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HOME CARE OF PERSONS WITH LONG-TERM MENTAL ILLNESS

**Nurses and mental health care workers' experiences of how changes in the
organisation of psychiatric services have changed their work**

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ABSTRACT

HOME CARE OF PERSONS WITH LONG-TERM MENTAL ILLNESS

Nurses and mental health care workers' experiences of how changes in the organisation of psychiatric services have changed their work

The overall aim of this thesis, consisting of five studies, was to explore nurses' and mental health care workers' experiences of how changes in the organisation of psychiatric care influence their daily work and how these changes may have contributed to ethical problems. The specific context in focus was the homes of mentally ill persons. Implicit to this aim was the assumption that the results of this research could be used to develop educational and mentoring programs, for nurses and mental health care workers that are suited to community psychiatric and mental health nursing. The design utilises both qualitative and quantitative research methods. In study I three focus groups with psychiatric nurses and mental health care workers were conducted in order to investigate ethical problems that arise within the framework of the caregiver-patient encounter. The constant comparative method of grounded theory was used for analysing of the data. The findings describe the central theme as a conflict concerning intrusion into patient's privacy. Four main themes were identified; 1/ Intruding in the home of the patient; 2/ Experiencing fluctuating boundaries; 3/ Respecting or transgressing the right to privacy; and 4/ Situating mutual vulnerability. As this was a small study a questionnaire was developed from the ethical problems identified in Study I and used as data collection in Study II and III to identify whether the ethical problems in Study I could be generalised to other professional care givers working in the home of the patient. Study II shows that district nurses and mental health care personnel had different views related to issues concerning privacy and autonomy in providing care to patients with mental illness. In contrast, the difference in views between psychiatric nurses and mental health care workers are few. The results in Study III emphasise the need for clinical supervision as support for the nursing staff. The group receiving supervision felt more secure in relation with the patient as well as their decision-making compared with the group that did not received supervision. In-depth interviews were conducted with 11 psychiatric nurses in Study IV and V. In study IV a constant comparative analysis revealed the core category, the process of attempting to reconstruct mental health nursing, from nurse-controlled care to client-centred care. Subsequently, moral values, assessment of patients' need and way of meeting patients and establishing relationship with them were also changed for the nurses in this study. In Study V a qualitative content analysis was used. The findings show that the participants attempted to achieve a form of control of the patient's state of health. By providing support and supervision to the patient they could help him or her in activities of daily life but not take over autonomy. In conclusion, it appears that ethical problems occur when the care of severe mentally ill patients is provided in their own homes in that nurses and mental health personnel had difficulty dealing with issues concerning privacy and autonomy; supervision is significant in supporting the professional role and may solve ethical problems arising in the home care of patient.

This thesis indicates that nursing educational programs should be oriented towards social mental health care and that the curriculum should to a great extent include ethics and ethical analysis of problems that arise in the home care of persons with severe mental illness.

Keywords: Assessment, autonomy, control, decision-making, ethical problems, home care, mental health nursing, privacy, professional role, psychiatric nurses, supervision

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ORIGINAL PAPERS

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

I Magnusson A. & Lützén K. (1999) Intrusion into patient privacy: A moral concern in the home care of persons with chronic mental illness. *Nursing Ethics* 6, 399-410.

II Magnusson A., Severinsson E. & Lützén K. (2002) Nurses' views on situations related to privacy in providing home care for persons with long-term mental illness: An exploratory study. *Issues in Mental Health Nursing* 23, 61-75.

III Magnusson A., Lützén K. & Severinsson E. (2002) The influence of clinical supervision on ethical issues in home care of people with mental illness in Sweden. *Journal of Nursing Management* 10, 37-45.

IV Magnusson A., Severinsson E. & Lützén K. (2003) Reconstructing mental health nursing in home care. *Journal of Advanced Nursing* 43, 351-359.

V Magnusson A., Lützén K. & Severinsson E. (2003) Swedish mental health nurses' responsibility in supervised community care of persons with long-term mental illness. *Nursing and Health Sciences* (accepted).

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INTRODUCTION

The transition from hospital-based to community-based psychiatric services has provided persons with severe mental illness the possibility of living in their own homes with long-term professional support. One important consequence of this organizational change is that psychiatric nurses and mental health care workers have 'followed' these patients out in the community. Providing care in the context of the patient's home is different from providing care in the hospital setting. During my role as clinical supervisor, I have listened to health care professionals' descriptions of difficult situations they have had to deal with on their own. Many of the concerns they wanted to discuss with me seemed to involve ethical issues, for example, the health care professionals' reflections about patients letting 'strangers', coming into their homes. My own thoughts about these issues were that these nurses were genuinely interested in the welfare of these patients but uncertain about jeopardising the patient's own sense of autonomy. Thus, nurses and mental health care workers' experiences of difficult situations in the context of the home of persons with long-term mental illness prompted my research interest. I began with an open design in order to develop a conceptual framework and, subsequently, specific questions concerning home care, emerged. This meant that during the process of analysing the results of the first study questions concerning the role of supervision also came into focus.

Disposition of the Thesis

The design of the thesis is both descriptive and theory generating, using both qualitative and quantitative methods (Figure 1). The thesis began with interviews of three focus groups to learn about psychiatric nurses and mental health care workers' experiences of ethical problems that arise within the framework of the caregiver – patient encounter. As this was a small study, according to the number of participants, (**Study I**) it was of interest in that the result could be used as a conceptual framework in a broader study. It was also of interest in investigating whether ethical problems concerning patient privacy and autonomy are unique to psychiatric nurses and mental health care workers or whether they may be consistent with the views of nurses with different clinical experiences i.e. district nurses. A questionnaire was therefore developed from the ethical problems identified in study I and used as data collection in **Study II** and **III**. In **Study III** the purpose was to investigate in what way clinical supervision can influence the ethical decision-making in home care by district nurses, psychiatric nurses and mental health care workers. In the following study (**Study IV**) the purpose was to obtain a deeper understanding of how changes in psychiatry may have

influenced psychiatric nurses' interaction when providing home care of patients with long-term mental illness. How the structural changes in psychiatric services influenced the autonomy in the exercise of nurses' profession was illuminated in **Study V**. **Study IV** and **Study V** are both interview studies using the same data material

The choice of using grounded theory (Glaser & Strauss 1967; Glaser 1978, 1992; Stern 1980, 1985) as a method for data-collection and analysis in two of the studies (**Study I** and **IV**) was considered appropriate since the aims concerned gaining an understanding of, essentially, an interactive process. In other words, using grounded theory means that the investigator is looking for processes and interactions that are going on in a social scene, in this case in the patient's home. As grounded theory is generated from and grounded in empirical data, it is important to be as open as possible to additional questions that arise. In order to enrich the qualitative analysis with further questions concerning the role of supervision, a questionnaire was developed from theoretical constructs obtained and used in **Study II** and **III**. The results of these two studies led to the research questions for **Study IV**. In the last study (**V**) a qualitative content analysis (Denzin & Lincoln 1998; Ryan & Bernard 2000) has been used as a method of analysis of psychiatric nurses' views on their responsibility for the patient's care. The autonomy of the nurses' profession and relationship to the patient was also important in different ways in Study V, which ties these five studies together in this thesis.

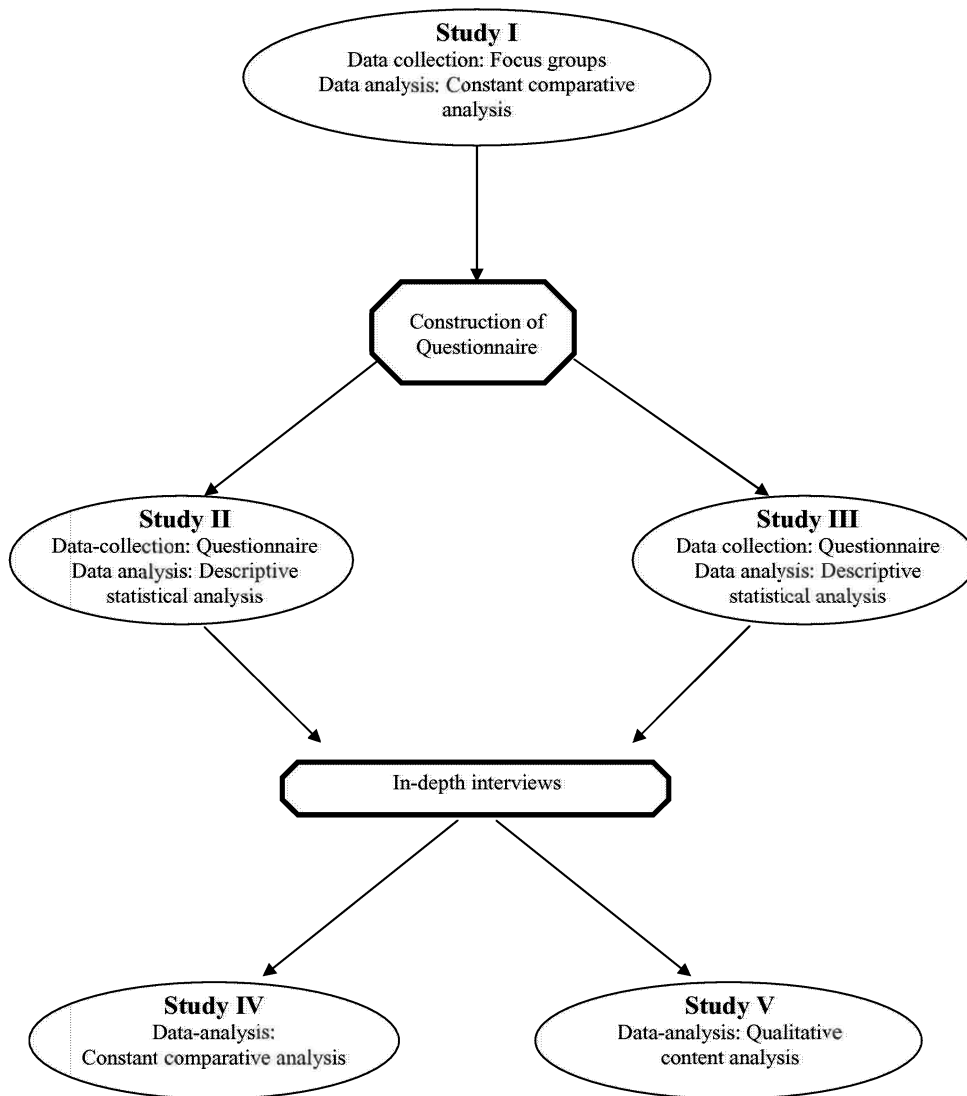


Fig 1: Development of research process

BACKGROUND

The Emergence of Home Care for the Mentally Ill

There are many documents that provide ideological perspectives as well as factual accounts of the de-institutionalisation of the mental hospitals in Sweden as well as in the Western countries (see for example, Björkman 2000; Bengtsson-Torps 2001; Brunt 2002; Markström 2003). For this reason, only a brief summary of aspects of the reform that led to the emergence of home care for the mentally ill and that is relevant for my research will be reviewed.

Historically, people suffering from what today is defined as mental illness, were confined to a life under constant surveillance in large mental asylums, often located outside the cities. One reason for the isolation of these asylums was that it was believed to be morally justified and thus, a social responsibility to hide the insane person or 'idiot' from the society (Foucault 1992). The establishment of mental hospitals in the 19th and early part of the 20th century in the European countries and USA was the beginning of an organised care and treatment for mentally ill persons. The aim was to offer humanitarian care and better living conditions for mentally ill than the medieval prisons, workhouse and families were able to offer (Häfner 1987).

During a period of one hundred years the number of patients being cared for in mental hospital in Sweden, increased from 971 patients in 1860 to 33,752 patients 1960 (Sjöström 1992). The majority of the mentally ill who were admitted to the mental hospitals suffered from severe mental retardation and dementia, or chronic illnesses, such as schizophrenia (Häfner 1987). These findings are similar to the study by Belfrage (1994) who found that 72% of the group of 302 patients admitted to Sundby Hospital in Sweden was diagnosed as psychotic of which 56% had the diagnosis of schizophrenia. However, as Bengtsson-Torps (2001) points out, with the steady rise in admission rates to mental hospitals resulting in overcrowded wards, low number of physicians and a lack of professionals with satisfactory education, it became obvious that the primary tasks of providing humanitarian care and providing mentally ill persons better living conditions were difficult to attain.

In the beginning of the 1950s, new treatment alternatives emerged. Pharmacological as well as psychosocial treatment facilitated the discharge of mentally ill patients from institutional care to community care. One of the first medical treatments, introduced in 1952, was

chlorpromazine, which had a superior effect on the patients who became calmer and showed a reduction in psychotic symptoms as well as a more adaptive approach to the social environment (Bengtsson-Torps 2001).

