992) may also have influenced citizens' awareness of their rights as patients. The increased number of complaints can also be seen as an indicator of better recognition of patients' rights in Finnish health care organisations. In psychiatric care, the number of complaints has not increased as vastly as that of complaints in general (Holi 2001, 2002, 2003, 2004, 2005).

Patients with mental health problems have a number of procedural avenues to complain about their treatment but the structure of the patient complaints process is complex and demanding for them (Kokkonen 1993). Writing official written complaints may also be a difficult task for patients, although they have a right to be helped free of charge by a patient ombudsman. Patients treated in psychiatric hospitals or inpatient units may have pessimistic attitudes towards the complaint process because of unbalanced power structures between staff and patients (Muir-Cochrane 1996, Sullivan 1998). They may also have difficulties in knowing what they can expect from a treatment approach (Wood 1996) or they may have fears about making a complaint (Sbaraini & Carpenter 1996), e.g. that they may receive poorer quality care, or that these will be reprisals (Bauer et al. 2003). Therefore, for mental health service users, it may be easy to keep quiet and passively accept the current situation (Latvala et al. 1999).

### *2.5.4 Methods supporting personal liberty in psychiatric care*

In psychiatric inpatient care deprivation of patients' liberty is used mainly in the management of disturbed, distressed or aggressive patients. There is a lack of knowledge about the most effective methods to manage such situations. Based on Cochrane reviews, the use of seclusion and mechanical restraints (Sailas & Fenton 2001), and use of non-pharmacological practices (Muralidharan & Fenton 2006) have been shown not to be effective in these situations. One possible way to increase patients' experiences of personal liberty is to decrease the various means by which patients are deprived of their liberty in psychiatric inpatient care. According to a literature review by Gaskin et al. (2007), use of seclusion in psychiatric care might be reduced, if not discontinued entirely, if staff implements several interventions. Need for change is due external pressures (changes in legislation, chief psychiatrists, patient or consumer groups) or pressures from staff within the organisation. Important elements of the programmes for change towards a reduction in seclusion rates are leadership, monitoring of seclusion episodes, staff education, and change in the therapeutic environment. In Finland, one example of programmes reducing seclusion and restraint rates is a study by Ala-aho et al. (2003), where a systematic three-year development project in psychiatric unit made it possible to reduce seclusion and restraint rates to one fifth.

It is possible that the same elements introduced by Gaskin et al. (2007) are useful with regard to other forms of deprivation of liberty, but further research is needed. One example is a study by Kjellin et al. (2004) where involuntary patients treated without locking the doors of the wards reported less coercion than in locked wards. However, when exploring the options to support patients' personal liberty during care, in addition to frequently used outcomes (e.g. the number of seclusion episodes) there is a need to develop instruments describing patients' self reports on the amount of deprivation of liberty. This is in line with the patients' rights guidelines highlighting the importance of service users' subjective evaluations of health services (Leino-Kilpi et al. 2000, Johansson et al. 2002, Urden 2002, Eurofound 2004, WHO 2005b).

One method supporting psychiatric patients' awareness of their rights, well being and coping with illness is patient education (Pekkala & Merinder 2002, Haynes et al. 2005). In the literature, patient education is associated with better compliance (Zygmunt et al. 2002) and improvements in quality of life (Dogan & Sabanciogullari 2003) and social functioning (Perry et al. 1999). Systematic information can increase patients' knowledge about their rights and e.g. options to lodge a complaint if not pleased with the treatment (Johnsen et al. 2007). However, it is still unknown whether patient education relates to experienced level of personal liberty. There is a lack of knowledge if patient education can decrease the amount of experienced deprivation of liberty in psychiatric care.

## 2.6 Summary of the overview of the literature

Based on previous research, it can be concluded that psychiatric patients in general are quite satisfied with their care internationally. There is, however, a lack of studies about patient satisfaction among Finnish psychiatric inpatients, and factors associated with patient satisfaction. Further, there have been only few studies in which psychiatric inpatients have been given the opportunity to describe in their own words how their have experienced deprivation of their liberty during hospitalisation. As psychiatric patients are a particularly vulnerable group in health care, it is justifiable to have a special focus on their opportunities to complain if there are not pleased with the treatment. Although there are quite a good number of studies describing patient complaints in Finland in the new millennium, it is important on a national level to monitor long-term trends in the number of complaints, and to explore complaints about psychiatric care in greater detail. There is also a need to develop and test systematic methods supporting psychiatric inpatients' personal liberty during hospital care.

By describing the current situation in different psychiatric settings it is possible to identify areas where patients and service users could be more involved with their own care. Involving people with mental health problems in their own treatment and giving them opportunities to evaluate the services can benefit both patients and organisations. Patients need to be educated about what they should except from services and the kind of treatment and respect they are entitled to. In Finland, partly due to extensive changes in the provision of mental health services during last two decades, service user involvement may have remained at a tokenistic level. It is important that in the future services move towards the recognition of the importance of personal liberty even in acute and the most demanding situations in psychiatric inpatient care. By supporting the most vulnerable individuals' opportunities to affect the content and quality of services, an ethically high standard psychiatric inpatient care will be guaranteed.

# 3 AIMS OF THE STUDY

The overall goal of this study was to develop the quality of psychiatric care by identifying areas needing better service user involvement. The contributory goals of this study were: 1) to describe patient satisfaction, and 2) deprivation of liberty in psychiatric inpatient care, 3) to explore patient complaints in Finland, and 4) to test the effects of different patient education methods on psychiatric inpatients' experiences of deprivation of liberty. The study was carried out in different phases between 2000 and 2009 according to the study goals. (see Figure 1.)

Following research questions were addressed:

**Patient satisfaction with psychiatric inpatient care** (Paper I)

1. How satisfied are psychiatric inpatients with different elements of care?
2. What factors are associated with satisfaction?

**Patients' experiences of deprivation of liberty in psychiatric inpatient care** (Paper II)

1. Have psychiatric inpatients experienced deprivation of liberty during their psychiatric hospital care?
2. How do patients describe deprivation of liberty in their own words?

**Patient complaints in psychiatric care** (Paper III, Paper IV)

1. How can patients complain if not satisfied with the treatment in Finnish psychiatric care? (III)
2. Are there changes in the overall number of complaints and especially complaints about psychiatric care in Finland 2000-2004? (IV)
3. What is the difference in the number of complaints between provinces, health care services and health care professionals in Finland 2000-2004? (IV)
4. What are the reasons for complaints in general and especially in psychiatric care in Finland 2000-2004? (IV)
5. How many of the complaints in general, and especially in psychiatric care, led to measures being taken in Finland 2000-2004? (IV)

**Effects of different patient education methods on experiences of deprivation of liberty** (Paper V)

1. What are the effects of two means of patient education delivery, conventional and information technology based, with standard care, on psychiatric inpatients self-reported amount of deprivation of liberty?

In this phase the following hypotheses were addressed:

H0: There are no differences in patients' experiences of the amount of deprivation of liberty between different education groups.

H1: Patients' experienced less deprivation of their liberty in the information technology based group.

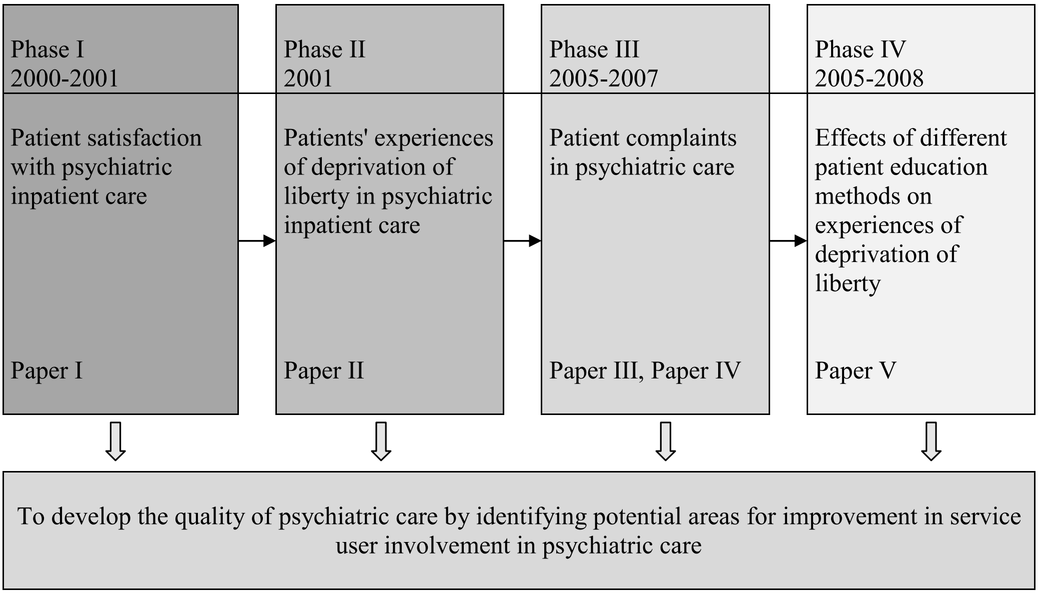


**Figure 1.** Phases, contributory goals and overall goal of the study

# 4 METHODOLOGY

## 4.1 Methodological approaches

In this study, a mixed method approach was used. Mixed method is exemplified when a single study uses multiple or mixed strategies to answer the research questions or test hypotheses (Sandelowski 2000). Mixed methods offers one option to address the complex problems in nursing and health care (Driessnack et al. 2007). In this study, strategies were combined at the level of design, sampling, instruments, data collection and data analysis techniques (Table 2). This approach was chosen because the phenomenon under investigation is complex. There was a need for a deeper insight on the topic (see Bliss 2001), and the use of mixed methods may generate deeper insights than one method alone (Sale & Brazil 2004, Moffatt et al. 2006.) It was assumed that use of mixed methods can shed light on phenomena that cannot be captured using a singular approach (Shepard et al. 2002).