During the latter part of the 20th century, large numbers of patients were discharged from the mental hospitals to the community based settings in both Europe and in USA (Hummelvoll 1995; Harris & Happle 1999; Lewis & Dehn 1999; Nyström 1999; Bengtsson-Torps 2001; Crowman *et al.* 2001; Brunt 2002). Similar changes in the form of de-institutionalisation of the psychiatric care have also taken effect in Sweden (Dufåker 1993; Nyström 1999; Björkman 2000; Pejler *et al.* 2000; Bengtsson-Torps 2001; Brunt 2002). As a logical consequence of this, the number of beds in mental institutions has been reduced to approximately 80% from the end of the 1960s, into the middle of the 1980s (Belfrage 1994). In 2000, the total numbers of beds in psychiatric clinics were about 5.500 in Sweden (The Federation of County Councils 2000). Approximately 40, 000 people or 0.6% of the population over 18 years living in Sweden are known to suffer from long-term mental illness (National Board of Health & Welfare 1999). Caring for homeless mentally ill persons has thus been one of the greatest challenges for society. A study by Ågren *et al.* (1997) shows that of approximately 3,000 already known homeless people in Stockholm 1997, this number was nearly the same as two years earlier. According to Lamb and Bachrach (2001), a third to a half of all homeless adults in United States have major mental illness, as schizophrenia, schizoaffective disorder, bipolar disorder or major depressive disorder. In a Swedish investigation about the number of mentally ill among the homeless population, the National Board of Health and Welfare 1999 concluded that the number had increased between 1993 and 1999. The National Board of Health and Welfare having no clear explanation for this increase, realized the great urgency of increasing knowledge about this problem. It may be that problems associated with living in the community for this group of people was not anticipated before the reform. It may also be that nurses and mental health care workers were not educationally prepared to meet the needs of severely mentally ill people in a new environment. Although the National Board of Health and Welfare pointed out that the intentions of the Mental Health reform had not been sufficiently implemented in practice, it may be that important aspects of caring for severely mentally ill patients in their own homes was neglected.

The Development of the Mental Health Reform in Sweden

In 1990 the Swedish government commenced a Parliamentary commission, named 'The 1995 Mental Health Reform' (SOU 1992:73) with the purpose of investigating the situation of mentally ill person in the whole country. The investigation demonstrated that persons with mental illness experienced worse living standards and levels of welfare than comparable groups. The Commission had to consider and suggest measures regarding responsibility, organisation and how to coordinate support, service and care to mentally ill persons. The results were that rehabilitation and treatment were to be separated but expected to have a collaborative organisation. The Social Services were to be responsible for care and support in the community for the target group and the psychiatric care organisation would be responsible for providing and developing treatment alternatives. The Commission emphasised in their final report that severe mentally ill persons ought to be seen as active persons, who 'know' how they want to live. In a state bill (Government bill 1993/94:218), the Swedish Government clarified the responsibility of the social and psychiatric services, which formed the background to the 'Mental Health Reform'. The constitution stated that the communities are responsible for planning, initiating and coordinating services for persons with long-term mental illness while the psychiatric care organisations have to provide and develop treatment alternatives. The basic idea behind the change was that people suffering from severe mental illness would be able to live an every-day life as normal as possible in the community with the same rights for societal as other citizens.

Definition of Long-term Mental Illness

The target group for the 1995 Mental Health reform is, according to the Swedish National Board of Health and Welfare, 1999, people who can not manage their daily lives because of a mental disturbance and thus have the need for continual treatment and care. The 'target group' refers to persons with long-term mental disturbance or illness. Although this definition can include those who suffer from a various mental disorders, the most common disorder in this group is psychosis.

What form of professional and auxiliary help that will be required varies between individuals and also over time for an individual person with mental illness. From a perspective of regarding each person's life situation and mental illness as unique, the needs of persons with long-term mental illness lack homogeneity. There are, however, some common behavioural characteristics that can directly be observed in a person with severe mental illness, for

example, they seem to be ‘living in their own world’ and their communication is difficult to understand and sometimes frightening for others. Since auditory hallucinations can be painful and frightening for the patients, they may act in aggressive behaviour directed towards their environment. Many persons with the long term mental illnesses have difficulty in attending to their personal care; hygiene, clothes and housekeeping. There is also the difficulty in being able to look after finances, family obligations and social rights. Those persons, who do not ‘appear’ to be mentally ill, but do have a diagnosis, may be expected to carry out obligations but are not able to do so.

Although the term, mental dysfunction (in Swedish: ‘psykiska funktionshinder’) is the formal term used, in this thesis, the term ‘long-term mental illness’ will be used since this seem to be the common international term.

Integration – Policy and Ideology

In a study by Pickens (1999) desire for normalcy from the patients point of view, included having ‘normal’ things and experiences, doing meaningful activities and being well, safe, free, and independent. As mentioned previously, the community has the ultimate responsibility to its inhabitants regarding their needs of support and other types of help. According to The Social Services Act (SFS 2001:453) in Sweden, the community is obliged to facilitate the social integration of people who meet considerable difficulties in their daily lives because of physical, mental or other reasons, into the community. The basic ideology of the Social Services is that all persons, regardless of illness, have the right to and should be given the opportunity to participate and to be part of the community. This means that the Social Services is obligated to contribute to the individual patient gaining a meaningful occupation and a place to live, adapted to the individual’s needs of support. Heginbotham (1998), Lamb and Bachrach (2001) discuss what can be learned from their experience with de-institutionalisation. The authors *ob cit* describe similar programmes that have been enacted in many other countries in the world. Where the community services have been available and comprehensive, the quality of care for these persons has improved substantially and, compared with the conditions inside psychiatric hospital, many individuals expressed much greater satisfaction with their lives today. Furthermore, mentally ill people that could initially have been cared for without being admitted to a psychiatric hospital, now live a more productive and active life in community settings (Heginbotham 1998). On the other hand, the programmes for mental health in developing countries are often, according to Sartorius

(1998), sparse due to resources and the provision of treatment and support to families of those suffering from mental illness ought to be, according to Sartorius, taken as a priority over all other efforts. Even in industrialised countries more things could be done for people with mental illness if there were better resources. Lamb and Bachrach (2001) point out the discrepancy between ideology and policy governing the distribution of and access to community resources. Now that de-institutionalisation is considered complete, a new 'generation' of persons suffering from severe mental illness, who have not lived the majority of their lives in hospitals, create other types of problems, such as homelessness and other social welfare problems (Lamb & Bachrach 2001) that are difficult to handle for the service system.

Another problem for social integration of the mentally ill is that society seems not to have become more tolerable towards mental illness, and as such, the basic ideology of the psychiatric reform is weakly grounded. In an article in *The Lancet* by Sartorius (1998), the author noted that schizophrenia was selected as the focus for an international programme initiated by the World Psychiatric Association (WPA) aimed to develop tools that would make it easier to fight stigma and discrimination because of schizophrenia. Sartorius (1998) indicated that the general public often associates mental illness with hallucinations, delusions (often of a bizarre kind), psychomotor abnormalities, and incoherent speech. This means, that if the environment is intolerant and hostile and stemming from ignorance and prejudice, the rehabilitation of these people will be difficult. That stigma and discrimination are the most significant obstacles to the development of mental health care and ensuring these people a good quality of life are well documented, see for example Sartorius (1998); Teschinsky (2000); Pejler (2001); Bonner *et al.* (2002); Gray (2002) and Zeeman *et al.* (2002).

Problem Area

Important developments in the care of severely mentally ill persons have taking place since de-institutionalisation during the second half of the 20th century in Sweden as well as in other western countries (Sjöström 1992; Dufåker 1993; Qvarsell 1993; Topor 1993, 1997; Hummelvoll 1995; Harris & Happle 1999; Lewis & Dehn 1999; Nyström 1999; Björkman 2000). Evidenced based care, systematic development of quality and new forms of co-operation between different caregivers influences the daily care of this group of people today.

The fundamental ideology that supports the de-institutionalisation of the psychiatric care was based on, among other things, that people with long-term mental illness have the same rights and obligations as other groups in the community. This group of people also has the fundamental right to service; support and care adapted to his or her individual condition and needs (SOU 1992:73). Despite good intentions, there are groups of mentally ill persons that, according to Lamb and Bachrach (2001) Sartorius (1998), have difficulties in fitting into a 'normal' everyday life in the society. Other studies by Bengtsson-Torps (2001) show that people suffering from long-term mental illness have comprehensive needs for care and support, which to a great extent is unmet, for example information about the condition and treatment, daytime activity, physical health, psychological distress and intimate relationships. Despite vast amount of research, there are still few studies providing knowledge about how to help people with long-term mental illness to get a better quality of life. Likewise there is limited knowledge about specific problems that professionals experience in their home care for mentally ill persons. There is also little knowledge about what sort of experiences and theoretical knowledge that will be required to handle new problems arising in a changed context of care. In Sweden, the National Board of Health and Welfare concluded in their evaluation in 1999 of the Mental Health reform that complete implementation had not sufficiently been transformed to practice because of unclear roles of responsibility between Social Services and psychiatric services. Furthermore, at times there have been co-operative difficulties between different caregivers, which often have to do with a lack of common attitudes and knowledge.

In addition to gaining knowledge of how de-institutionalisation has influenced psychiatric nursing, it is also necessary to gain knowledge about what educational needs and support nurses and mental health care workers need in order to provide good care in these persons' homes. There is also a need to explore ethical problems nurses and mental health care workers experience in their interaction with mentally ill persons in their homes.

In a study by Mattiasson and Hemberg (1998) caring responsibility as a right to act against the wishes of the patient is discussed as an ethical problem in the nursing of elderly people. These ethical problems may have similarities with the care of mentally ill people, because both groups sometimes may have difficulties caring for themselves. Malmsten (1999) raises the issue of the nurse's power as a professional relating to a dependent patient and the risk for some kind of paternalism. The moral dilemma between respect for autonomy on the one hand

and beneficence on the other is also stated by Breeze (1998) who states that paternalism can be justified when the nurse is confident that the patient is unable to make an autonomous decision. O'Brien and Golding (2003) state that making a decision for oneself is a good thing, even if one is incompetent or lacks autonomy, because of the feeling of being in control of yourself and the benefits of learning to make decision for yourself. The authors state that it is important to take into account the possible harm of coercion and the possible benefits of allowing someone to make his or her own decision. Modifying autonomy, according to Lützén & Nordin (1994), may be one way to adjusting the patient's self-choice, which in practice could entail enhancing, or limiting the self-determination. Another way for nurses to handle this ethical problem may be what Lützén (1998) calls subtle coercion, which means judging the patient's competency and employing subtle coercive strategies that modify the patient's autonomy. Making judgements of what is good or not good or what is in the best interest for the patient in consideration of the nurse's own responsibility for the patients' health may be especially problematic in the home of the patient. This thesis focuses on home care of persons with severe mental illness with a special focus on ethical problems. As described above, many of the psychiatric nurses and mental health care workers 'followed' the patients from institutional care out into the community. They are now working in the patient's private home, where they have to handle many specific problems that seem to be related to a new arena of nursing. The literature shows that few studies describing home care of persons with severe mental illness from the perspective of the staff (psychiatric nurses and mental health care workers) have been conducted, in Sweden as well as internationally. Moreover, my clinical experiences as well as earlier studies indicate that there is a need to discern what aspects are involved in the ethical problems that arise in the home of the mentally ill patient.

AIMS OF THE STUDY

The overall aim of this thesis was to explore nurses' and mental health care workers' experiences of how changes in the organisation of psychiatric care influence their daily work and how these changes may have contributed to ethical problems. The specific context in focus was the homes of long-term mentally ill persons. Implicit in this aim was the assumption that the results of this research could be used to develop educational and mentoring programs for nurses and mental health care workers that are suited to community psychiatric and mental health nursing.

The specific aims of the five papers were to:

- I Identify and analyse ethical problems within the framework of the nurse-patient encounter. A focus was placed on how nurses conceive and actualise patient autonomy, as well as how they justify their actions.

- II Explore the views of district nurses, registered psychiatric nurses, and mental health care workers on issues relating to privacy and autonomy in home care of persons with long-term mental illness. An additional aim was to identify whether or not differences in views could be related to age and gender.

- III Investigate in what ways clinical supervision can influence district nurses', psychiatric nurses' and mental health care workers' ethical decision-making in home care of people with mental illnesses.

- IV Explore and describe mental health nurses' experiences of how structural changes have influenced their interactions when providing home care to patients with long-term mental health problems.

- V Describe the psychiatric nurses' experience of how the changing focus of mental health care in Sweden, from in-patient treatment to community based care, has influenced their professional autonomy.

PERSPECTIVES AND RESEARCH APPROACH

Since the overall focus of this research was on nurses' and mental health care workers' experiences resulting from their interaction with the patient, and that ethical issues arose in this interaction, symbolic interactionism has been used as a research perspective. Congruent to this perspective is the symbolic meaning of home, the nursing relationship and a relational approach to ethics.

Symbolic Interactionism

Symbolic interactionism (Blumer 1969; Charon 1998) is rooted in social psychology as a perspective and one way of understanding reality. The emphasis is placed on how to understand the influences of society in form of dynamic activities among individuals in their attempt to create meaning in their lives. This means that one always sees reality through

perspectives and that the individual and the context where the individual exist are inseparable. As Charon (1998) points out, a perspective is only an angle of the reality and that particular angle limits what one will see when one tries to understand the individual's world. As one only can see a part of a real situation, it is the perspective that forces us to pull out certain stimuli from our environment and ignore other stimuli. Whatever is seen, a perspective is made up of words that the observer uses to make sense out of a situation. How the reality looks like depends on which words an individual uses to look at a situation. It is also important to see that an individual usually has more than one perspective that is important for him or her and that these perspectives can be changed over time. Despite this, one has one's perspectives and one must realise that one can never claim to have found all the possible perspectives one think one might use to capture the reality. People are, as Charon (1998) points out, limited by their perspectives and one can not see outside them.

Many people consider that the ideas and thoughts of George Herbert Meads (1863-1931) are the mainstays of the perspective symbolic interactionism. Meads' works were carried forward first by his students. One of these was Herbert Blumer who worked actively to make his work well-known. Simultaneously, he created his own version out of the ideas of Meads and coined the term symbolic interactionism (Blumer 1969). To see the world from the perspective of symbolic interactionism means according to Blumer (1969 p.2) that:

- *human beings act toward things on the basis of meanings that the things have for them*
- *the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows*
- *these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters.*

Starting from the proposition that the human being always has his or her existence in society also contributes to the quality of the human being, and the quality as an individual. This means that the culture that one grows up in forms one as a human being and shapes how one looks at reality, one's basic ideas, values, roles and beliefs. Social reality is always changing. Certainly, the social objects are not changing, but it is our definition or our assessment of the social objects that will be changed.

Social interactions are, according to Blumer (1969), of essential importance in symbolic interactionism. In society, Blumer states, the individual has to point out to himself the things towards which he is acting and the things that have meaning, which indicate an internalised

social process, where the individual is interacting with himself. This is according to Blumer an instance of the person engaging in a process of communication with himself. By virtue of this process of communication with himself, interpretation becomes a matter of handling meanings.

Choosing symbolic interactionism as a research perspective is suitable since the organisation in psychiatric care is an ongoing process in which nurses and mental health care workers have to create and find their own way to behave towards things and situations in their daily work on the basis of the meaning these things have for them. Home care is a new form of caring of patients with long-term mental illness for the psychiatric personnel. How nurses and mental health care workers interact with patients and other human beings in the patient's home and surrounding depends on the meaning these meetings have for them. For the psychiatric personnel, this means that they have to arrange their behaviour in accordance with these different meanings in their relationship with the patient and in relating with other colleagues. By using symbolic interaction as a research perspective the purpose is to explore nurses' and mental health care workers' experiences of the changes in the organisation of the psychiatric care and ethical problems that arise out of their interactions with the patient.

The Symbolic Meaning of Home

According to Somerville (1997) several studies have expressed the same recurrent meaning of the home as the centre of the family, a place for retreat, security and relaxing, freedom and independence, social state, a place for privacy, continuity, financial property, support for work and recreational activities. People refer to their home as a symbol, according to Després (1991), how they see themselves and how they want viewed by other people. For many people it is important that their home represent good taste, interests and character, by furniture and adornment in the form of different things meaningful for the person who lives there. The home is also a place to strengthen and secure the relation to other persons one pays attention to. Likewise, the home can be seen as place to withdraw to, from the pressures outside. The home is, as Després means, a place where one can control and keep the level of social interactions and a place of privacy and independence. According to Silfverberg (1996 p. 85) the home constitute –'hyphen between the special and the common, the link between the unique situation of the individual and the outer world'.

To have a private life, according to Dworkin (1995), includes the power of an individual to maintain control over the information about oneself that is available for others. Nevertheless, a better control over the knowledge about ourselves is the most important part of our privacy that we can keep for ourselves. Andersson (1996) emphasises the human being's rights to protection on one hand against intrusion according to different statutes and on the other hand by what can be called an intrusion according to social and moral norms. According to Lantz (1996) the boundary of the home is important and starts at the doorstep. The 'climb over' the doorstep into another person's home is surrounded with social rites. One knocks at the door, asks to come inside, one says hello and so on. If you enter another person's home without being permitted, you have committed a violation of the privacy, as the home has a very strong protection of the law (Lantz 1996). What ethical and practical consequences will working in a severely mentally ill person's private home have for nurses and mental health care workers or those whose decision will be regarded as the final one. Another question is what does it mean for nurses' and mental health care workers' relationship to the patient to work in the patient's private home.

The Nursing Relationship and Ethical Aspects

Nursing, according to Peplau (1991), can be viewed as an interpersonal process, often therapeutic, between a professional nurse and the patient. Many actions that nurses carry out are, according to Peplau, more technical than relational. This means that the operations involved in the nursing process are both interpersonal and technical ones. Yet, as Peplau points out, the process can not be defined as technical. Peplau see the relationship between the patient and the nurse, like a relationship where the patient is sick and needs help from the nurse who is especially educated to recognise and respond to the need for help. The purpose of nursing will be to foster and promote growth of the personality in the direction of a creative, constructive and productive personal and social life. The process in the relationship between nurse and the patient, according to Peplau, consists of four phases; orientation, identification, exploitation and resolution. In his or her relationship with the patient, the nurse defines roles in which he or she wishes to function or how he or she ought to function as a nurse. Also, the patient assigns the nurse different roles in relation to their own needs. In the beginning of their relationship both the nurse and the patient are strangers to one another. However, in situations like this, it is important for the nurse to meet the patient as he or she usually meets other strangers, i.e. with respect and positive interest. In their role as resource persons, the nurses may see themselves as a source of knowledge and technical procedures; in

their teaching and counsellor role, the nurses today may be the persons that help the patient to live in his or her own home and to be aware of the function of society.

A similar perspective on the nurse patient relationship is described by Hummelvoll (1996) who emphasises in his 'Nurse-Client-Alliance model' that the mutual agreement (between the nurse and the patient) is the basis of an alliance. According to Hummelvoll the alliance is the consequence of the patient's need for help and the nurse's response to this need. The alliance is, as Hummelvoll states, characterised by a spirit of community when working together and increases the patient's insight and comprehension of the situation and his or her ability to solve health problems. This form of alliance is significant in the care of long-term mentally ill people, because it may compensate for loneliness, helplessness, isolation and angst that many of these patients are experiencing. In a truthful and real relation both parts are as Tschudin (1986) states, equal, both are equally important. The relationship that will be created between a nurse and a patient differs from other relationships because it is not equal; it is based on to give and to take, needs and retorts, sick and healthy. As professionals one has the knowledge and power to help other people and this is, according to Tschudin, a privilege. Nursing implies that one does something in an active way for another person, and this constitute the foundations of the ethical aspect of nursing. To acknowledge and listen to another person's needs implies, as Tschudin states, helping another person to be what he or she is. It is characteristic in nursing, according to Curtin and Flaherty (1982), to reach a sense of well-being for other human beings which is a moral and not a scientific goal. The nature of the relationship between the nurse and the patient is determined by the patient's human needs and how the nurse will meet those needs. From this foundation in every meeting, the nurse and the patient will structure the specific content in their relationship. The patient's unique needs as a person are the essential focus of the ethical aspects of nursing. Curtin and Flaherty (1982) also point out that the nurse is a moral agent of the patient and responsible for his or her own actions and must act as a human being in accordance with his or her convictions, values and principles to preserve his or her integrity. To force a nurse to act against his or her convictions is a violation of his or her rights as a human being.

In the nurse patient relationship it is the nurse who has the responsibility and the professional knowledge to help the mentally ill patient who is in need of help. This implies that the purpose of nursing must be to help the patient to grow as a person and solve his or her health problems to reach a sense of well-being. To provide nursing care for severely mentally ill

patients in their own home may be specially complicated because of their illness and possible unwillingness to let the nurses into the privacy of their home. In such a situation, the nurses have to find a balance between the patient's right to self-determination and their own responsibility for the patient's health. The patients' previous experiences and incapacity to take care of themselves in the community will also make this a difficult task for the nurses. The question is then, how do health care professionals interpret and deal with the principle of autonomy in actual situations?

Articles	Aim	Data collections/ subjects	Methods for analysis and interpretations
Title/ Paper I Intrusion into patient privacy: A moral concern in the home care of persons with chronic mental illness <i>Nursing Ethics</i> 1999, 6 (5):399-410	To identify and analyse ethical problems within the framework of the nurse-patient encounter. A focus was placed on how nurses conceive and actualise patient autonomy, as well as how they justify their actions.	Three focus groups, consisting of psychiatric nurses and mental health workers (5-6 participants in each group)	Constant comparative methods of grounded theory
Title/ Paper II Nurses' views on situations related to privacy in providing home care for persons with long-term mental illness: An exploratory study <i>Issues in Mental Health Nursing</i> 2002, 23: 61-75	To explore the views of district nurses, registered psychiatric nurses, and mental health care workers on issues relating to privacy and autonomy in the home care of persons with long-term mental illness An additional aim was to identify whether or not differences in views could be related to age and gender	A total of 1,139 questionnaires was sent to 726 district nurses and 413 psychiatric nurses and mental health care workers	SPSS was used for analysis of the questionnaire. The Chi-square test was used to compare differences in views between the three groups
Title/ Paper III The influence of clinical supervision on ethical issues in home care of people with mental illness in Sweden <i>Journal of Nursing Management</i> 2002, 10:37-45	To investigate in what ways clinical supervision can influence district nurses', psychiatric nurses' and mental health workers' ethical decision-making in home care of people with mental illnesses	A total of 1,139 questionnaire was sent to 726 district nurses and 413 psychiatric nurses and mental health care workers	SPSS was used for analysis of the questionnaire. The Chi-square test was used to compare differences in views between the group who received supervision and those who did not.
Title/ Paper IV Reconstructing mental health nursing in home care <i>Journal of Advanced Nursing</i> 2003, 43 (4):351-359	To explore and describe mental health nurses' experiences of how structural changes have influenced their interactions when providing home care to patients with long-term mental health problems.	Eleven psychiatric nurses, four men and seven women, working in home care in different areas in Sweden were interviewed.	Constant comparative method of grounded theory
Title/ Paper V Mental health nurses' responsibility in supervised community care of persons with long-term mental illness <i>Accepted</i>	To describe psychiatric nurses' experience of how the changing focus of mental health care in Sweden, from in-patient treatment to community based care has influenced their professional autonomy.	Eleven psychiatric nurses, four men and seven women, working in home care in different areas in Sweden were interviewed.	A qualitative content analysis was used for the analysis

Fig 2. Overview of the papers included in the thesis

METHODS

Focus Groups as a Technique for Data Collection

The purpose of a focus group is to investigate how human beings think, feel and handle in relation to phenomena that have been defined in advance (Morgan 1988). The main advantage of a focus group interview over other styles of qualitative or quantitative research is the possibility of stimulating spontaneous exchanges of ideas, thoughts and attitudes. Often this will be more easily expressed in a group where the group offers the participants a safer environment than an individual interview (Morgan 1988; Nyamathi & Shuler 1990). For these reasons, focus groups were chosen for data collection in **Study I**.

Focus groups constitute one specific technique within the broader category of group interviewing to collect qualitative data (Morgan 1988 p.12). Morgan states that the hallmark for using focus groups is *the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group*. As a group interview, focus groups have the ability, according to Morgan, to combine the best data from individual interviews and participating observations, i.e., to give a collective picture of the phenomena. Another advantage that focus groups offer is the possibility of observing a large amount of interaction on a topic in a limited period of time.

While initially, focus groups were used foremost as marketing research, they have recently, more commonly, been used as a method for collecting data for nursing research (Reed & Payton 1997; Ekblad *et al.* 2000). As a method, focus groups can be used as a self-contained research method to explore new research areas or to examine well-known research questions from the research participants' own perspective (Ekblad *et al.* 2000; Morgan 1998). In combination with other methods focus groups can be used either in preliminary research to prepare for specific issues for a larger project or as follow-up research in other data. To perceive the best result from the focus group interviews, it is important, according to Morgan (1998), that the criteria in using this form of interview technique is well defined, i.e., that the focus to be used, for example in this thesis, ethical problems, is clear. It is also important that the focus group produces data that is as specific as possible and that the group interactions are supported. In this way the feelings of the participants will be expressed. Finally, it is important that the personal context that the participants are using when they produce their answers on topic will be used in assessing the data. To reach the above goal the interviewer is a key person (Nyamathi & Shuler 1990). The interviewer should be experienced in group

interview as data collection method. This experience is important to ensure that the focus for the discussion is maintained. In addition, there can be another risk factor, namely, that one or more of the participants in the group will be too dominant which may result in that the opinion of other participants not being heard. Reed and Payton (1997 p. 770) notes the importance of the researcher paying attention to issues of time and the contributions the participants if anything more than 'a list of things that people have said' is to be produced.