In the first phase, in order to obtain general knowledge about patient satisfaction with psychiatric care, a cross-sectional survey was conducted. This information was enhanced in phase II with qualitative data from patient interviews about deprivation of liberty in psychiatric care. In order to attain a complete picture of patients' rights to complain in psychiatric care, and the number of complaints at national level, a descriptive overview of the literature and a nationwide register study were conducted in phase III. Finally, in phase IV a randomised controlled trial testing the effects of different patient education methods on patients' experiences of deprivation of liberty was conducted. Different methods of data collection and analysis at different phases of the study created a more complete picture of the studied phenomena.

Table 2 and the following section describes the methodological approaches of each phase of the study in more detail.

**Table 2.** Phases, designs, samples, settings, instruments, methods of data collection and analysis of the study

| Phase | Paper | Design | Sample, setting | Instrument | Data collection | Data analysis |
|---|---|---|---|---|---|---|
| I | I | Cross-sectional survey | Inpatients (n = 313)<br>Psychiatric hospital | SPRI questionnaire (Hansson 1989) | Self-reports | Descriptive statistics, T-test, one-way ANOVA, Post-hoc Tukey's test, MANOVA |
| II | II | Explorative study | Inpatients (n = 51)<br>Psychiatric hospital | Semi-structured interview schedule | Interviews | Inductive content analysis |
| III | III | Descriptive overview of the literature | Selected literature | Purpose designed classification frame | Database and manual searches | Content analysis |
|  | IV | Register study | Patient complaints (n = 4645)<br>National registers | Purpose designed analysis frame | Nationwide register data | Descriptive statistics, Poisson regression analysis |
| IV | V | Randomised controlled trial | Inpatients (n = 311)<br>Psychiatric hospitals | Visual analogue scale<br>PANSS (Kay et al. 1987)<br>PSS-Fin (Virta et al. 1994) | Self reports | Descriptive statistics, chi-square test, T-test, one-way ANOVA, repeated measures ANOVA, intention to treat analysis |

## 4.2 Designs, settings and sampling

In **phase I**, a cross-sectional survey was conducted. The aim was to reach a large number of respondents to elicit their satisfaction with psychiatric care. A questionnaire was used because it is suitable when gathering data that can be acquired through self-report (Burns & Grove 2005). All patients during a one-year period (May, 2000 – April, 2001) from three wards of one psychiatric hospital in Finland (Hospital District of Helsinki and Uusimaa, Kellokoski Hospital) who were able to read Finnish language and were over 18 years of age, who gave their oral consent, and were willing to participate, formed the study population. (Paper I.)

In **phase II**, patients were interviewed using structured interviews. The aim was to gather in-depth information on patients' experiences about deprivation of their liberty during psychiatric inpatient care. Interviewing allows the researcher to explore a greater depth of meaning when little is known about the research topic. A purposive sampling was used in order to reach respondents who were likely to be able to provide information about the phenomenon under investigation, thus the sample was targeted to represent patients who were treated in closed acute psychiatric units, and were likely to have experienced deprivation of their liberty. (Burns & Grove 2005.) Patients during a five-month period

(May, 2001 - October, 2001) from two wards of one psychiatric hospital who were able to speak Finnish language, were over 18 years, gave their written informed consent and were willing and able to participate formed the study population. In this study, the study hospital was not identified in order to ensure the anonymity of the participants. (Paper II.)

**Phase III** was conducted in two parts. First, an overview based on the legislation, the literature, web pages and research articles on the topic of interest was conducted. The aim was to systemise the knowledge related to patients' rights to complain in Finnish psychiatric care. A multiprofessional collaboration between authors ensured that all relevant information could be included in the overview, and a complete picture of the situation in Finland could be described. Second, a nationwide retrospective register study was conducted in order to explore the number of all patient complaints lodged against Finnish health care, with special attention to psychiatric care. (Paper III, Paper IV.)

In **phase IV**, a randomised controlled trial design was used. The aim was to test the effects of patient education method on patients' experienced amount of deprivation of liberty. Patients' were randomised into three groups: control group, comparison group and intervention group. The patients in the control group received patient education according to ward standards. The comparison group included patients who received five education sessions with oral information by staff and written leaflets in addition to the standard care. During a one-month period, one information session and five education sessions were hold. The content of the education sessions was as follows: illness, treatment, well being, support, and patient rights. At the end of the session, patients received written material used in the sessions. Patients in the intervention group received needs-based education using an information technology based patient education system in addition to the standard care. The content and number of the sessions were the same as in comparison group. If necessary, patients received education in computer and Internet use. All patients during a 19-month period (March, 2005 – October, 2006) from nine acute psychiatric wards in two psychiatric hospitals in Finland (Hospital District of Helsinki and Uusimaa, Kellokoski Hospital and Pirkanmaa Hospital District, Pitkäniemi Hospital) who were in the age group of 18-65 years, who had a diagnosis of schizophrenia, schizotypal and delusional disorders (ICD-10; F20-29) (WHO 2007), who gave their written informed consent, and who were able to speak Finnish language were eligible for the randomisation. (Paper V.)

## 4.3 Instruments

In **phase I**, patient satisfaction was measured with a self-rating questionnaire (SPRI) originally developed by Lars Hansson in collaboration with the Swedish Institute for Health Services Development (Hansson 1989, Svensson & Hansson 1994, Hansson & Höglund 1995). The questionnaire has been used in psychiatric inpatient satisfaction studies (Gjerden & Moen 2001, Sørgaard 2004), and has been translated into Finnish by the National Research and Development Centre for Welfare and Health (Stakes 1995). The SPRI contains seven different satisfaction components: staff-patient relationship, ward atmosphere and physical milieu, information, treatment interventions, restrictions and compulsory care, qualities of treatment design and treatment program as a whole. Out of 48 original items, 46 were used in this study. The questionnaire was a Likert scale, with a value of 1 given to the most negative response and a value of 5 to the most positive response. Response choice 0 was used when the question was not relevant to a respondent. The instrument included five items concerning patients' demographics (age, gender, duration of mental health problems, previous treatments and length of present hospital stay). The applicability and feasibility of the SPRI questionnaire have been validated in earlier studies, and the instrument's internal consistency is satisfactory (Cronbach's alpha 0.87, a split-half reliability of 0.79) (Hansson & Höglund 1995). (Paper I.)

In **phase II** interviews were conducted using a, semi-structured interview schedule developed for this purpose. This phase was part of a larger study exploring the realisation of patients' rights and access to information in psychiatric care (Välimäki et al. 2002). The questions used in this phase were open-ended, allowing the patients to express their own views about possible experiences related to deprivation of liberty. Two basic questions were asked: 1) Did you experience deprivation of liberty during your hospital stay? 2) (If yes), could you describe it in your own words? Demographics included patients' age, gender, marital status, educational level, time of the first contact with mental health care services, number of earlier inpatient care episodes, length of treatment and self-reported diagnosis or name of the illness. (Paper II.)

In **phase III**, a literature-based overview was conducted in order to explore patients' rights to complain in Finnish psychiatric care. Selected literature, based on the research questions, was classified using a classification frame. (Paper III.) Further, register data used when exploring the number of complaints was accessed as an Excel-file from the TEO where it is administrated. Systemised data is available from the beginning of 2000, and includes information from both the State Provincial Offices and TEO. The data includes information about number of complaints lodged and processed, and number of complaints against different health care services and health care professionals. In addition, the data contains information on the outcomes of complaints. (Paper IV.)

In **phase IV**, patients' self-reported deprivation of liberty during treatment was measured using a visual analogue scale (VAS) developed for this study. VAS is particularly useful in scaling stimuli, e.g. pain, mood and anxiety, and when obtaining fine discrimination of values (Wewers & Lowe 1990, Burns & Grove 2005). The instrument used in this study was a line 100 mm in length with right-angle stops at each end with one question: "To what extent are you currently deprived of liberty?" The endpoints of the VAS were marked as "I don't experience any deprivation of liberty" (0 mm), and "I experience the severest possible deprivation of liberty" (100 mm). Patients were asked to place a vertical mark on the line that represented their current experience. (Paper V.)

Demographics included patients' age, gender, level of education and the total score of the Finnish version of PANSS, which is a widely used semi-structured interview for rating the positive and negative symptoms of schizophrenia. In Finland, Current Care Guidelines for Schizophrenia recommend the use of PANSS in the evaluation of schizophrenia patients' symptoms. (Schizophrenia: Current Care Guideline 2008.) PANSS includes seven positive-symptom items, seven negative-symptom items and sixteen general psychopathology symptom items. Items are rated on a scale of 1 (absent) to 7 (extreme). (Kay et al. 1987, Leucht et al. 2005.) Personnel trained in psychiatric interviewing techniques, and who are experienced in working with populations with schizophrenia can administer the scale (Sajatovic & Ramirez 2006). In this study, nurses working on the study wards did the ratings after training. Alpha-coefficient has indicated high internal reliability and homogeneity among PANSS items, with coefficients ranging from 0.73 to 0.83 (Sajatovic & Ramirez 2006). (Paper V.)

Patient satisfaction was measured with a Finnish adaptation, PSS-Fin, of the Patient Satisfaction Scale (PSS) (Virta et al. 1994). The scale includes 10 questions on three different care needs (technical-scientific, information, interaction/support) on a scale from 1 (very dissatisfied) to 4 (very satisfied). The scale demonstrated good psychometric properties in a study with surgical patients. Cronbach's alpha coefficient varied from 0.79 to 0.89, test-retest reliability of 0.7 showed stability over time, and the factors explained approximately 77 % of the variance. (Suhonen et al. 2007.) (Paper V.)

## 4.4 Data collection

In **phase I**, nurses working in the study units elicited patients' willingness to participate, and evaluated their capability to answer the satisfaction questionnaire. This was done during the discharge process. Patients received written and oral information about the survey, they completed the questionnaire independently, and returned it in a closed envelope. Out of 513 eligible patients leaving the wards, 316 (62 %) received a questionnaire, and 313 patients returned a completed questionnaire: response rate 61 %. The study participants represented 52 % of all patients discharged during the data collection. (Paper I.)

In **phase II**, four psychiatric nurses who were trained to conduct study interviews collected the data. The interviewers were informed about the study units when a patient was leaving the ward. The interviewers informed patients about the study, evaluated patients' capability to participate, and requested a written consent from patients. The answers were written down during the interviews, each lasting between 20 and 90 minutes. A total of 114 patients were discharged from the study wards. Out of all eligible patients, 51 were willing to participate the interviews. Response rate was 45 %. (Paper II.)

In **phase III**, the legislation, research articles and web pages related to patients' rights and Finnish health care system, the patient complaint process, and the role of the patient ombudsman were explored. The database searches were based on Medline and Cinahl (1980-2005) using the keywords "patient complaints", "patient rights", "patient ombudsman", and "psych*". The Finnish legislation was searched from the FINLEX database and information about different Finnish authorities from Google™. (Paper III.) The register data was obtained from the TEO. All complaints processed (n = 4,645) in the five State Provincial Offices of Finland (representing five provinces; South Finland, West Finland, East Finland, Oulu, and Lapland) and the TEO were included in the data. (Paper IV.)

In **phase IV,** the data collection was carried out after randomisation. Out of 2,793 patients referred for the first assessment, 1,964 did not meet the inclusion criteria. Out of 829 eligible patients, 518 (62 %) refused to participate in the study. Altogether, 311 patients were included in the trial, and were randomly allocated to three groups: control group (n = 105), comparison group (n = 106) and intervention group (n = 100). The data collection took place at two points: baseline and discharge (= endpoint). Research assistants explained the instrument (patients' experienced amount of deprivation of liberty) to the patients who completed it independently. Measurement at discharge was conducted in a similar manner. (Paper V.)

## 4.5 Data analysis

In **phase I**, data were analysed using statistical methods. Sum variables for seven satisfaction areas were constructed by summing the value of each item in the component and dividing a sum value by a number of items (= average score). The higher the score for each sum variable, the more satisfied a patient was with care. In cases when a value "0" was used, it was deleted to ensure that all the sum variables were comparable. The sum scores for different satisfaction areas differed from normal distribution. Because of the large sample size, however, they could be treated as a normal distribution (central limit theorem). (Koopmans 1987, Burns & Grove 2005.) Further analyses were conducted in three parts. First, the differences between groups and associations of patients' background variables with their satisfaction scores were tested using independent samples T-test and one-way ANOVA. Post-hoc Tukey's test was used to examine differences among means. Second, a MANOVA with main effects and two-way interactions was examined to identify the possible joint influence of two variables. Partial ETA Squared was calculated to examine the proportion of variation connected to main effects and interaction effects. And third, Pearson product-moment correlation coefficient was used to examine the correlations between scales. In the tests, p-values of 0.05 or less were interpreted as statistically significant. (see de Vaus 2002.) Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 10.0. (Paper I.)

In **phase II**, the qualitative data were analysed using inductive content analysis. The unit of analysis was a word, sentence or part of a sentence consisting of thematic content relevant to the research question. Transcribed text was read several times after the choice of the unit of analysis, and reduction of data was done by asking a research question and picking out phrases answering the question. When the data were coded, the reduced phrases were given a description according to the thematic content. In this study, subcategories were developed for coded phrases by grouping together those with similar contents. Main categories were created by grouping together subcategories with similar meanings. (Polit & Hungler 1999, Graneheim & Lundman 2004, Burns & Grove 2005.) (Paper II.)

In **phase III**, statistical methods were used for analysing the data. Number of complaints about different health care professionals, and number of complaints leading to measures were described in frequencies and percentages. When changes in the number of all complaints and complaints about psychiatric care, and number of complaints between provinces and health care services were compared, Poisson regression analysis was used (Petrie & Sabin 2005). The year 2000 was used as a reference category in order to explore possible changes in the number of complaints between study years. Results were expressed using risk ratios (RR) with their 95 % Confidence Interval (CI). P-values lower than 0.05 were considered significant. In this phase, SPSS version 15.0 was used. (Paper IV.)

In **phase IV**, data were analysed using statistical methods. When background characteristics at baseline between groups were compared, chi-square test was used for categorised variables and one-way analysis of variance for continuous variables. One-way analysis of variance was used to explore VAS scores between groups, and repeated measures T-test within groups. Repeated measures analysis of variance was used when exploring changes in the deprivation of liberty scores between groups from baseline to end-point. Intention to treat analysis was performed to ensure that drop-out had not produced bias in the results (Hollis & Campbell 1999, Lachin 2000). P-values lower than 0.05 were considered significant. Statistical analyses were performed using SPSS version 15.0. (Paper V.)

## 4.6 Ethical questions

The basic principles of research ethics were followed at every stage of the study (The Nuremberg Code 1949, The Medical Research Act 488/1999, World Medical Association Declaration of Helsinki 2004, ETENE 2007). As people with mental disorders are a particularly vulnerable group in health care (WHO 2005a), and as mental illness may affect people’s competence in decision-making (Koivisto et al. 2001) it is especially important to ensure how e.g. Nuremberg Code guidelines for voluntary consent, withdrawal of subjects from studies, protection of subjects from physical and mental suffering, injury, disability, and death, and the balance of benefits and risks in a study are taken into account (Nuremberg Code 1949). At the same time, it is important to remember that the knowledge needed to improve the care of vulnerable people can be gained only by studying them (Burns & Grove 2005).

In this study participation was voluntary in all phases. Written or oral consent was obtained, patients received oral and written information about the study, they were told that participation or refusal would not affect their care, and patients were free to withdraw from the study at any stage. The data were treated in confidence, and only researchers were allowed to handle it. In this study all patients involved in phases I, II and V were treated in acute psychiatric inpatient wards, and it is possible that some of our patients may have had substantially impaired decision-making abilities. In phases I and II data collection took place at discharge and it was assumed that patients at this stage were in better psychological condition, and more competent to give their informed consent. (Paper I, Paper II, Paper V.)

In **phase I**, permission for data collection was obtained from the study hospitals' scientific committees (2nd March, 2000). Patients completed the questionnaires independently, and they returned them in sealed envelopes. The survey was done at discharge so that patients felt free to give their opinions honestly and without being afraid that their answers would affect their care. Patients had an opportunity to talk with personnel if the patient satisfaction questionnaire had raised questions. (Paper I.)

In **phase II**, the hospital ethics committee of the Hospital District of Helsinki and Uusimaa approved the study protocol. Permission for data collection was obtained from the medical director and the director of nursing of the hospital. During the interviews, the aim was to promote a relationship of trust and confidence so as to make the interviewees feel free to say what they wished. Nurses conducting the interviews were not working in the study units, in order to avoid patients' possible fears that the interviews would affect their care. The patients' answers were not tape-recorded to avoid giving cause for paranoid thoughts. The answers were written down during the interviews and the patients could check the notes if they wished. After the interviews the nurses ensured that the interviews were not too emotionally sensitive for the respondents. (Paper II.)

In **phase III** the study proposal was evaluated by the ethics committee of the Hospital District of Southwest Finland (Dnro 435/2005). Permission for data collection was obtained from the TEO (Dnro 730/04/046/06). (Paper IV.)

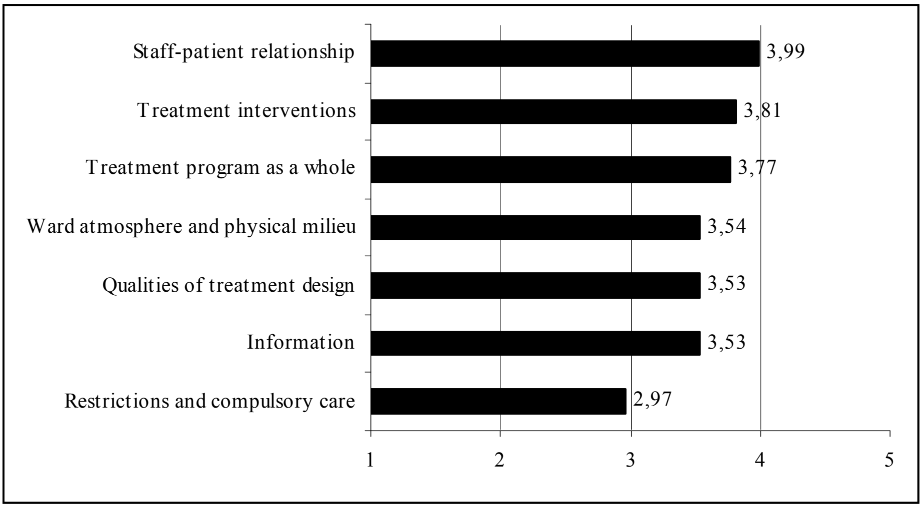
In **phase IV**, the study protocol was approved by the ethics committee of Pirkanmaa Hospital District (Dnro ETL R01181, ETL R04028H, ETL R03138H). Patients' ability to participate was evaluated by a research assistant in collaboration with unit personnel, and based on this evaluation only very few patients were excluded from the study or were able to participate a little later. In addition, the study was explained to the patients, and they also received a leaflet describing the study. In the trial, there was no placebo group, thus all patients received treatment as usual. (Paper V.)