As psychiatric nursing primary is an interactive and communicative activity in which problems concerning patients care often are discussed in different sorts of formal and informal groups setting, it was determined that using the interactions in focus groups in **Study I** to discuss ethical problems, would throw more light upon the subject than individual interviews. In line with the tradition of grounded theory, the analysis of the data collected in each group generated new questions for the next focus group.

Grounded Theory as Data Analysis

The overall aim in this thesis was to explore nurses' and mental health care workers' experiences of how changes in the organisation of psychiatric care influence their daily work and how these changes may have contributed to ethical problems. To describe and explore these processes the constant comparative method of grounded theory was used for analysing the data collection in **Study I** and **IV**. A short summary of the method will be described in the following section.

In grounded theory, reality is socially and culturally based. Furthermore, grounded theory (Glaser and Strauss 1967; Glaser 1978, 1992; Stern 1980, 1985) is linked to symbolic interaction(ism) and generated from and grounded in the data. According to Glaser (1978), grounded theory has had its impact, almost wholly on qualitative research, where the theorist looks for process. The reason for choosing a grounded theory approach is to understand the nature of human behaviour by generating theories about social and psychological phenomena or, in an other words, as Stern (1980) points out, 'for investigations of relatively uncharted waters' (p. 20). According to Stern (1980) grounded theory differs from other methodologies in that the conceptual framework is generated from the data even if previous studies influence the final outcome of the actual study. Hallberg (2002) emphasises that data are reconstructions of informants' experiences of their reality, not facts or objective statements. This implies, when using interviews as data collections that the interviewer is, according to

Hallberg (2002), an important instrument. It also implies that the interview must build upon a trusting relationship between the interviewer and the informant in order to obtain as rich data as possible. To obtain such rich data it is necessary, as Hallberg (2002) states, to select informants strategically i.e. to compare narratives from informants with different views, social situations, age, gender, education and so on. Grounded theory also differs from other studies in its way of analysing the data where every piece of data is compared with every other piece of data. Glaser and Strauss (1967); Glaser (1978) and Stern (1980) have described the method in grounded theory as a constant comparative method, where the researcher, by comparing coded incident for incident in the data establishes categories that explain the data. Glaser and Strauss (1967) points out that in this way theory generation is inductive, with categories emerging from the data and becoming more focused as the research progresses. Once categories begin to emerge they are used to advance further data collection. This process whereby the analyst jointly collects codes and analyses and decides what data to collect next is termed 'theoretical sampling'. Glaser (1978) states that it is important that a theory explains what happened, predicts what will happen and interprets what is happening in an area of substantive or formal inquiry. If the theory is to work, its categories must 'fit'; it must say something of what is going on, as Glaser points out; it must be relevant to the action of the area. It is also important in grounded theory that the generating theory must grow out of the data, without any influence of theoretical requirements. According to Glaser (1978) the researcher should not try to receive an answer of what he or she expects is important; but must instead attempt to answer the question 'what is going on here'?

The first open phase coding (Glaser 1978) should lead to categories. These categories are 'found' by analysing and comparing the coded data, collected through interviews and observations. When no more information about the core processes is forthcoming from ongoing data collecting, saturation is reached. Category is compared with category to see how they cluster or connect to each other, which is a more theoretical form of analysis than clustering coded data. The investigator is looking for any higher order of category, in other words the 'core category.' The category has to describe the central problem. In the next phase, the selective phase implies, according to Glaser (1978) concentration on some of the categories and the abandonment of the others, not specific to the issue explored. The categories selected will all be related to the core category. The last phase according to Glaser is the theoretical phase, in which the investigator will determine how the different categories relate to each other.

Constructing of a Questionnaire for Data Collection

The construction of questionnaires as the measuring instrument is common in most research areas. DeVillis (1991), Frankfort-Nachmias and Nachmias (1996) and Oppenheim (1992) emphasise the importance of being clear about what is going to be measured from the very beginning. There are, according to the authors, many technical aspects involved in the developing and validating of a questionnaire. There must be at least one theory that can be used as a guide for developing the questionnaire. In **Study II** and **III**, the theory was that while the ethical problems in **Study I** would be relevant for other nurses and mental health care workers, there would be differences in views of ethical problems between the district nurses and psychiatric personnel. Accordingly, it is important that the focus and content of the questions be correct and that the questions be short and easy to understand. It is also important that the terms be adapted to the persons that are expected to answer the questionnaire. That each question, according to Oppenheim (1992), should motivate the participants to continue to co-operate, implies that the questionnaire and the answering process be more attractive.

In **Study II** and **III** a specifically designed questionnaire with twenty questions was developed from the theoretical constructs obtained in the qualitative **Study I**. The main theme in this study, 'intrusion into patient privacy', that constituted the conceptual framework, describes the moral reflections of the respondents' role related to the patients' privacy and autonomy. The statements in the questionnaire are derived from Study I. a a psychiatric context. Each item was formulated into an assumption with alternative responses on a 6-point Likert-type scale cf. Polit & Hungler (1995) with the anchors 'totally disagree' = 1 and 'totally agree' = 6. The final selection of twenty items was based on a critical review by five psychiatric nurses who had more than 10 years of clinical experience in psychiatric nursing. The sorting of the items resulted in renaming the categories as follows: A: Intrusion; B: Integrity; C: Insecurity and D: Self-confidence. The categories 'intrusion' and 'integrity' related to patient privacy and autonomy and the categories 'insecurity' and 'self-confidence' related to the nurses' professional role. Each item was coded according to one of these categories (see Appendix 1).

Interview Method

Oppenheim (1992) points out that an interview is not an ordinary conversation even if there appear to be similarities. In a research interview, the aim is to collect information in some area, for example, factual replies to factual questions or responses feelings thoughts ideas and

perhaps the respondents' expectation in a certain way. The most common form of interviewing involves, according to Fontana and Frey (2000) individual or group interviews, mailed or self-administered questionnaires and telephone surveys. By using unstructured interviews instead of structured interviews the interviewer can provide a greater breadth of data than possible with other types of interviews. Gaining trust is, according to Fontana and Frey (2000), essential to the success of the interviews; but, trust can be very fragile and a piece of tactlessness may destroy trust that has been painfully gained over a long period of time. Kvale (1997) states that the personal nearness existing in the interview creates demands strictly that the interviewer, in sensitivity, decide whether to continue or not in each moment with the questioning. It is also important that the interview is carried out in a place that is private, quiet and comfortable and that is not intimidating. The question of the number of interviews that should be conducted for a study cannot be definitely answered. Among other factors to be considered is the content in the interview. Oppenheim (1992) points out that thirty or forty interviews are probably typical, however since in-depth interviews are costly and time-consuming, there is pressure to reduce the numbers of interviews as much as possible. An interview will last between one hour and one hour and a half.

Participants

In **Study I** the participants (psychiatric nurses and mental health care workers) from three outpatient settings were asked by a letter to participate in focus groups. The potential recruits all provided care for patients with long-term mental illness in a region of Sweden. The letter advised the participants of the purpose of the study and guaranteed confidentiality that would not reveal their personal identity. The letter was sent to the head chief of each team. All the nurses and mental health care workers who were willing to take part in the study had full experience in community mental health nursing. Three focus groups consisted of five to six psychiatric nurses and mental health care workers in each group; both men and woman were interviewed.

In **Study II** and **III**, all district nurses in the primary care and all psychiatric nurses and mental health care workers in outpatient settings providing home care for patients with long-term mental illness were asked to participate in a study. All participants worked in the same health care region in Sweden. A total of 1,139 questionnaires were sent out to 726 district nurses and 413 psychiatric nurses and mental health care workers. In the original lists of names, psychiatric nurses and mental health care workers were not distinguished according to

their individual profession. The sampling was not random since not all district nurses have contact with long-term mental illness patients and there was no way of obtaining information regarding the names of district nurses who specifically worked with long-term mental illness patients. However, the district nurses were informed by letter and asked that if they had experiences in providing care for patients with long-term mental illness to respond and return the questionnaire.

To find respondents (**Study IV** and **V**) on a voluntary basis from various regions of Sweden, an advertisement was placed in a Swedish national journal for mental health nurses (*Psyche*). In the advertisement psychiatric nurses, who had experience of institutional care of long-term mental illness patients and were presently employed in the community care of patients suffering of long-term mental illness were invited to participate in the study. The nurses who responded to the advertisement and met the above criteria were contacted by e-mail or telephone by the researcher.

Eleven psychiatric nurses, four men and seven women, from various regions of Sweden were interviewed. Their ages ranked between thirty-six and fifty-nine years. All had experiences in providing care for long-term mental illness patients both in an institutional and a community setting. Their professional experiences varied between four and twenty-one years and most had worked more than eleven years as a nurse in different areas in Sweden. The respondents selected the location for the interview, which lasted between forty-five minutes and one hour. One of the interviews was a telephone interview.

Method of Data Collection

Within a three-month period, three focus groups were conducted for data collection in **Study I** following the principle of theoretical sampling in grounded theory. Psychiatric nurses and mental health care workers were interviewed by collecting the interactions in focus groups as data. Two investigators participated in each focus group. One of the investigators guided the discussion while the role of the other investigator was to take notes and facilitate interaction by asking additional questions to clarify what was being discussed.

In **Study II** and **III** a questionnaire was used for to collect data. To make contact with the participants, a research assistant determined the number of questionnaires that would be required by contacting the chief nurse at each unit and asking for a list of all nurses and

mental health care workers. The questionnaire was mailed to each of these nurses and mental health care workers with a letter explaining the purpose of the study and the procedure for completing the questionnaire together with information about anonymity and informed consent. The completed questionnaire was returned in a non-coded sealed envelope. At the same time, each participant sent a separate letter to the research assistant with the information that they had completed and returned the questionnaire. By way of this letter anonymity was maintained and the return rate established.

In **Study IV** and **V** unstructured individual interviews, so called ‘in-depth’ interviews, were used to explore and describe (**Study IV**) the psychiatric nurses’ experiences of how structural changes in psychiatric nursing have influenced their interactions and how the changing focus (**Study V**) of mental health care has influenced psychiatric nurses’ professional autonomy. It was important that the right informants were selected for the interview, that is, those nurses who were willing to share their experiences of working in the patient’s home. The respondents selected the location for the interview. Each interview lasted between forty-five minutes and one hour and began with the following opening question: ‘What does the shift from institutional care to community care mean for you as a nurse?’ In accordance with the sampling technique of grounded theory, saturation (Glaser 1978) was reached when no new information came out of the interviews.

Method for Data Analysis

The constant comparative method of grounded theory was used for data analysis in **Study I** and **IV**. A short summary of the method of grounded theory is described earlier in this thesis. This method was chosen in **Study I** on the assumption that ethical decision making is an interactive and interpersonal process that lends itself to the constructivist approach of this method. The ‘first level coding’ consisted of reading through the text line by line, analysing the text in order to select phrases, words and incidents that would describe nurses’ and mental health care workers’ interactions, and ethical problems within the framework of the nurse-patient encounter. The ‘the second level’ of coding involved examining and reducing codes into categories. Nine categories were identified: feelings, opinions, emotional difficulty, sensitivity, trust and safety, responding to the patient, acting in response to the patient, tacit understanding, and specific interventions. In ‘the third level’ of analysis the categories were compared and linked to each other. All categories were found to conceptually relate to the symbolic meaning of ‘home’. The theme, ‘intrusion into patient privacy’, formed a conceptual

framework for explaining the confusion of the nurses and mental health care workers when entering the home of the patient. Four main dimensions of the theme 'Am I an intruder or professional?' were identified: 'Intruding in the home of the patient'; 'Experiencing fluctuating boundaries'; 'Respecting or transgressing the right to privacy' and 'Situating mutual vulnerability'.

In **Study IV** the same method was used to analysis the transcribed interviews. The selection of method was made with the intention of exploring and describing the psychiatric nurses' experiences of how structural changes had influenced their interactions when providing home care to patients with long-term mental health problems. By subsuming and abstracting the categories identified in this study (**Study IV**) a core category was identified: attempting to reconstruct mental health nursing by entering into the everyday reality of people with long-term mental health problems. This process consisted of three interrelated subcategories: 'Moral positioning', 'Making assessments' and 'Establishing relationships'.