# 5 RESULTS

The results are reported in four parts according to the research questions. The first part describes psychiatric inpatients' overall satisfaction with care, and factors associated with satisfaction and dissatisfaction (Paper I). The second part describes the results of the qualitative study on patients' experiences of deprivation of liberty during psychiatric inpatient care (Paper II). The third part describes patients' rights to complain in Finnish psychiatric care. In addition numbers of complaints in Finnish health care and psychiatric care between 2000-2004 are presented. (Paper III, Paper IV.) The fourth part presents the results of a randomised controlled trial testing the effects of different education methods on psychiatric inpatients' experiences of deprivation of liberty (Paper V).

## 5.1 Patient satisfaction with psychiatric care (Paper I)

Patient satisfaction data was collected by questionnaire from 311 patients treated in three psychiatric wards. In general, patients were quite satisfied with their care. Out of seven different satisfaction areas patients were most satisfied with the staff-patient relationship and reported most dissatisfaction in the area of restrictions and compulsory care (Figure 2, modified from Table 2 in Paper I). Eighty five per cent of the patients reported that admission to hospital was good or excellent, and 76 % felt that the staff was caring and showed sympathy often or always. In addition, 74 % of the patients reported that their received good or excellent help from their primary nurse. Only 7 % of the patients were of the opinion that they would never want to return to the same unit if they needed hospital care. (Paper I.)



(Mean, scale 1-5: 1 = the most negative response; 5 = the most positive response)

**Figure 2.** Patients' satisfaction with seven satisfaction areas

On the other hand, patients reported dissatisfaction e.g. in the areas of restrictions and compulsory care, information, and physical milieu. Almost half (47 %) of the patients evaluated restrictions on movement as negative or very negative. Less than half (44 %) of the patients reported that they had been well informed about their right to lodge a complaint. Sixty-four per cent of the patients felt that the opportunities for meaningful activities on the ward were only moderate or poor. (Paper I.)

Satisfaction with the staff-patient relationship was related to respondents' age, gender and length of treatment. Patients aged 45-65 years were more satisfied than patients aged 18-24 years (mean 4.22 vs. 3.80, $p < 0.001$), and men were more satisfied than women (mean 4.08 vs. 3.91, $p = 0.033$). Patients with hospital stay under two weeks were more satisfied than patients with hospital stays of 1-3 months (mean 4.10 vs. 3.76, $p = 0.012$). Further, patients with hospital stay over 3 months were more satisfied with the ward atmosphere and physical milieu than patients with stays of 1-3 months (mean 3.74 vs. 3.42, $p = 0.025$). First time patients were more satisfied with the quality of treatment design than patients who had three or more previous treatments (mean 3.64 vs. 3.34, $p = 0.012$). (Paper I.)

When identifying possible interaction between all five background variables and sum scores of the satisfaction areas, it was found that there was a statistically significant interaction between satisfaction with staff-patient relationship and gender and duration of mental health problems ($p = 0.004$, Partial Eta Squared = 0.054). Male patients with occasional symptoms or symptoms persisting for less than a month were more satisfied with staff than women. When symptoms persisted from a month up to one year or more, women were more satisfied with staff than men. (Paper I.) Based on these findings, an explorative study with patients' interviews was conducted in the second phase. The aim was to have in-depth information about deprivation of liberty from the patients' perspective.

## 5.2 Patients' experiences of deprivation of liberty in psychiatric care (Paper II)

Patients' deprivation of liberty was analysed based on interviews with 51 psychiatric inpatients. Of the patients, 35 reported that they had been deprived of their liberty during their hospital care. Patients' experiences were classified into three categories: a) types of deprivation of liberty used in psychiatric hospital, b) patients' feelings about the deprivation of liberty, and c) reasons for deprivation of liberty perceived by patients. (Paper II.)

Different types of restrictions from the patients' perspective were restrictions on leaving the ward, restrictions on communication, coercive measures, and confiscation of property. Patients considered that they had been deprived of their liberty because they were not allowed to leave the ward freely. Patients reported that they had too few opportunities to communicate with people other than those on the ward. This resulted from limited time of being allowed to meet relatives and friends. Patients considered that short or limited visiting hours keep them isolated from the outside world. Patients were not allowed to use their cell phones or were allowed to use them only at certain times. Coercive measures, such as use of a seclusion room, mechanical restraints and medication by coercion (orally or injection) were seen as deprivation of liberty. In addition, patients had experienced the hospital policy of confiscating property (clothes, money, and personal belongings) as deprivation of liberty. (Paper II.)

Patients' feelings about deprivation of liberty were negative. Patients reported being distressed and sad because they were not able to leave the ward freely. Confiscation of property was seen as unnecessary and "hair-splitting", and they felt humiliated being able to have their personal belongings and money at their disposal only at certain times. They regarded coercive measures as excess of self-defence and unnecessary exercise of power. Some patients saw deprivation of liberty as having its reasons. They saw it as being part of hospital regulations and were of the opinion that an acute psychiatric ward has to have strict rules. In addition, patients considered that restrictions on leaving the ward were based on these hospital rules. Some patients reported that mechanical restraints were used for medical reasons. (Paper II.)

## 5.3 Patient complaints in psychiatric care (Papers III, IV)

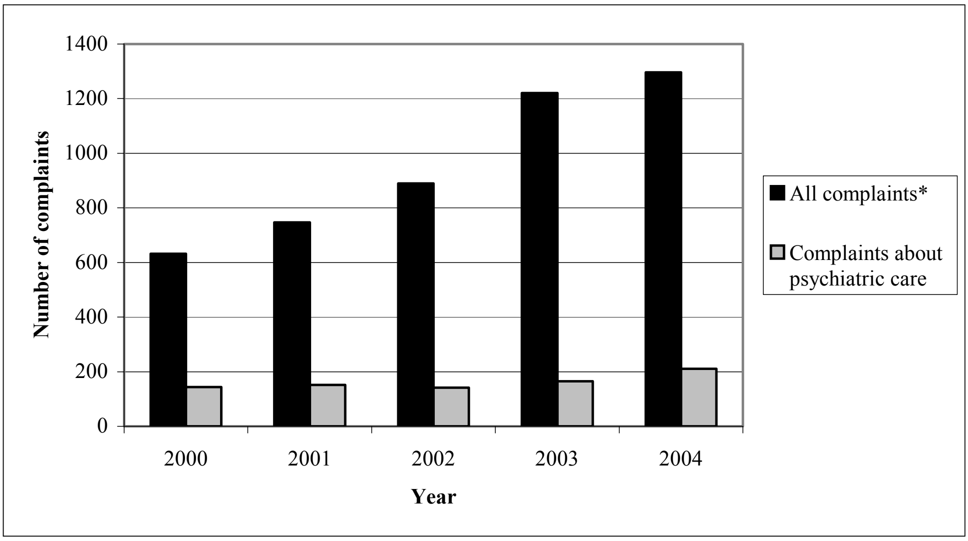
Phases I and II showed that patients treated in psychiatric inpatient care reported dissatisfaction in the area of compulsory care and access to information. Less than half of the patients were well informed about their right to lodge a complaint. In light of this information, a study on the current situation about patient complaints was conducted. This was done using two different methods: 1) a literature based overview of patients' rights (Paper III), and 2) a nationwide register study on the number of complaints (all complaints and complaints against psychiatric care) in Finland between 2000 and 2004 (Paper IV).

First, according to the overview, there are various ways to express a complaint in Finland if patients are not satisfied with the treatment. These different options are presented in Table 3 (modified from Table 1 in Paper IV). The structure of the patient complaints process is complex, and it is demanding for patients with e.g. severe mental health problems. Writing official written complaints may be a difficult task for patients, although in all health care organisations a patient ombudsman should be available to help in the preparation of the complaint. Not all patients are knowledgeable enough about their right to appeal, and to whom complaints should be addressed. Therefore, for patients, it may be easy to keep quiet and passively accept the current situation. It is problematic in the Finnish system that the processing of appeals takes a long time, and a patient is often discharged before the authorities obtain the outcomes from the appeal. (Paper III.)

**Table 3.** Options to lodge a patient complaint in Finland

| Cause for complaint or compensation | Processing authority |
|---|---|
| Complaint against health care in general | Chief medical officer of organisation in question<br>State Provincial Offices<br>National Authority for Medicolegal Affairs<br>Chancellor of Justice<br>Parliamentary Ombudsman |
| Appeal against involuntary psychiatric treatment | Administrative District Court<br>Supreme Administrative Court |
| Complaint against private health services | Committee of Consumer Complaints<br>State Provincial Offices<br>National Authority for Medicolegal Affairs |
| Compensation in respect of bodily injuries sustained by patients in connection with health care | Patient Insurance Centre |
| Compensation for medical error | District Court<br>Supreme Court |
| Medicine-Related Injuries | Finnish Pharmaceutical Insurance Pool |
| Dissatisfied with functioning or decisions of other legal authorities | European Court on Human Rights |

Second, analysis of the register study showed that the number of patient complaints increased considerably during the study period (Figure 3, modified from Table 2 in Paper IV). Complaints increased by 90 %, and the number of complaints/100 000 inhabitants by 88 %. Compared to 2000, the increase was statistically significant every year. In psychiatric care, complaints increased by 47 %, and complaints/100 000 inhabitants by 45 %. There was a statistically significant increase in the number of complaints between 2000 and 2004. (Paper IV.)



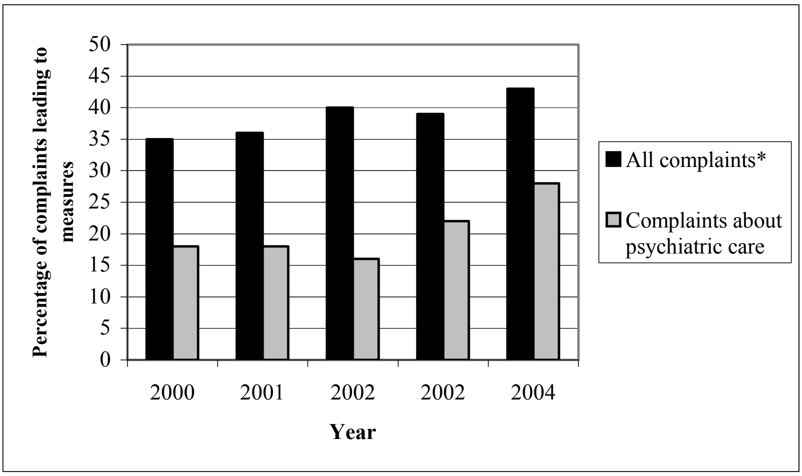
* Including complaints about psychiatric care

**Figure 3.** Number of patient complaints (all complaints and complaints about psychiatric care) in Finland 2000-2004

In every province in Finland, except Oulu, the number of complaints/100,000 inhabitants increased statistically significantly between 2000 and 2004. The mean incidence/100,000 population was highest in eastern Finland and lowest in western Finland. The annual increase in patient complaints was greatest in private health care (213 %), where the increase was statistically significant every year. In public health care and in specialized health care services the increase on average was 71 %, and in psychiatric care 45 %. (Paper IV.)

The majority (80 %) of the complaints processed concerned physicians. Of the rest of the complaints, 8 % were against nursing staff and 5 % against dentists. Against most of the 39 officially registered health care professions in Finland there were only a few complaints. Over half of the complaints were made because of medical error. Other reasons related to prescriptions, professional's behaviour, certificates and statements, and compulsory hospital care. In psychiatric care, patients more often complained about unsatisfactory certificates and statements and compulsory hospital care. (Paper IV.)

Of all complaints between 2000 and 2004, 39 % led to measures being taken (n = 1,826). The number of complaints leading to measures increased from 35 % to 43 %. Most (92 %) of the outcomes were classified as administrative reprimand, which is the most lenient form of response. Restrictions on practice and warnings were used only in a few cases. In psychiatric care, 20 % of complaints led to measures being taken: an increase from 19 % to 28 % (Figure 4, modified from Table 5 in Paper IV), and nearly all (99 %) of the outcomes were classified as administrative reprimand. (Paper IV.)



* Including complaints about psychiatric care

**Figure 4.** Proportion (%) of complaints leading to measures; all complaints and complaints about psychiatric care in Finland 2000-2004

## 5.4 Effects of different patient education methods on experiences of deprivation of liberty (Paper V)

The results of the earlier phases of this study showed a clear need for interventions supporting psychiatric patients' personal liberty during treatment. Deprivation of patients' liberty is a common source of treatment dissatisfaction; patients have negative experiences of it and it is a one major reason for patient complaints in psychiatric care. Thus, in the last phase of this study, the effects of different patient education methods on patients' perceived deprivation of liberty were examined with a randomised controlled trial with 311 psychiatric inpatients. Patients in the control group received patient education according to ward standards, and patients in the comparison group received five education sessions with oral information by staff and written material in addition to the standard care. Patients in the intervention group received needs-based education using information technology based patient education system in addition to the standard care. (Paper V.)

Deprivation of liberty was measured using a VAS. Patients experienced that they had been less deprived of their liberty at discharge than at the beginning of the treatment. VAS scores in the whole study population (n = 217) decreased statistically significantly from baseline (47.7 mm, SD 31.7), to endpoint (30.5 mm, SD 28.2, change -17.2 mm, p < 0.001). When the change in the VAS scores for deprivation of liberty within groups from baseline to endpoint was explored, the scores decreased in all three groups. At the endpoint, patients in the intervention group reported less perceived deprivation of liberty than patients in the comparison and control groups (Figure 5, modified from Table 2 in Paper V). This finding, however, was not statistically significant. In addition, no statistically significant between-group differences in the change (mm) of the VAS scores were found either in the intention-to-treat or in the completer populations. (Paper V.)

The average length of stay in the total study population was 62.6 days, and there were no statistically significant between-group differences: 63.9 days in the intervention group; 58.1 days in the comparison group; 65.3 days in the standard treatment group, p = 0.699.

In the standard care group and in the intervention group patients with longer length of stay reported more perceived deprivation of liberty (Spearman's rho 0.272, p = 0.018 in the standard care group; Spearman's rho 0.270, p = 0.025 in the intervention group).

Drop-out analysis was carried out with regard to patients' age, sex, level of education, and PANSS total score. The analysis revealed that in the standard treatment group, men dropped out more often than women (20 drop-outs among 58 men vs. 8 drop-outs among 47 women, p = 0.049).

In general, patients in the whole study population were quite satisfied with their treatment: mean score 3.09 on scale from 1 to 4 (1 = very dissatisfied; 4 = very satisfied) at endpoint. There were no statistically significant differences in satisfaction with different care needs (technical-scientific, information and interaction/support) between groups.

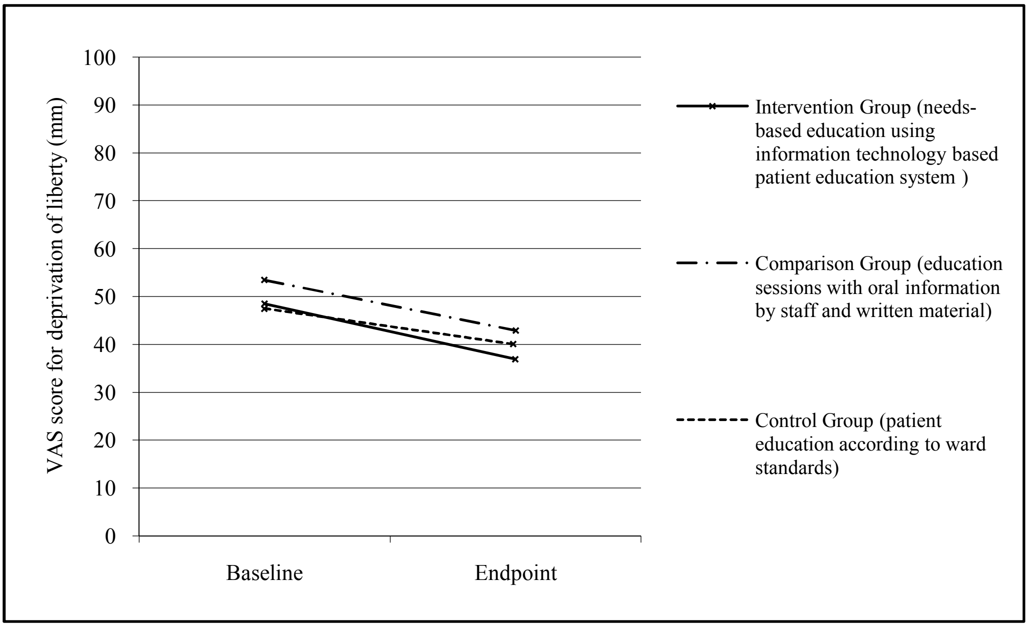


**Figure 5.** Deprivation of liberty scores between groups at baseline and at discharge

# 6 DISCUSSION

The purpose of this study was to improve the quality of psychiatric care by identifying areas needing better service user involvement. Studies on patient satisfaction, patients' experiences of deprivation of liberty, patient complaints, and the effects of different patient education methods on perceived deprivation of liberty have produced information about the realisation of personal liberty and service user involvement in Finnish psychiatric care in the new millennium. For the development of psychiatric nursing, this study identifies several areas where nurses could work as advocates of the patients (Negarandeh et al. 2006) and support their autonomy and dignity (Grönroos et al. 1994). This study generates new knowledge which can have direct influence on nursing practice, which is one of the main goals for nursing research (Burns & Grove 2005).

This discussion begins by looking at the validity and reliability of the study following with repetition and discussion of the results. Finally, potential areas for improvement in service user involvement in psychiatric care are presented as well as suggestions for further research.

## 6.1 Validity and reliability of the study

Validity and reliability were examined through different phases of the study. In the first phase, validity and reliability of the survey and the questionnaire used was evaluated. In the second phase, soundness of the qualitative study was described through a criteria proposed by Lincoln & Guba (1985) which was offered as an alternative to more traditional quantitatively-oriented criteria of internal and external validity, reliability and objectivity. In phases III and IV, a Critical Appraisals Skills Programme (CASP) tool was used for the evaluation (Public Health Resource Unit, England 2006a,b).