To investigate whether the results in **Study I** are consistent with the view of nurses with different clinical experience, a questionnaire had been constructed for data collection in **Study II** and **III**. A factor analysis was completed in order to establish whether the items clustered into the four original conceptual categories in **Study I** (Nunnally & Bernstein 1994 p. 447). However, the factor showed weak loading, i.e., weak correlation between the items and the original categories. This meant that, since inter-item correlation was weak within each category, the questionnaire could not be regarded as consisting of four composite scales. Because of this the items were analysed independently of each other. As the alternatives of the responses given by the respondents in the questionnaire were not normally distributed, (**Study II** and **III**) a non-parametric test was used, chi-square test, to evaluate whether there were any differences between the three groups according to their opinions about the assumptions in the questionnaire (Frankfort-Nachmias & Nachmias 1996). Generally, the chi-square test may be used to determine whether the difference between the observed and the expected frequencies are statistically significant. The six alternatives of the responses in the questionnaire were dichotomised according to two variables, 0 and 1, in order to compensate for the skew. This meant that the responses 'disagree more or less' (alternatives 1, 2 and 3) convert to 0 and the responses 'agree more or' less (alternatives 4, 5 and 6) convert to 1. A chi-square test also was used to identify significant differences between the three groups with

regard to age, gender and type of professional experience. Significance level was set to $p < 0.05$.

For analysing of data in **Study V**, a qualitative content analysis (Denzin & Lincoln 1998) was used to identify topics related to the aim of the study, i.e., responsibility, assessment, control, work situation, loneliness/ independence, support, and supervision. Inspired by Ryan and Bernard (2000), the following steps were taken in analysing the transcribed text from the interviews: The text from the interviews was read several times in order to obtain an impression of the whole content of each interview as well as an overall feeling of the total text-content. This was followed by reading the text, making notes about the content, sentence by sentence and looking for what was essential in relation to the nurses' experiences of how changes in the organisation of the psychiatric care had influenced their professional autonomy. When the whole text had been coded, the codes were compared to each other in order to reduce the data into themes. Three themes were constructed; 'Pattern of responsibility', 'Pattern of clinical judgement' and 'Pattern of control through support and supervision'. The results of the analysis of the data were discussed and compared by all of the investigators in order to validate results of the study.

ETHICAL CONSIDERATIONS

In **Study I, IV and V** the nurses and mental health care workers had been informed verbally as well as in writing about the purpose of the study, the content and the extent of the study. They were also guaranteed that neither they nor their place of work would be identified in the study. They were also informed that participating in the study was voluntary, that their information would be handled confidentially and that they could terminate the interview if became unhappy with any aspect. This is also stated by Kvale (1997), i.e., that the researcher has to achieve a balance between being too detailed in the investigation and leaving out aspects that can be important. Both Polit and Hungler(1995) and Kvale (1997) state that the researcher has to protect the participants from harm and according to Kvale (1997) the close contact between the researcher and the interviewee means that the researcher must be sensitive about the questions in the interview situation. Kvale (1997) also points to three ethical aspects in the role of the researcher: the scientifically responsibility, the relationship to the participants and the independence of the researcher. With the agreement of the respondents, all interviews were audio-taped and the tapes were transcribed as carefully as possible before being locked away. In **Study II and III**, consisting of a questionnaire, a

research assistant determined the number of questionnaires by first contacting the chief nurses of district nurses in the primary care units and the chief nurses of psychiatric nurses and mental health care workers in outpatient settings to get a list of names of all nurses and mental health care workers. The questionnaire was sent with a letter informing each nurses and mental health care workers in accordance with Kvale (1997) of their rights, the purpose of the project and the procedure for completing the questionnaire. The questionnaire was returned in an un-coded, sealed envelope. To keep the anonymity of the participants, a separate envelope with the name of the participants was sent back to the research assistant to inform the assistant that the questionnaire had been returned. Sending the questionnaire and the information to the assistant in separate envelopes ensured that the principle of the participants' rights' to protection against their personal integrity was maintained, in accordance with the standard defined by (Kvale 1997) that private data that may identify the participants must be handled confidentially.

All studies have been approved by the ethics committee at Huddinge University Hospital AB: **Study I** Reg.nr. 171/97; **Study II and III** Reg.nr. 279/98; **Study IV and V** Reg.nr. 246/01.

SUMMARY OF FINDINGS

The findings of **Study I** describe the central theme as a conflict concerning intrusion into patients' privacy. The meaning of home was felt and perceived as a private domain for the preservation of the patient's personal identity and a place where he or she could exercise self-determination. The most important social signal permitting nurses and mental health care workers to enter a patient's home was the feeling of being invited. When they did not feel invited they felt like an intruder. The main dimensions of the theme 'Am I an intruder or professional' were identified as: 1) Intruding in the home of the patient; 2) Experiencing fluctuating boundaries; 3) Respecting or transgressing the right to privacy and 4) Situating mutual vulnerability. Visiting a patient in his or her own home often resulted in uncomfortable feelings concerning the professional role of the nurses and mental health care workers. When the patient did not 'willingly' open the door to let them in, the professionals saw themselves as an intruders or uninvited guests. A question that was often raised was: 'Is it possible to be a 'friend' and the same time approach the patient as a professional? Both the professional and the patient may have known they were not 'friends' but the professional role was not as clear in the personal atmosphere. When the patient did not let the nurses and

mental health care workers in, the professionals had to invent ways of gaining entrance. Another common therapeutic strategy, which also can be interpreted as an ethical principle, was to allow the patient to make and take responsibility for his or her own decisions. Encouraging the patient to make his or her own decision was believed to be of importance for increasing self-sufficiency. The professionals also felt they needed courage to 'wait and see' and have trust in patients' capacity to take responsibility for their own decisions. Caring for persons with long-term mental illness in their own home did not provide the same sense of security and support as working in the institution. Solving the question of whether to go alone or together with a colleague to the patient home was difficult, ethically. The patient could feel outnumbered and powerless if the staff came together. For both the patient and the staff this was perceived as a vulnerable situation.

The findings in this study indicated the need for a broader study of community nursing to identify whether the ethical dimensions in this study could be generalised to other professional care givers working in the homes of the patients suffering from long-term mental illness.

The response rate in **Study II** and **III** for district nurses was 54.1% (n = 393) and for psychiatric nursing staff, 64.6% (n = 267). Of the returned questionnaires from 386 district nurses, 377 were female, 2 male and 7 unknown. Of the psychiatric nursing staff, 87 were psychiatric nurses, 77 female, 8 male and 2 unknown and of the 168 mental health care workers who answered the questionnaire, 88 were female and 77 male and 3 unknown. Nineteen participants had other occupations. The percentage of participants aged 42 and over was 64.4% (n = 56) among the psychiatric nurses and 85.5% (n = 330) among the district nurses, while the corresponding figure for mental health care workers was 53% (n = 89). The mean values for length of professional experience show that the study group had more than 14 years experience. The mean length of experience for district nurses was 22.3 years (n = 367), psychiatric nurses 16.7 years (n = 82), and mental health care workers 14.0 years (n = 165).

The findings in **Study II** show that all three groups agreed that it is necessary for them to feel invited by the patients when providing care in the patient's home. The most consistent pattern revealed in the study was that district nurses and psychiatric health care personnel had different views on privacy and autonomy in providing home care to patients with mental illness. On the other hand, there were few differences in views between psychiatric nurses and

mental health care workers. However, the professional groups differed in views on their professional role. The district nurses indicated that they were more confident in their professional role but felt alone in crisis situations. In comparison with district nurses, both psychiatric nurses and mental health care workers felt confident in waiting for the patient's participation and would rather wait patiently before taking over the patient's decision making. Mental health care workers comprise the group that spends the most time in the patient's home in comparison with the other two groups. At the same time, this is the group that felt most insecure in their professional role and often felt insecure if they were by themselves while visiting a patient in his or her home. Differences in views according to gender should be treated with caution. Since there were few men in two of the groups (district nurses and psychiatric nurses), the differences in responses have to be regarded as representative for mental health care workers and not for the other two groups. However it is interesting that men more than women viewed themselves as intruders and that men were more unsure of their professional role than women.

The findings in this study strengthen the findings in **Study I**, i.e., that psychiatric personnel as well as district nurses daily had to deal with many ethical problems that rose in the care of mentally ill persons in their homes. These ethical problems seemed to have to do with the nurses and mental health care workers experiences of the home of the patient as a private sphere and their wishes to respect the patient's rights of integrity, autonomy and self-determination. The findings from this study raises the question if and how clinical supervision influences psychiatric nurses and mental health care workers ethical decision-making in home care.

In **Study III** the findings show that 50.9% answered 'yes' 47.9% answered 'no' and 1.2% did not answer the question 'Are you receiving clinical supervision at your workplace?'. There were significant differences in perception between those who received supervision and those who did not in regard to the assumptions stated in the questionnaire. One of main findings was that the supervised group's awareness that feelings can provide useful information about the patient's needs and the supervised group's ability to trust in their feelings. The influence of reported differences in clinical supervision on the health care professionals' decision-making was related to four ethical issues: emotional awareness, autonomy, integrity and respect for individual differences. The group who received supervision in their clinical nursing work reported that they felt more secure in their role in making decisions, felt safer in

their relationship with the patient and had a deeper insight into the meaning of security for the patient as well as for the care giver compared with the group who did not receive supervision. Both groups accepted the assumption that when they provided care in the patient's home they were there as a guest. However the group who received supervision were less accepting of this assumption than the group who did not receive supervision. Furthermore, the group who received supervision felt more confident in waiting for the patient's participation in the care process and believed that they had to respect the patient's decision not to let them in. Both groups agreed that 'to do good' meant to make decisions for the patient when his or her health might be threatened.

The finding in this study emphasises the need for clinical supervision for nursing staff and their ability to make decisions and to take care of severe mentally ill people in their homes. It also shows that clinical supervision may give nurses and mental health care workers a greater sense of self-esteem.

In **Study IV** the process of attempting to reconstruct mental health nursing from institutional to home care was shown as a pattern in the analysis of the data. In this interactive process changes occurred in the nurses' moral position, their assessment of the patient's needs and how the relationship was established.

In the institutional setting the nurses' description of their responsibility for the patients was identified as care managers which seemed to indicate that the nursing role was linked to an illness perspective. They described the ward as the staff territory where the nurse had the privilege and right to interpret the patient's need. This meant that it was important for the nurses to have control over the situation and the patient's health status and treatment by their nursing care. Their pre-conceptions of the patients' life and assessment of patient's needs were usually based on recognising the symptoms of illness and signs of dysfunction related to the patient's particular diagnosis. They also thought that the nursing tasks involved much routine work, such as administering medication and blood tests. When they looked back on their institutional experience, they seemed to characterise the patient as an object, someone they had to motivate to take his or her medication and to follow the decisions made concerning his or her care.

In the home care the nurses saw themselves as guests while at the same time they were there in their professional role. The nurses emphasised that their responsibility was based on a process of negotiation grounded in mutual trust and in their assessment of the client's functional resources. The goal for the nurses was to enhance the client's self-determination and gain a deeper understanding of insight into the patient's everyday life. Visiting the client in his or her home implied that they saw a new aspect of the client's every-day life, such as what home looked like, relationship to neighbours and others. For the nurses, working in the patient's home meant a much of freedom while at the same time an increase in responsibility and decision-making. The nurses also experienced in their new job the need to collaborate with many other caregivers, family members and others, which meant that the nurses found it necessary to be able to think and act independently. Compared to institutional care the nurses had less control in providing care in the patient's home, which they saw as the territory of the patient. If the patient got worse and the nurses had to intervene and decide what was the best for the patient, the nurses' moral responsibility and duty as a nurse became problematic.

The findings in this study illuminated the ethical problems of the psychiatric nurses to enhance the patient's autonomy and self-determination to make his or her own decisions while at the same time they had to exercise their responsibility for the patient's health. To make decisions against the patient's wish often meant that much time would be required to restore their relationship, which was based on mutual trust. To work in the patient's home meant much freedom for the nurses while at the same time there was less control of the patient's care and but increased responsibility for the nurses in their decision-making.

The study above raised the question if, and if it has, in which way the structural changes in the mental health nursing had influenced the nurses' independence or autonomy in the exercise of their profession. Which ethical problems will arise according to the patient and nurse? Whose independence and autonomy will be more valuable and how will the nurses handle their responsibility to the patients?

In the last study (V), three themes were constructed: 'Patterns of responsibility', 'Patterns of clinical judgement', and 'Patterns of control through support and supervision', all relating to the nurse's identity and their moral responsibility for their daily work. The nurses stated that their role as a nurse had developed into a more responsible one with more freedom. At the same time it had become a lonelier one as a result of being without other staff members to

turn to and confer with. One important obligation was to motivate the patient to take the medication prescribed. On the other hand, the nurses had the same obligation to support the patients' right to self-determination and to take responsibility for themselves. Home visits, often alone, gave the nurses a better understanding of the patient's problems and thus enabled them to collect data for an assessment. The nurses pointed to the ease of making hasty conclusions about the patient's home situation when their only meeting with the patient was at the out-patient clinic. To maintain a balance between respect for the patient's self-determination and the need to act against the patient's will if the patient got worse was felt to be very frustrating for the nurses.

The nurses had many ways of keeping control over the patients' state of health. From the support and supervision of the staff members the nurses received information and were able to get a full understanding of the patients' state of health. Other ways, which helped the nurses maintain their responsibility for the patient's health by providing a feeling of control, were visiting the patient's home, having telephone contact with the patient and his or her family. Creating a trusting relationship with the patient constituted the foundation for their common work. Working together and focusing on the patient's special problems could be described as a kind of supervision and support for the patient as the nurse took part of the patient's daily activities while at the same time acquiring a general view of the patient's ability to manage his or her daily life.

In this last study ethical problem relating to the nurses professional autonomy and their ability to take care of their patients' mental health was discussed. The nurses' moral responsibility for their daily work was related to their obligation to support the patient's right to self-determination and to take responsibility for themselves. By giving support and supervision to the staff members, the nurses were able to exert control in the same time as they uphold their responsibility for the patients' health.

GENERAL DISCUSSION

Methodological Considerations

The main purpose of the first study (I) was to identify and analyse ethical problems within the framework of the nurse-patient encounter in the patient's private home. To determine the psychiatric professionals' attitudes about how to carry out work in the patient's home and any ethical problems that may arise in their daily work, focus groups were used for data

collection. By using focus groups participants' own experiences about the topic could be revealed without interrupting the participants with too many questions. This was an advantageous choice based on the assumption that it can be easier to share personal experiences of ethical problems with others who have similar experiences. In a one-to-one interview, the interviewee could feel a sense of self-reproach in their interaction with patients and thus be reluctant to share this with the interviewer. As this study showed, all of the nurses and mental health care workers interacted actively in the discussion about their common work situation and ethical problems. A disadvantage in using focus groups is that the interaction is contextual, limited to the experiences of the persons participating in the study. However, new questions emerged from the analysis of the focus group interviews that facilitated the progress of the research.

Methodologically, since the first study involved a small group of participants, there was a need to validate the findings in a broader investigation. By constructing and using a questionnaire (II and III) in a fairly large sample, consistency was found between the results of the qualitative and the quantitative data that was collected. Unfortunately, as often is the case with questionnaires, there were drop-outs (response rate 57,9%). There could be several explanations to this, yet the most important may be the nature of questions asked. Ethical questions can rarely be answered 'right' or 'wrong' or be given a numerical value. Moreover, ethical questions may be too complex to be investigated by a questionnaire or the questions may not have been relevant for all of the participants. Since the questionnaire was sent to all nurses and mental health care workers in an area, it is likely that many did not have contact with people suffering from mental illness. The instruction in the questionnaire was that only nurses who had contact with these patients, should respond to the questionnaire. Viewed from this perspective, the response rate may be realistically rated.

In the last two studies (IV and V) interviews have been used for data collection. By using the constant comparative method of grounded theory for data analysis, the interview questions were open and consistent with the method of grounded theory. Compared to the first study, the participants came from different regions of the country and one interview was via telephone. By using one-to-one interviews, questions that arose both from the first study and the survey study, could be further explored in a constant comparative process of analysis.

Discussion of Findings

Changes in Perspective; from Institutional to Community Care

The aim of the Mental Health Reform in Sweden was to improve the life of the mentally ill person, and to increase the possibilities they would have to participate in community and the social life. Today, about eight years after the carrying out of the Mental Health Reform, one may state that there has been and still is much work and changes to do. The results of the follow-up by the National Board of Health and Welfare (1999) showed a lack of consensus between the two organisations claiming to present areas of knowledge or responsibility. However this can also be the result of lack of delineation between the responsibilities of Social Services for support and those responsible for the psychiatric non-institutional care. Markström (2003) also states that the views of the Mental Health Reform as to autonomy and liberty of choice for persons with psychiatric dysfunctions have been difficult to defend, since these views are often associated with abandonment and the unsatisfactory state of things.

The transition from mental hospital care to community based home care has been a long, and for many patients as well as psychiatric personnel, a painful process in Sweden. Today, the large mental hospitals are closed; this does not mean that nothing is happening. There are processes being carried out constantly between institutional care and community care, as well as between psychiatric care and other caregiver, family members, friends and so on. However, the main purpose of this thesis has been to explore nurses' and mental health care workers' experiences of how changes in the organisation of psychiatric care have influenced their daily work and how these changes may have contributed to ethical problems.

The specific context in focus was the home of mentally ill persons. What was unknown was the process that nurses and mental health care workers got through as they moved from institutional care to home care. In this process the concern was their experience of this process and how their experiences influenced their own role as professionals and their nursing of severe mentally ill persons in their homes. It was also unknown what ethical problems arise when the care will be carrying on in the patient's private home. In which way clinical supervision might help nurses and mental health care workers to handle problems that arise in the nursing of severe mentally ill people was the final question. To obtain an understanding of these problems, nurses and mental health care workers who had earlier worked in institutional settings and now worked in the community in the patient's home were examined. In so doing, research methodologies that revealed the changes in perspective were used. The different

tasks and obligations for nurses working in the community care have been studied before (see for example Reda 1995; Hedelin & Svensson 1999; O'Brien 1999; MCKenna *et al.* 2000) but what the changes in the professional roles and ethical problems in the working situations of nurses and mental health care workers have meant for those professionals and the consequences have not. Symbolic interactionism (Blumer 1969; Charon 1998) provided the framework for carrying out this study as symbolic interactionism focuses on the relationships that make up society or in other words, an organised process of ongoing interaction among individuals in the society. This is congruent with the nurses' and mental health care workers' experiences, as the members of both groups are believed to view themselves in the context of relationships with other staff members and patients rather than as isolated individuals.

The psychiatric nurses and mental health care workers described experiencing their roles as professional care givers to be changed. In **Study I** psychiatric nurses and mental health care workers described their difficulties in finding their new roles as professional. When entering the home of the patient they often felt as an intruder or an uninvited guest. The patient's home symbolized personal privacy and integrity for the nurses and mental health care workers (**I** and **IV**), which implied it was important for the personnel to be invited before entering the patient's home. In **Study IV** the nurses illuminate the differences in working in the institutional care where their role was clearly defined as opposed to working in the home of the patient where their roles were much more diffuse, fluctuating between to be a guest, personal or professional. These fluctuating boundaries within themselves influenced their boundaries with the patient and their mutual relationship to each other. To respect the patient's right to privacy and to make and take responsibility for their own decisions was an important therapeutic strategy for the psychiatric personnel (**I** and **IV**). This principle of autonomy, meant that self-determination and self-choice was difficult to uphold especially when a patient became worse and the nurse had to decide whether to take over the responsibility for the patient's health or not. This created a dilemma for many nurses. (**I** and **IV**) The nurses knew they had an obligation in certain situations to make decisions for the patient, at the same time they were concerned about their often vulnerable relationship with the patient. Though the nurses in **Study IV** described themselves as well educated they asserted quite strongly their need for a new type of knowledge in order to make relevant assessment and decisions for the patient. Even if the nurses and mental health care workers were aware of the importance to the patient to take care of him or herself, it was obvious that many of the patients had difficulty dealing with their everyday life.

That the ethical problems concerning the patient's home as personal and private which created the conflict between the nurses' professional role and the patient's right to integrity, and to self-determination, found in **Study I**, could be relevant for a larger group of psychiatric personnel and district nurses were confirmed in **Study II**. The result showed that psychiatric health care personnel and district nurses had different views on issues concerning privacy and autonomy. In contrast, the differences in views between psychiatric nurses and mental health care workers were few. The psychiatric personnel were stronger in their agreement, their needs to be invited, and their feeling to being an intruder, than district nurses. The district nurses were more confident in their role but felt more alone in crisis situations compared to the psychiatric personnel.

According to Schopp *et al.* (2003) privacy concerns a person's decision to deny or grant access to the self, including among other things personal space and territory. It also includes social privacy, which means an individual's ability and efforts to control social contacts. As mentioned before by Hydén (1996), for people that have lived for a long time in an institution the home will not be a private space, because it will also be a working place for the psychiatric personnel who are required to provide the patient a safe, secure environment.

Similar to Peplau (1991), the psychiatric nurses and mental health care workers in this thesis emphasised the great importance to building a trusting relationship with their patients. What Peplau does not conceptualise, as this thesis illuminates, is the ethical nature of this relationship. Since the nurse-patient relationship is not equal (Hummelvoll (1996; Tschudin 1986) this may be one explanation of the issues concerning privacy and the dilemma that nurses and mental health care workers experience about their professional roles when providing care in the patient's home. According to Peplau one of the nurses' many roles related to the patient is the role of a stranger. 'Am I a guest or intruder, a private person or a professional nurse', which was discussed in both **Study I** and **Study IV**. In the first meeting with the patient, the nurse is a stranger to the patient; what happens at their first meeting may well have a great meaning for their relationship today and in the future and of course, by visiting the patient in his or her home, their mutual relationship may be uncertain for both of them. Another explanation of the nurses' and mental health care workers' experience of their unclear roles may have to do with their decision-making. As Curtin and Flaherty (1982) points out, the nurse is moral agent of the patient and responsible for his or her own actions; however, as Hummelvoll (1996) also points out, sometimes there are clients who need

beneficence and guidance in periods when they cannot function autonomously by themselves. The nurses in this thesis knew they had a responsibility and obligation to take care of and make decisions for the patient in situations where they had to limit the patient's autonomy and self-determination. This is also pointed out by Pellegrino (1985); Martinsen (1990); Lützn (1997; 1998); Olofsson *et al.* (1998); Marangos-Frost and Wells (2000); Haglund *et al.* (2003) In addition, they also have the obligation to foster and promote growth of the personality (Peplau 1991) i.e. to encourage the patient to make his or her own decisions (cf. Lützn 1990; Sarvimäki 1994; Crowman *et al.* 2001), to protect the patient from harm, Lützn (1998) and according to Hummelvoll (1996) to solve his or her own health problems. This meant that the nurses were required to both support the patient's self-determination and to make decisions for the patient when he or she changed to a poorer state of health. Lützn (1998) questions if the principle of autonomy should be uphold in all types of situations. Lützn asserts that in order to give 'good' care, the freedom of some patients may need to be restricted.

The alteration of the nurses between working in the home of the patient today instead of working in an institutional is described in **Study IV**. In this process the nurses saw themselves as negotiators instead of care-managers and saw the patient as a client, which implied to the nurses that they should be sensitive to the client's lifestyle in order to support health and acceptable social behaviour. According to McKie and Swinton (2000) it is in the community that one learns virtues and comes to understand the gestures that make for a good life. It is also, as McKie and Swinton states, in the community that one discovers who one is as an individual. One way to support the patient may be, as stated of McKie and Swinton, in friendship, allowing for the development of a 'conversational' model of care i.e. as when the nurses in **Study IV** visited the patients in their home 'talking with the client about everything often over a cup of coffee'. It also meant for that the nurses established a mutual trust with their clients. This trust is, according to Meize-Grochowski (1984), often very fragile but despite their easily damaged relationship, the nurses dared to let the client make his or her own choice and determine his or her own life. Helping the patient to take responsibility for their own life is similar in view to that of Liaschenko (1994) who states that *the goal for the nursing is not merely in helping patient stay alive or even healthy but in helping them to have a life. To have a life is to have a sense of agency, to occupy social and political space, to live a temporally structured existence, and to die* (p.24).

The Meaning of Home from an Ethical Perspective

The home and the meaning of home for psychiatric nurses and mental health care workers has been the main thread for this thesis. The question has been what does it mean for psychiatric personnel to work in the patient's privacy home and what does it imply for nursing? The symbolic meaning of home has been discussed earlier in this thesis but how the home as a private domain where the patient's autonomy or integrity ought to be exercised has influenced psychiatric nursing has not.

For many patients, such as those in this thesis, who have been cared for in an institutional ward for many years, their new home may be very important. To have one's own home suggests that one is like anyone else in the community. However, as Liaschenko (1994) states, rooms and places have an identity for most people; *places are symbolic constructions remaining us of our connections to others, to the natural world and animals, and to projects – they give meaning to our lives* (p. 19). If places and rooms have the same symbolic meaning for patients suffering from a severe mental illness, one cannot be sure, but may guess that, apart from who you are the home symbolizes something for all human beings. Hydén (1996) states that the home constitutes a cultural institution that sometimes serves as a social arena, associated with persons that will be very near i.e. the family or friends. As an institution, the home is associated with a private sphere separate from public life. For people that have lived for a long time in an institution the home will not be first and foremost a 'private castle' i.e. a protection against the environment of the society. It will be as Hydén states a home in the crossroad between the institutional world and the home, a weak, an insecure 'life-world', a social arena where the housing by the psychiatric personnel will offer stability, initiative and way of direction. With their help it will be possible for the person with mental illness to develop his or her 'life-world'. Even if it is a private sphere for the patient, as Hydén points out, it is also the nurses' and mental health care workers' place of work and it can also be the place of work for many other caregivers. As the nurses in this thesis often expressed 'it is the patient who lives there, who has to desire what to do, and as another nurse stated 'the home is the territory of the patient'. However, at the same time, it is the nurse who has to take care of the patient and who is responsible for his or her every-day life. As Liaschenko (1994) states, protecting and fostering patient's autonomy, or agency as concept that Liaschenko prefers to use, these vulnerable patients are particularly fundamental features of the moral work of nursing practice. Hydén (1996) states that many people who have spent a long time in institutional care, are missing 'the life-world' that normally is guiding the human being when he or she creates his or her home. For these people, the hospitalisation will be a part of their

own identity. When they are discharged from the institution they will bring this identity with them, out into the society. In their new home people who have spent a long time in the institutional care, are forced to recreate or develop a social identity and existence i.e. the 'life-world'. To care for persons with long-term mental illness in the home implies for the psychiatric personnel that they are to support the patient in his or her ambition to create his or her own 'life-world' by, as autonomous, professional practitioner acting as an intermediary of their knowledge to the patient.