### *Phase I*

The SPRI patient satisfaction questionnaire is widely used both in international (Hansson 1989, Svensson & Hansson 1994, Gjerden & Moen 2001, Sørgaard 2004) and national studies (Stakes 1995). Content validity studies have been performed earlier, and dimensions of care given the highest priority by patients were well covered in the instrument (Hansson & Höglund 1995). Thus its structure was not tested in the present study. The draft questionnaire was piloted with 30 patients and was found suitable for acute psychiatric settings.

The number of patients who were not offered the opportunity to participate was fairly high: 32 % of all eligible patients. The non-respondents were mainly patients with very short hospital stay, and cases where the staff forgot to distribute the questionnaires to the patients. In this study, it was not possible to have any information from the group non-participants.

In previous research among people with severe mental illness, it is estimated that those who have the most severe course of illness are least willing to participate. This may affect the internal validity of the study, and may have led to biased estimates. (Burns & Grove 2005, Haapea et al. 2007.) In addition, this study was performed on only three wards in one hospital and generalization of the results needs to be approached with caution.

The reliability of the instrument has been tested, and internal consistency was found satisfactory (Cronbach's alpha 0.87, a split-half reliability of 0.79) (Hansson & Höglund 1995). In this study, Cronbach alpha values for different satisfaction areas varied from 0.43 to 0.89. The low value of one sum variable (Qualities of treatment design) is probably due to it being based on three items. All other sum variables had Cronbach alpha values over 0.70 (see Suhonen et al. 2007). In order to estimate the correlation between satisfaction areas, Pearson product correlation coefficients were analysed. This showed that in all cases there was a positive and statistically significant correlation between all the sum variables describing patient satisfaction. Correlation coefficients (*r*) varied from 0.19 to 0.67. Traditionally, an *r-value* of 0.1 to 0.29 is considered a weak linear relationship, 0.3 to 0.5 is a moderate linear relationship, and above 0.5 is a strong linear relationship (Burns & Grove 2005). In this study, out of 21 correlation coefficients' values, twelve had strong, seven moderate, and two weak linear relationship. (Table 4.)

**Table 4.** Correlation coefficients between satisfaction areas in patients' data

| Satisfaction areas | Staff patient relationship | Ward atmosphere and physical milieu | Information | Treatment interventions | Restrictions and compulsory care | Qualities of treatment design |
|---|---|---|---|---|---|---|
| **Ward atmosphere and physical milieu** | .54*<br>(n = 310) | | | | | |
| **Information** | .62<br>(n = 307) | .56<br>(n = 308) | | | | |
| **Treatment interventions** | .60<br>(n = 301) | .58<br>(n = 302) | .67<br>(n = 301) | | | |
| **Restrictions and compulsory care** | .32<br>(n = 243) | .42<br>(n = 244) | .34<br>(n = 243) | .27<br>(n = 244) | | |
| **Qualities of treatment design** | .42<br>(n = 293) | .41<br>(n = 294) | .54<br>(n = 293) | .56<br>(n = 293) | .19<br>(n = 237) | |
| **Treatment programme as whole** | .61<br>(n = 298) | .48<br>(n = 299) | .60<br>(n = 298) | .67<br>(n = 298) | .38<br>(n = 242) | .52<br>(n = 293) |

*In all cases, correlation is significant at the 0.01 level (2-tailed) and $p < 0.001$, except here $p = 0.004$

*Phase II*

Credibility (parallel to internal validity) means that the results are credible from the perspective of the participant (Polit & Beck 2004). In the data collection phase, this was supported by letting the participants check the written answers, and give feedback if notes were not in line with their responses. It is important that participants have personal experience of the phenomena under investigation. In this study, patients who were willing to participate, and likely to be able to provide information about the topic (information-rich cases), formed the study sample (Malterud 2001, Kylmä et al. 2003). However, probability sampling can cause bias, because it is not possible to know if these patients actually were typical or atypical patients (Burns & Grove 2005). It is possible that patients who had negative experiences of being deprived of their liberty were more willing to participate in the study and describe their experiences. On the other hand, this study was a part of a larger study exploring patients access to information and questions related to deprivation of liberty constituted a small part of the whole structured interview. Thus, it is unlikely that patients with only negative experiences were involved in the interviews.

Transferability (parallel to external validity) refers to the degree to which the findings can be generalised or transferred to other settings (Polit & Beck 2004). In this study, due to the small sample size the results cannot be generalised to represent the whole study population, although according to the hospital records there was a similar distribution of patients' age and gender in the study population and all patients discharged from the study units during the data collection period. On the other hand, the purpose of this study was more to gain in-depth information about the phenomena under investigation, rather than the generalisation of the findings to a target population (Malterud 2001, Burns & Grove 2005). The findings were, however, consistent with those of earlier studies and therefore likely to have wider relevance.

Dependability (parallel to reliability) refers to the stability of data over time and conditions (Polit & Beck 2004). This was supported in the present study by describing the research process, the environment in which the study was carried out and other solutions in detail so that other researchers could follow the research path. The use of a second categoriser in the data analysis process might have increased the dependability of the study. For practical reasons, this was not possible. However, the analysis was discussed in doctoral students' seminars in order to increase the conformability of the results.

Conformability (parallel to objectivity) refers to the objectivity of the data. It is essential that the results be based on data, not merely the researcher's conceptions. (Polit & Beck 2004.) This was supported by describing the different stages of data analysis in detail. In addition, direct quotes were provided in the research report to support the analysis. Four independent interviewers collected the data, and data analysis was done in collaboration with two researchers, both involved in the interviews.

### *Phase III*

Literature related to the research topic was searched in scientific databases and the national legislation database. The focus of the overview was on the situation in Finland, and in addition to database searches, a general search was conducted in Google™ of Finnish-language pages. This ensured that information merely published in the Internet could be included. Literature searches were conducted in multi-professional collaboration, and the researchers represented areas of nursing, psychiatry and jurisprudence. This ensured that that all relevant published and unpublished information about patients' rights and Finnish health care system, the patient complaint process, and the role of patient ombudsman were included in the overview. This overview based on selected literature does not meet all the criteria for systematic reviews (Public Health Resource Unit, England 2006a). However, clearly focused questions and limitation to national level improve overviews' validity and usability in Finnish mental health care context.

When appraising the reliability and validity of the register study on patient complaints, it is important for the researcher to be familiar with the content of the register and how the data is filed in it (National Public Health Institute 2005). In this study, the literature based overview was conducted before the register study in order to avoid this pitfall. In addition, the study was conducted in close collaboration with the administrator of the register and one of the researchers is in charge of the data in the National Authority for Medicolegal Affairs (see National Public Health Institute 2005). The results are representative in the Finnish context, as the data is nationwide and the study covers a period of five years. However, the main limitation is that the data is not classified on the level of individual complaints, and does not permit more sophisticated statistical methods. Thus, the results remain at the descriptive level.

### *Phase IV*

Based on the CASP three broad issues need to be considered when appraising the report of a randomised controlled trial: 1) is the trial valid? 2) what are the results? and 3) will the results help locally? (Public Health Research Unit, England 2006b). The validity of the trial is evaluated through randomisation, blinding, data collection, data analysis and minimising the role of chance. In this study all participants were randomly allocated to different groups. The process was random, and it was done by drawing chance. There were no differences between the groups at baseline. However, blinding was not possible, and it is possible that information may have flowed from the patient education groups to the treatment as usual group. Data were collected in a similar manner in all groups in both measures (baseline and endpoint). Data analysis included both the intention to treat and the completer populations (see Hollis & Campbell 1999). Power calculations were made before the data collection in order to minimise the role of chance. The results are presented according to the change in primary outcome measure from baseline to end-point between different groups.

In this study, it was estimated that to get 10 scores differences between group means to be statistically significant at the 0.01 level with 90 % power, group size should be at least 80 observations. To obtain a weak estimated effect size 0.1 between groups to be statistically significant at the 0.01 level with 90 % power, group size should be at least 60 observations, which was achieved. As the instrument was developed for the study, it was estimated on the basis power calculations that a 20 % improvement in VAS scores over baseline values is clinically important (Wewers & Lowe 1990). The meaning of the results for clinical work in acute psychiatric settings is presented in a way that staff working in these units can utilise them in their daily work. Further studies are, however, needed on the overall reliability of the VAS scale, and whether e.g. one measure point in the middle of the scale should also be used (see Mielonen 2000). Based on PANSS total scores, patients had quite severe symptoms and were not fully recovered (Lauronen 2007), and naturally this has impacts on the validity of patients' evaluations.

## 6.2 Discussion of the results

Nursing research should include studies on nursing education, nursing administration, health services, and nurses' characteristics and roles, as well as clinical situations. Research conducted in these areas will add to the body of knowledge in nursing. (Burns & Grove 2005.) This study has produced new knowledge for nursing practice, and has highlighted areas where psychiatric nurses can positively influence the quality of care. In addition, results can be used for the development of mental health care systems, and in promotion of advocacy of people with severe mental health problems (see ANA 2003).

In Finland, research on severe mental disorders has been very active for over fifty years. Nowadays the emphasis of research is on epidemiology and biological topics, which is in line with international recommendations. However, there is also a clear need for research having immediate clinical relevance and giving answers to everyday patient work. (Koskinen et al. 2004.) This study describes the current situation in Finnish psychiatric settings, and has produced information on how to improve the quality of psychiatric care by increasing patients' involvement in their own care.