One's own home can, as Després (1991) points out, be seen as a place for freedom, control and security. For patients with a mentally illness it can also become a place of isolation, especially for the patient that has spent a long time in institutional care with lack of contact with family and friends, as is the case for many of the patients in this thesis. The professional personnel may be the only continuous contact the patient has with other persons. Despite this, one question to be asked for the future is, when most of the care will be transferred to the community and the patient's home, what will happen with the patient's home as a privacy space? This question is similar to a study by Noddings (1995) who discusses the costs of medical care, which has grown enormously, especially in the care of severely handicapped, chronically ill and terminally ill persons. What happens with the family members and the home as a private space when care for physical or mentally ill persons in the future to a large extent will be provided in the patient's home. This is not only an economic question it is also a moral one.

Support and Supervision Essential for Nursing and a Strategy of Control

The importance of supervision and support for nurses and mental health care workers has been examined in this thesis (III and V). In **Study III** the purpose was to investigate in what way clinical supervision can influence nurses' and mental health care workers' ethical decision making in home care. The result showed that nurses and mental health care workers who received supervision felt more secure in their relationship with the patient and in their decision making. They also were better able to wait for the participation of the patient in his or her own care and were of the opinion that it was important to respect the patient's own decision. Making decisions for the patient in critical situations was seen as problematic for most of the nurses but the nurses who received supervision felt less uncertain in such situations. However, for the group who received supervision and the group who did not, 'to do good' implied making decisions for the patient when his or her health may be threatened,

but for the group who received supervision a higher degree of threat was required. When visiting the patient in his or her home, the group that received supervision perceived that they had intruded the home of the patient, while at the same time they thought that they intruded upon the patient's privacy by giving injections in the patient's home in a higher degree than the group who did not receive supervision.

Earlier studies show the importance of clinical supervision for the development of the professionals' identity, competence skill and ethical attitude (Severinsson 1995, 1996). The supervision as a reflective process with the aim of increasing the personal and professional growth of the participants is emphasised by Skoberne (1996); Öhlén and Segesten (1998).

Several studies also describe the importance of clinical supervision to promote the developing of professional identity, including increased emotional understanding and ability to express feelings by integration of theoretical knowledge, practical competence and experiences (Holm *et al.* 1998). A study by Severinsson (1998) describing nursing students' views of supervision programme showed that the students felt more secure in severe cases; were more sensitive to the patient's needs, took more responsibility in clinical settings and showed that the students' ability to reflect upon difficult situations increased. This may support the importance of clinical supervision for all nurses and mental health care workers and may also be an explanation for the differences between the two groups in **Study III**. In a study by Andersson and Glesner-Andersson (1987) the authors maintained that ethical dilemmas arise in a variety of relationships in a health care organisation, such as conflicts between health care professional and patients, or between a professional and another employee. Conflicts were often about the patient's right to privacy, information and the patient's competency to consent to treatment or neglect treatment. The decision-making process depends on the decision-maker's knowledge, experience and flexibility (Berggren & Severinsson 2000) and as the authors state, increased self-assurance implies increased courage to make decisions. As was showed in **Study III** nurses and mental health care workers are intimately involved inpatient care and are confronted with numerous ethical problems that may arise in the patient's home. The home was seen as a sphere of privacy, and at the same time, the personnel's working place. This meant that the nurses and mental health care workers had to strike a balance between respecting the patient's integrity and the home of the patient as a sphere of privacy and their own obligations and responsibility to take care of the patient's health. This concept and substance of integrity as well as the ethical principle of autonomy is also emphasized in a

study by Berggren and Severinsson (2003) to be frequently reflected on in supervision. The feeling of being an intruder (**I, II, III**) when entering the patient's home may have to do with the nurses and mental health care workers wishes to fulfil the intention of the Mental Health Reform to respect the patient's right to privacy and thereby enhance the quality of care of the patient. Feelings of violating the patient's integrity by giving injections in his or her home may also have to do with the nurses' respect for the patient's integrity and endeavour to strengthen his or her self-determination and decision-making. But as Sarvimäki (1988) states, to give an injection to a patient also implies to communicate to the patient that she care about his welfare and wants to do him good. The signification of supervision to support nurses and mental health care workers in their professional development is also stated in a study by Öhlén and Segesten (1998). In this study, (Öhlén & Segesten 1998), the professional identity is viewed as integral part of the nurse's personal identity. For nurses and mental health care workers, (**III**) to get support and the ability to reflect upon ethical problems together other professional nurses may strengthen their professional identity and provide the possibility of meeting ethical problems in a better way. This may explain why nurses and mental health care workers who received supervision are better able to wait for a patient to participate on their own instead of making the decision for the patient. In a study by Bucknall and Thomas (1997) the results show a clear link between decision-making, responsibility and autonomy. Even if the nurses in **Study III** had the power to make decision for the patient if the patient had deteriorated, it was important for the nurses, as long as possible, to let the patient keep the responsibility for him or herself by thinking I have to 'wait and see'. In situations like this the nurses expressed an inner conflict between their own responsibility for the patient's health and their wish to satisfy the patient's need for self-determinations and privacy. However, nursing care is, according to Sarvimäki (1988), *an expression of a value according to which it is morally good to help other people towards something good, and a norm that tells you to act in such a way* (p. 463).

Sharing experiences and reflecting over problematic situations in clinical supervision may help nurses and mental health care workers to achieve a deeper understanding of their ethical problems and a personal development of their professional role (Agélii *et al.* 2000).

In the final study (**V**) the autonomy of the nurses was discussed. The findings showed that nurses experienced that their role had developed in a more responsible one, freer, but at the same time this freedom had exposed them to loneliness in their role as responsible nurses.

Being responsible meant for the nurses, being responsible for the treatment and motivation of the patients in taking their medications. It also meant supporting and motivating patients in taking responsibility for themselves and their daily life. The nurses experienced professional autonomy in their assessment-making as well as in planning their work in agreement and together with the patient. By supporting and supervising the staff, the nurses received information as well as a sense of control in full knowledge of the patient's state of health, aimed at reducing the stigma attached to mental illness.

To have professional autonomy is, as discussed earlier (Bucknall & Thomas 1997) important and linked to decision-making and responsibility. Feeling responsible for the patient's health is a moral value that influences nurses and mental health care workers in their daily nursing. To be responsible for many patients and co-workers the nurses in **Study V** had to trust their co-workers and to find a way to obtain a sense of control over the situation. By support and supervision their own co-workers enabled the staff to have the opportunity to narrate and reflect on their caring for the patients (Holst *et al.* 1999) (V) in order to increase the quality of care (Hyrkäs and Paunonen-Ilmonen (2001) (V). At the same time the nurses achieved a sense of control and an understanding of their area of responsibility. However their own responsibility for the patient and the nursing (V) was as important as the patient's rights to live their own life in accordance with the Mental Health reform (1995). This meant for the nurses a need to achieve a balance between themselves, their responsibility for the patients and the wishes of the patients wishes to live. As Antrobus (1997) states, the goal of nursing is to enhance the quality of life defined by the patient, who according to Antrobus becomes the expert on his or her own health and their life. Since caring for patients in **Study V** involved severely mentally ill persons, many nurses found it necessary to have some form of control over the patient's every-day life. By support and supervision over the patient in **Study V**, the nurses achieved this sense of control or ability to monitor the patient's state of health at the same time as they helped the patient to manage their daily life and to get integrated into the society. This is similar to a study by Godin and Scanlon (1997) where supervised discharge, stated as a law by the Mental Health Act in UK, is discussed. The nurses in the study by Godin and Scanlon (1997) experienced themselves as becoming state agents of social control as a result of the supervision register and supervised discharge instead of to being the patient's advocate, which they saw as their central role as nurses. Feeling and thoughts (V) experienced by the nurses in their relationship with the patient may later, consciously or unconsciously, be

brought into and reflected on by the nurses in their own supervision like a parallel process (Playle & Mullarkey 1998).

Normalizing and integrating the patients, (Nirje 2003) into the society, according to the Mental Health Reform, has been and still will be a long process, from the institutional care to home care. This process includes, from the patient's point of view, according to Pickens (1999), establishing and performing meaningful activities, being well, safe, free and independent. From the views of Social Services this means to provide the mentally ill person with the opportunity of participating and being a part of the community.

MAIN CONCLUSIONS

To care for severely mentally ill persons in their home is still a rather new kind of care in Sweden in comparison with many other countries in the world. From the psychiatric nurses' and mental health care workers' point of views, caring for patients with mental problems means, to having less security than in the institutional care. Furthermore, there is a lack of models for nurses and mental health care workers to help them carry the ethical principles into actions when every situation is specific and unpredictable. In the institution, clear rules and regulations and nearness to support and guidance connected with moral position provide an important prerequisite to the care of the patient. Kopelman (1989) states that moral problems in clinical psychiatric care often arise because there are different opinions about persons' right to self determination about their actions, when their capacity to understand, argue, choose or act becomes worse because a mental illness. On the other hand the nurses and mental health care workers were aware of and saw it as important to maintain the patient's home as a sphere of privacy, which may have been one reason for their unclear roles and their feeling of being an intruder. These complex moral problems may be sensitively discussed by clinical supervision offering the professional a possibility to reflect over their feelings of being an intruder and other moral problems that arise in their every-day work in the patient's home.

There are few research studies illustrating the psychiatric personnel's experience of ethical problems related to home care of persons with long-term mental illness. Therefore, the result of this thesis consists of new knowledge that will have implications for the future:

Implications for Practice and Research

Questions that have to do with providing care in the patient's private home are complex. This thesis may help nurses and mental health care workers to recognise and discuss similar ethical

problems, which occur in their own working place and to share their experiences with each other. Even if the nurses in this thesis considered themselves experienced and well educated psychiatric nurses, with many years of experience in working with mentally ill persons, they believed that they needed new knowledge from other disciplines such as social sciences and ethics. This may indicate that nurses and mental health care workers working in the community in the patient's home need to create a new nursing model involving a clear collaboration with other caregivers. It is of importance that further knowledge as to how patients with severe mental problems may be integrated into the community be developed. It is also importance to change the attitude of fear, ignorance and intolerance towards people suffering from mental health problems.

SUMMARY IN SWEDISH (svensk sammanfattning)

VÅRD I HEMMET AV PERSONER MED EN LÅNGVARIG PSYKISK STÖRNING

Sjuksköterskor och mentalskötares erfarenheter av hur förändringar i organisationen av den psykiatriska verksamheten har förändrat deras arbete

Bakgrund

Sedan de stora mentalsjukhusen slutligen avvecklades i mitten på 90-talet har betydelsefulla ideologiska, organisatoriska och ekonomiska förändringar skett inom den psykiatriska vården i Sverige. Liknande förändringar i form av en avinstitutionisering av den psykiatriska vården har även skett i övriga Europa och USA. En logisk konsekvens av detta är att antalet vårdplatser inom den slutna vården har minskat med ca 80% från slutet av 1960 till mitten av 1980. År 2000 var det totala antalet vårdplatser på de psykiatriska klinikerna omkring 5.500 i Sverige.

Förändringar inom den psykiatriska vården från institutionell vård till vård i hemmet har möjliggjort för människor med en långvarig psykisk störning (psykiska funktionshinder) att bo hemma och leva ute i samhället med stöd från professionella vårdgivare.

Föreliggande avhandling innehåller fem delstudier, tre kvalitativa och två kvantitativa studier. Deltagarna i studierna består av kliniskt verksamma distriktsköterskor, psykiatriska sjuksköterskor och mentalskötare. Samtliga deltagare har hela eller delar av sin yrkesverksamhet förlagd till patientens hem.

Övergripande syfte med avhandlingen

Det övergripande syftet med denna studie var att undersöka sjuksköterskors och mentalskötares erfarenheter av hur förändringar i organisationen av den psykiatriska vården påverkar deras dagliga arbete och hur dessa förändringar kan ha bidragit till etiska problem. Den speciella kontexten i fokus var psykiskt störda patienters hem. Underförstått i syftet var antagandet att resultatet av denna forskning skulle kunna användas för att utveckla utbildning- och mentor program för sjuksköterskor och mentalskötare, som är anpassat till kommunal psykiatrisk hälso- och sjukvård.

De specifika syftena med studierna var att:

- I Identifiera och analysera etiska problem inom ramen för mötet mellan sjuksköterska-patient. Fokus var inriktat på hur sjuksköterskor uppfattar och omsätter i handling så väl patientens autonomi som hur de försvarar sina handlingar.
- II Undersöka distriktsköterskors, psykiatriska sjuksköterskors och mentalskötares syn på frågor relaterade till privatliv och autonomi vid vård i hemmet av personer med en långvarig psykisk störning. Ett ytterligare syfte var att identifiera huruvida skillnader i syn kan relateras till ålder eller kön.
- III Undersöka på vilka sätt klinisk handledning kan påverka distriktsköterskor, psykiatriska sjuksköterskors och mentalskötares etiska beslutsfattning vid vård i hemmet av människor med en långvarig psykisk störning.
- IV Undersöka och beskriva de psykiatriska sjuksköterskornas erfarenheter av hur strukturella förändringar har påverkat deras interaktioner i utövandet av vård i hemmet av patienter med en långvarig psykisk störning.
- V Beskriva de psykiatriska sjuksköterskornas erfarenhet av hur ett förändrat fokus på psykiatrisk vård i Sverige, från behandling inom slutenvård till öppna vårdformer, har påverkat deras professionella autonomi.

Eftersom ett övergripande fokus för denna forskning var sjuksköterskors och mentalskötares erfarenheter, som ett resultat av deras interaktion med patienten, samt etiska frågor som uppstår i denna interaktion, har symbolisk interaktionism används som forskningsperspektiv. I överensstämmelse med och relaterat till detta perspektiv återfinns den symboliska innebörden av hemmet, omvårdnadsrelationen, samt hur de som vårdpersonal moraliskt skall förhålla sig till sin professionella kunskap.

Föreliggande doktorsavhandling fokuserar på sjuksköterskors och mentalskötares upplevelser av hur organisatoriska förändringar inom den psykiatriska vården påverkat deras yrkesroll och vård av svårt psykiskt störda patienter i hemmet.

Metoder

För insamling av datamaterial till **Studie I** har tre fokusgrupper bestående av 5-6 gruppdeltagare (psykiatriska sjuksköterskor och mentalskötare) i varje intervjuats. Analysmetod har varit en konstant jämförande metod (constant comparative method) enligt grounded theory. Utifrån resultatet i **Studie I** har ett frågeformulär utformats med 20 frågor i form av antaganden. Frågeformuläret har skickats till samtliga distriktsköterskor, psykiatriska

sjuksköterskor och mentalskötare i ett landsting i Sverige (**Studie II och III**). SPSS har använts för att analysera de returnerade enkäterna och för att jämföra skillnader mellan de tre grupperna användes en chi-2 test, en icke parametrisk testmetod. **Studie IV och V** består av intervjuer med 11 psykiatriska sjuksköterskor, som arbetar i hemmet hos patienter med en långvarig psykisk störning. I **Studie IV** har intervjuerna analyserats med en konstant jämförande metod (constant comparative method) enligt grounded theory och i **Studie V** har en kvalitativ innehållsanalys använts som analysmetod.

Resultat

I **Studie I** identifierades fyra teman; 1/ *tränga sig på i patientens hem*, 2/ *upplevelse av fluktuerande gränser*, 3/ *respektera eller överskrida gränser*, 4/ *benägenhet för ömsesidig sårbarhet*. Patientens hem symboliserade privatliv och integritet, vilket innebar att vårdpersonalen ofta upplevde att de trängde sig på, då de besökte patienten i dennes hem. De upplevde också att deras yrkesroll blev otydlig, det vill säga att gränsen mellan den professionella relationen och vänskap kunde upplevas som otydlig för såväl patienten som vårdpersonalen. Oklarheten bestod av huruvida de skulle utöva sin auktoritet, som är förenad med deras professionella ansvar för patientens hälsa, eller respektera patientens rätt till självbestämmande. Att vårda svårt psykiskt sjuka patienter i hemmet gav inte vårdpersonalen samma känsla av säkerhet och stöd som inom den slutna vården. Deras valmöjlighet att besöka patienten tillsammans med en kollega eller att gå ensam till patienten vägdes mot patientens integritet och autonomi det, vill säga patientens eventuella känsla av underlägsenhet och maktlöshet, samt deras gemensamma sårbarhet.

Det mest framträdande resultatet i **Studie II** visar att distriktsköterskor och psykiatrisk vårdpersonal har olika syn på frågor som rör patientens privatliv och autonomi. Däremot är skillnaden i åsikt mellan psykiatriska sjuksköterskor och mentalskötare liten, vilket kan förklaras med att såväl de psykiatriska sjuksköterskorna som mentalskötarna har sin huvudsakliga arbetsfunktion i och erfarenhet från den psykiatriska verksamheten. Den psykiatriska vårdpersonalen upplevde sig i högre grad som inkräktare samt mer osäker sin yrkesroll i jämförelse med distriktsköterskorna då de besökte patienten i dennes hem. Emellertid kan skillnaden mellan de två grupperna bero på att de psykiatriska sjuksköterskorna och mentalskötarna är mer försiktiga i sin önskan att besöka en patient, då de är osäkra på om deras omvårdnadsidentitet och deras "nya" professionella roll är "godkänd" av patienten. Den psykiatriska vårdpersonalen instämde i högre grad i betydelsen av att

invänta patientens medverkan och att respektera patientens beslut i jämförelse med distriktssköterskorna. De ansåg också att ”göra gott” innebär att ta över ansvaret för patienten, när detta är nödvändigt för patientens hälsa. Mentalskötarna är den yrkesgrupp som känner sig mest osäker i sin yrkesroll, mer jämlik med patienten och i mindre grad som gäst i patientens hem. Distriktssköterskorna känner sig säkra i sin yrkesroll, men uttrycker en osäkerhet i sin beslutsfattning i samband med kritiska situationer.

Resultatet av **Studie III**, visar signifikanta skillnader mellan den personal som fick handledning och de som inte fick handledning på sin arbetssituation. Den vårdpersonal som fick handledning, kände sig säkrare i sitt beslutsfattande, säkrare i sin relation till patienten och hade förvärvat en djupare insikt om betydelsen av trygghet för såväl patient som personal i jämförelse med gruppen som inte hade tillgång till handledning. Gruppen som fick handledning hade större förmåga att invänta patientens medverkan i vården och att respektera patientens egna beslut. De ansåg också ”att göra gott”, som en etisk värdering, innebär att det var moraliskt riktigt att ta över ansvaret för patienten när det visade sig vara nödvändigt för patientens hälsa.

Resultatet i **Studie IV** visade på en förändring i perspektiv från en sjuksköterske-kontrollerad vård relaterat till ett sjukdomsperspektiv mot en mer klient-centrerad vård. Detta innebär att moraliska värderingar, bedömningar av patientens behov och sättet att möta och etablera en relation med patienten hade förändrats. Att vårda svårt psykiskt störda patienter i hemmet innebär för sjuksköterskorna att stödja patienten i dennes beslutsfattning och ansvar för sitt dagliga liv. Detta i sin tur innebär att sjuksköterskornas ansvar var fokuserat på bedömning av patientens vardagsliv istället för dennes sjukdom. Då sjuksköterskorna arbetade inom den institutionella vården upplevde sig själva som läkarens assistent, det vill säga någon som hade till uppgift att bedöma patientens behov av behandling och omvårdnad. I patientens hem fick sjuksköterskorna en mer allsidig bild av patientens funktionella resurser, vilket hjälpte dem i deras beslutsfattning, i idealiska fall i samarbete med klienten. Inom den institutionella vården sågs patienten som ett objekt, någon som sjuksköterskorna hade till uppgift att motivera till att ta sin medicin och rätta sig efter de beslut som fattats rörande deras vård och behandling. I vården av patienten i hemmet var det viktigt för sjuksköterskorna att skapa en allians med patienten, att lyssna, vara kreativ och känslig för patientens behov och önskningar.

Sjuksköterskornas upplevelse av en ökad frihet i sitt arbete innebar samtidigt ett ökat moraliskt ansvar i samband med beslutsfattning. I de situationer då de tvingades fatta beslut mot patientens önskan kände de sig ofta mycket ensamma i sin beslutsfattning.

I resultatet av **Studie V** framkom tre huvudteman; 1/ *mönster av ansvar*, 2/ *mönster av klinisk bedömning*, 3/ *mönster av kontroll genom stöd och handledning*. Inom den slutna vården upplevde sjuksköterskorna det som viktigt att ha total kontroll över såväl patienter som medarbetare, till skillnad mot den öppna vården där sjuksköterskorna måste lita på medarbetarnas förmåga och kompetens. Genom att ge stöd och handledning till sina medarbetare erhöll sjuksköterskorna samtidigt viktig information, som var till hjälp i deras bedömning av patienternas hälsa, det vill säga genom att ge stöd och handledning till sin personal kunde sjuksköterskorna samtidigt upprätthålla en form av kontroll över sitt ansvarsområde. Möten med patienten i dennes hem, miljö och kultur, ofta tillsammans med någon av patientens familjemedlemmar eller andra för patienten betydelsefulla personer, var viktigt och medförde ofta att kommande möten underlättades. Att stödja och handleda patienten i att klara av att bo i sitt hem, innebar för sjuksköterskorna samtidigt en form av kontroll eller "koll" på patientens egen syn på och insikt om hur de klarade av sitt vardagsliv. Att besöka patientens i dennes hem gav sjuksköterskorna en helhetsbild av patientens sociala livssituation, vilket var av betydelse för bedömning av patientens senare möjlighet till integrering i samhället.

I sjuksköterskornas berättelse framkom att rollen som sjuksköterska upplevdes som friare i deras nuvarande arbete, vilket innebar mer tid och ett givet område att arbeta inom. Den ökade friheten innebar samtidigt en större ensamhet med ökade krav och trötthet som följd.

Slutsatser och betydelse

Resultatet av psykiatrireformens genomförande i form av såväl organisatoriska som vårdideologiska förändringar indikerar:

- att flera etiska problemsituationer uppstod i samband med att vården av svårt psykiskt störda patienter flyttade från institutionell vård till vård i hemmet.
- att det finns en skillnad mellan distriktsköterskors och psykiatriskt skolad vårdpersonals uppfattning och hantering av etiska problem som uppstår i samband med vård i hemmet,

vilket kan bero på att vårdformen är relativt ny för den psykiatriska vårdpersonalen till skillnad från distriktsköterskorna, samt att distriktsköterskorna har en utbildning anpassad för vård i hemmet.

- att handledning har en betydelse som stöd i den professionella rollen att lösa etiska konflikter som uppstår i den nära relationen till patienten.

- att den förändring som har skett i och med psykiatrireformens genomförande har inneburit att vården idag i större utsträckning än tidigare utgår från patientens/klientens behov, med en integrering i samhället som mål.

Sammanfattningsvis kan framhållas att studien indikerar att vården av patienter med svåra psykiska funktionshinder i hemmet kräver specifik kunskap det vill säga ny kunskap från andra discipliner som samhällsvetenskap och etik. Detta kan innebära att psykiatriska sjuksköterskor och mentalskötare, som arbetar i patientens hem behöver skapa en ny form av omvårdnad, som involverar ett tydligare samarbete med andra vårdgivare och med inriktning mot en integrering av patienten i samhället.

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Appendix I

Assumptions/items

1. I need to feel invited by the patients in order to care for them in their own home.
2. I often feel like I am intruding when I visit patients in their homes.
3. It feels like a violation of the patient's integrity to give an injection in his or her own home.
4. I often feel insecure in my professional role when I provide home care.
5. I often feel alone in my decision whether to intervene or 'wait and see' in a critical situation in a patient's home.
6. I often feel insecure if I am by myself while visiting a patient in his or her home.
7. When I provide home care, I am there as a guest.
8. I think that my professional role and the role of a friend overlap when I am providing care in a patient's home.
9. When a patient refuses to take his or her medication it is my responsibility to see to it that the patient is seen by his doctor.
10. In most situations, I feel confident in waiting for the patient's participation.
11. Providing home care means to keep a balance between respect for the patient's right to make own decisions and my responsibility for the well being of the patient.
12. If a patient refuses to co-operate, the responsibility for the consequences is the patient.
13. I think that there should always be two persons who go home to a patient.
14. If a patient does not want to let me in, I think that it is a decision that I have to respect.
15. To provide home care means that the relationship between myself and the patient is on equal grounds.
16. When I am visiting patients in their home, it is the patient who makes up the rules.
17. In most cases, a patient feels more secure if two nurses are there at the same time.
18. 'To do good' means to make decisions for the patient when his or her health may be threatened.
19. Whether to go alone or with another nurse should be a free choice for nurses to make when they provide home care.
20. My decision to wait and see before I intervene is based on my opinion of what is best for the patient.