The main findings of this study were that in general, psychiatric patients were quite satisfied with their care, but reported dissatisfaction in the area of restrictions and compulsory care and information dissemination. According to the interviews, the types of deprivation of liberty in psychiatric care reported by patients were restrictions on leaving the ward and on communication, confiscation of property and various coercive measures. Patients experienced these interventions as negative.

The overview of the literature permits the conclusion that in Finland the patient complaint process is complicated and not always accessible to those with severe mental health problems. During the study period 2000-2004 patient complaints increased considerably in Finland. Interestingly, in psychiatric care the number of complaints was quite stable and complaints more seldom led to consequences. When the effects of different patient education methods on patients' self reported deprivation of liberty were explored it was found that Internet-based patient education system was equivalent to other methods. In this chapter the results are discussed in more detail according to the research questions.

### *6.2.1 Patient satisfaction with psychiatric care*

The patients in our study expressed that personal liberty and access to information during psychiatric inpatient treatment are important values: they reported dissatisfaction in situations where they were deprived of their liberty, and stated that they had not received sufficient information on the topics in which they were interested. This is consistent with earlier findings (Alexius et al. 2000, Middleboe et al. 2001, Allen et al. 2003). According to our finding, basic patients' rights to personal liberty and information are not fully realised from the patients' point of view (see Act on the Status and Rights of Patients 785/1992, European Charter of Patients' Rights 2002). It is possible that organisations have problems developing methods to reduce the use of measures depriving patients of their liberty (e.g. seclusion and restraints) because there is controversy on the effective interventions for so doing (Bower et al. 2003, Donat 2005, Muralidharan & Fenton 2006, Gaskin et al. 2007). Access to information, on the other hand, can be supported by patient education (Pekkala & Merinder 2002) tailored to patients' individual needs and provided using innovative methods, such as information technology (Hätönen et al. 2008).

It seems that there are some gender-related features in patients' satisfaction with the staff-patient relationship, which needs to be taken into account in clinical work (see European Parliament 2006). Male patients with occasional symptoms or symptoms persisting for less than a month were more satisfied with staff than were women. When symptoms persisted for a month or up to one year or more, women were more satisfied with staff than men. This finding is not completely supported by other studies, where no clear association was shown between gender and patient satisfaction (Leavy et al. 1997, Middleboe 2001). It is important to explore, whether psychiatric units pay enough attention to female patients' life situation, and, for example, their worries related to children, home or companions. This poses new challenges for psychiatric nurses, who in practice create the cultures and treatment ideologies in psychiatric units. From male patients' perspective, it seems that the longer their symptoms persisted, the less satisfied they were with the staff. This raises the question whether nurses have taken into account male patients' needs, for example, for occupational and physical activities as a counterbalance to psychological treatment.

### 6.2.2 Patients' experiences of deprivation of liberty in psychiatric care

As patients in Phase I reported dissatisfaction when they were deprived of their liberty, it was important to explore patients' views on deprivation of liberty in more detail. According to the interviews, patients reported different types of deprivation of liberty during hospital care: restrictions on leaving the ward, restrictions on communication, confiscation of property, and coercive measures. The results can be understood in relation to patients' medical condition in Finnish psychiatric hospitals. Nowadays, more severe problems are treated in psychiatric hospitals (Pirkola & Sohlman 2005, Stakes 2008), and this can lead to a greater need for patient restrictions.

From the organisations' perspective it is demanding how to balance between the dilemma posed by caring for patients in the least restrictive way (Council of Europe 2000, WHO 2005a) and at the same time protecting other patients, staff and society from harm (Samele et al. 2007). It is a challenge to treat aggressive or violent psychiatric patients in a safe environment without restricting all other patients on the ward. From the patients' perspective, it is possible that they understood some of the ward rules as deprivation of their liberty, because they were not informed about the reasons for the restrictions. Further, from an individual care perspective, it seems that patients' advance options express their wishes and preferences related to involuntary treatment and possible restrictions were not used on the study wards (see Allen et al. 2003, Scheyett et al. 2007). Development and testing of psychiatric advanced directives is a major challenge for Finnish psychiatric nursing in the near future (Ministry of Social Affairs and Health 2009).

In this study, patients' feelings about deprivation of liberty were mainly negative, consistent with earlier findings (Frueh et al. 2005, Nijman et al. 2005). Some patients saw the rationale for the restrictions, and stated that a hospital has to have certain rules. Deprivation of liberty was understood to be justified on some occasions during hospitalisation. It is possible that patients who saw the rationale for restrictions or coercive measures were able to cope with these situations with personnel, but it seems that coping is not as systematic as it should be. From the existentialistic point of view patients' experiences per se are very important, and the goal should be that patients' have opportunities to process situations where they have been deprived of their liberty afterwards in order to avoid negative experiences and trauma. However, in certain situations, part of this process can be a complaint if a patient is not pleased with the treatment or in the way how difficult situation was handled afterwards.

### 6.2.3 Patient complaints in psychiatric care

In Finland, there are several ways to make a complaint. It is possible that the system is too complicated for people with severe mental health problems (see Kokkonen 1993). Although patients can receive help from a patient ombudsman, unbalanced power structures in psychiatric hospitals (Bauer et al. 2003), lack of access to information about the complaint process (Hätönen et al. 2008) and slow evaluation of complaints makes the whole process demanding for patients. In general, problems should be processed in the organisation in which they occurred (Bark et al. 1994). This is a challenge to personnel in psychiatric hospitals, and naturally requires systematic education and support (Dagher et al. 1995), and utilization e.g. of Internet technology to report when things go wrong (Wasson et al. 2007).

Patient complaints increased considerably in Finland during the period 2000-2004. An especially marked increase occurred in the area of private health care, which possibly relates to the marked increase in private health services in Finland (Stakes 2006). One explanation for the increase of patient complaints is that more difficult and complex situations are addressed and treated in health care (Stakes 2006, Holi 2007). In addition, Finnish people have become more aware of their rights and they are better equipped to formulate the complaint, and they know to what authority to address it. The level of education has risen, and physicians' authority has diminished. The increased number of complaints can also be seen as an indicator of better recognition of patients' rights in Finnish health care organisations. (Holi & Riihelä 2001.) In psychiatric care, the number of complaints has been quite stable. It remains unclear how the complicated complaints process (see Paper III) explains this finding. On the other hand, it is possible that special legislation in the area of mental health care (Mental Health Act 1116/1990, Amendment of the Mental Health Act 1423/2001) has improved the realisation of the rights of people with mental health problems. In this study, it was found that complaints about psychiatric care more rarely led to measures being taken, and it is possible that some of the complaints made by mental health patients are formulated in such a way that it is not possible to process them due to patients' psychotic illness or cognitive disabilities. In these situations, the role of nursing personnel is essential in helping the patient to formulate the complaint or helping the patient to handle difficult situation with professionals, thereby avoiding the complaint process.

### *6.2.4 Effects of different patient education methods on experiences of deprivation of liberty*

Based on Phases I, II and III it can be concluded that personal liberty is a basic patient right and an important value for patients. Therefore, there is a need to develop the most effective methods to increase a sense of personal liberty in all phases of the treatment period. The patients in this study reported less deprivation of liberty at discharge than at baseline. The finding is understandable, because some psychiatric patients in the acute phase of their illness may require involuntary treatment, different restrictions based on their medical condition, and sometimes use of seclusion or restraints (Fisher 1994, Kaltiala-Heino et al. 2000). On the other hand, not all patients even in acute psychiatric units require restrictions at the beginning of their treatment. The finding thus challenges acute psychiatric wards to compare the amount of different types of deprivation of liberty at the beginning and at the end of the treatment period. This analysis may produce valuable information on whether wards' restriction practices are adequate, and at what level they are carried out according to individual needs. The finding that male patients more often dropped out from the study in standard treatment group challenges staff to develop gender-related patient education methods in psychiatric settings.

Internet-based patient education system was equivalent to other methods. Although systematic patient education is promising in increasing treatment compliance, quality of life and satisfaction with care (Zygmunt et al. 2002, Dogan & Sabanciogullari 2003), it is not as clearly associated with psychiatric patients' experiences of personal liberty and satisfaction. The results are encouraging, though, as information technology solutions are rapidly becoming part of mental health services, it is important to familiarise patients with severe mental illnesses with computer and Internet use during their treatment. From a user involvement perspective, computer and Internet education is one way to help patients obtain information about their rights, and encourage them to be active partners in care (see Pierre 2002). Naturally, the use of technology should not hamper the therapeutic relationship between the patient and the nurse, which is ultimately the core element of psychiatric nursing (Peplau 1997). It is important to remember that patients want to receive information through discussions with staff (Hätönen et al. 2008), and this relationship cannot be totally replaced with modern technology (Lähdesmäki & Nyholm 2007).

## 6.3 Potential areas for improvement in service user involvement in psychiatric care

According to the research findings, the following areas where service user involvement could be improved were identified (see Figure 6).

1. In general, patients were quite satisfied with their care. However, they reported dissatisfaction in the areas on restrictions and coercive care and information access. Systematic programmes to increase psychiatric inpatients' opportunities for personal liberty are needed in clinical work. Patients' information access needs to be ensured with personally tailored and innovative methods. More emphasis on gender-related needs of patients is needed in psychiatric inpatient care.

2. Patients' reported different types of deprivation of liberty in psychiatric care. Since patients' experiences were mainly negative, it is important to support their opportunities to personal liberty during treatment. Patients' opportunities to communicate outside a closed ward need to be ensured by means of modern technology and by increasing relatives and friends opportunities for visits. Patients' involvement needs to be supported by increasing their awareness of their rights. All situations where seclusion

or mechanical restraints are used should be discussed afterwards with an independent evaluator. If patients' personal liberty needs to be deprived, it should occur on individual bases, without having to restrict all other patients on the ward.

3. The process for lodging patient complaints in Finland is too complicated for persons' with severe mental health problems, and it should be simplified. In addition, patient ombudsmen's activities needs to be increased in psychiatric hospitals and inpatient units. As the number of patients complaints is increasing, mental health personnel's capacities to handle difficult situations already in the organisation need systematic support, and structured procedures in the processing of difficult situations need to be developed.

4. Information technology based patient education is one way to increase users' involvement in their own care. Male patients especially may benefit from structured patient education. All patients need to have basic skills in Internet and computer use in order to avoid their alienation from high-technology society.

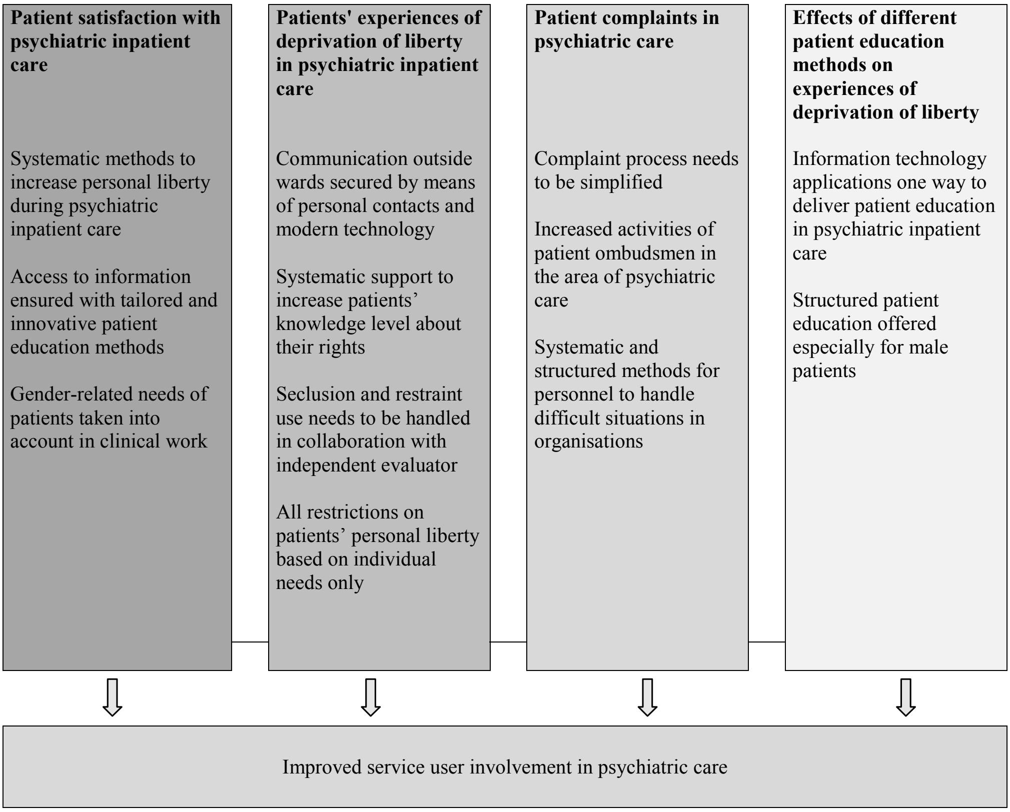


**Figure 6.** Potential areas for improvement in service user involvement in psychiatric care

## 6.4 Suggestions for further research

The following research ideas have arisen on the basis of this study:

1. The reliability and validity of PSS-Fin patient satisfaction scale with psychiatric inpatients need to be studied.

2. A randomised controlled trial exploring the most effective and cost-effective methods in the management of aggression in psychiatric inpatient care needs to be carried out.

3. There is a clear need for a multi-centre, national research and development project in Finnish psychiatric inpatient units aiming to increase the realisation of basic patients' rights. Patient satisfaction and patients' experiences, numbers of different types of deprivation of liberty, patients' options to address difficult situations with the staff, and patients' access to information should be the main outcomes of this project.

4. A qualitative analysis of psychiatric patients' complaints with no outcomes needs to be conducted in order to find out why they lead to consequences more seldom than complaints from the other areas of health care.

5. The options in information technology applications supporting mental health care organisations' own feedback mechanisms need to be explored.

6. Patients' experienced deprivation of liberty needs to be studies with 3, 6 and 12 months of follow-up. The correlation of the VAS scale with other scales measuring e.g. perceived coercion, and availability of the scale in somatic health care need further research.

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# ACKNOWLEDGEMENTS

This study was carried out at the Department of Nursing Science, University of Turku. During the process I have been happy to receive support and encouragement of many people working and studying in the Department. I would like to express my warmest thanks to everyone. I am deeply grateful to Professor Helena Leino-Kilpi, PhD, Head of the Department, for providing excellent studying facilities.

I wish to express my profound gratitude to my supervisor, Professor Maritta Välimäki, PhD, who has guided me through this process, ever since the early stages of my Masters' thesis. She has encouraged me at every stage of this process and believed that this goal could be achieved. Her contribution to the completion of this dissertation has been indispensable. It has been a privilege to work with you. I also want to thank the members of my thesis committee Professor Jyrki Korkeila, MD PhD and Adjunct Professor Riitta-Kerttu Kaltiala-Heino, MD PhD, also co-author in Paper IV, for their valuable comments and support throughout this work.

I express my particular thanks to Professor Matti Isohanni and Professor Unni Å. Lindström, the official reviewers of this thesis, for their careful review and valuable comments on the manuscript.

I wish to sincerely thank all my fellow students, the "Techno Group", Heli Hätönen MNSc, Tiina Jakobsson MNSc, Marita Koivunen PhD and Anneli Pitkänen MNSc for sharing your ideas, visions and expertise from the very beginning of this project. I really hope our close collaboration will continue in other areas of mental health nursing. Thanks also to Jouko Katajisto MSocSci for statistical help in Papers I and V and Tero Vahlberg MSc for statistical help in Paper IV. I am very much obliged to my other co-authors Grigori Joffe MD PhD, Anna-Riitta Jyrkinen RN PhD, Jouko Katajisto MSocSci, Diane Kjervik JD RN, Martin Knapp PhD, Jari Kylmä RN PhD, Jukka Kärkkäinen MD PhD LLM, Heikki Malkavaara RN, Sakari Suominen MD PhD, Anita Patel PhD and Seppo Ranta MD PhD. Your contribution to the papers has indeed been extremely valuable and really improved them in many ways. In addition, I would like to thank all doctoral students who have participated in Professor Välimäki's seminars during years 2005-2008. I also want to express my gratitude to Virginia Mattila MA for the revision of the English language of Papers I, III, IV and V and this thesis, and to Maija Lehtonen MA for the revision of Paper II.

My very special thanks are due to all the nurses working in our study units in Kellokoski and Pitkäniemi hospitals. Without your commitment, this dissertation would not been accomplished. In addition, I would like to thank Director of Nursing Raija Kontio MNSc, Riitta-Leena Rimpiläinen RN and Minna Anttila MNSc for their valuable contribution in the last phase of this study. In this phase, the help from Anita Patel and Martin Knapp from King's College London, Institute of Psychiatry, was also invaluable.

I thank all my colleagues on the ePsychNurse.Net Project in Finland, Ireland, Italy, Lithuania, Portugal and the UK for wonderful international collaboration which really had major impact on my thinking and on this dissertation. It is such a privilege to network with mental health professionals from different cultures and backgrounds and realise that we have so much in common.

During these years, I have had a wonderful opportunity to work in on the Sateenvarjo Project in the City of Vantaa. I would like to thank my fellow workers, especially Maria Vuorilehto MD PhD, Hannele Peräkoski RN and Sirpa Kumpuniemi RN for introducing me to the world of primary care mental health. This has been an extremely fascinating journey. I am also very grateful to Chief Medical Officers Timo Aronkytö MD and Kirsi Savolainen MD for their support.

My heartfelt gratitude to my parents, Arja and Pertti Kuosmanen who have supported me in numerous ways during these years. I also gratefully acknowledge my mother-in-law, Pirkko Melartin, for her kind help during my many visits to Turku. I want to thank Timo, Paula, Rita, Kalle and other relatives and friends for reminding me that there are also other things in life than research. Olli, Mika, Heikki, Jukka and Çetin, now we have more time to enjoy the Finnish Sauna Association!

My warmest and most profound gratitude is reserved for Tarja, my wife. You have always supported my studies and believed in me. I want to thank you for sharing this process with me and for being there for me during these years. Without you, I would neither have started nor finished this work. My lovely daughters, Siiri and Heta, have kept me in touch with the real world. You were all over me, even when I was stressed and absent-minded. I am so proud to be your dad; you are the most important achievements in my life.

This study was a part of Mieli.Net Project, which was financially supported by the Academy of Finland (Research Programme on Health Services Research), the Yrjö Jahnsson Foundation, Pirkanmaa Hospital District, the Hospital District of Helsinki and Uusimaa, and the Finnish Foundation for Nursing Education. The study was also supported by the Jalmari and Rauha Ahokas Foundation, Finnish Nurses Association, and the Finnish Cultural Foundation Uusimaa Regional Fund. I gratefully acknowledge all the sponsors.

Finally, I express my deepest appreciation to all those people using the services who participated in this study.

Järvenpää, February 2009

Lauri Kuosmanen