

Institution of Neurobiology, Nursing Sciences and Society

Department of Nursing, Karolinska Institutet

Features of Swedish municipal elderly and
psychiatric group dwelling care after the 1990s the
health-care reformations

Lisbeth Porskrog Kristiansen



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To my dearly beloved
children Sebastian and Maja
and to my love Erik

Abstract

Features of Swedish municipal elderly and psychiatric group dwelling care after the 1990s the health-care reformations

The over all aim of this thesis, consisting of six studies, was to explore features of the Swedish municipal elderly and psychiatric group dwelling care after the 1990s health care reformation era. Focus is primarily on the municipal psychiatry. The mixed design, used here, employs both quantitative and qualitative methods. In **paper I** all psychiatric municipal care providers' caring approaches towards a fictitious elderly long-term client with schizophrenia was explored through a questionnaire. Approximately 70 per cent of the nurses had a symptom-orientated approach which focuses on correction of disease-related symptoms towards the clients. If the nurses had been working for less than 10 years they tend to have a more person-centred approach, which indicate that long-term job experience might affect the care providers' attitudes towards the clients negatively. In **paper II** the existence of a visible pattern in care providers' attitudes and their arguments for the preferred approaches towards a fictitious elderly person (Mrs NN) with a diagnosis of long term schizophrenia was investigated. Forty-eight (73%) of the respondents (n = 66) emphasized the importance of meeting Mrs NN within the framework of reality and the need as a care provider to focus on the present or the 'here and now' when they communicate with her. Twenty-seven per cent stressed the importance of meeting Mrs NN within the framework of a person-focused approach to the same question. The majority was unable to see the client as anything else than what the diagnosis said. The purpose of **paper III** was to investigate twenty care providers' experiences of job satisfaction, whose work involves taking care of clients suffering from dementia and elements of 'aggressiveness' and 'psychomotor agitation'. The individual narrative interviews indicated exposure, insufficiency, a feeling of not being valued and doubt, as well as respect and importance and devotion towards the residents. The interpretation of the narrations showed that an ambiguous and complex core-theme: 'job satisfaction as a process moving between breaking down and occasionally building up the working person'. The care providers experienced that they only got support from each other and the positive relationship with colleagues was mentioned as the primary reason for care providers' continuing to work at the group dwellings. The organisation and resident behaviours were seen as very negative. Just a small degree of support was experienced from the side of the organisation. In **paper IV** the aim was to investigate how clients at two psychiatric group dwellings spend their time using the Patient Activity Classification (PAC). The clients who displayed a predominant picture of negative symptoms were left alone for 84% of the day. Of this 29.5% could be explained by their illness. The results indicated that, even if the dwellings had a creative climate, there was a negative process in terms of care providers' well-being with a moderate degree of emotional exhaustion, depersonalisation, and personal accomplishment. In **paper V** the aim was to investigate the connections between the time spent together and the care providers' opinion of client behaviour and social functioning in community-based psychiatry. Twenty nine clients' were assessed by 30 care providers, who answered the Global Assessment of Functioning Scale (GAF) and the Positive and Negative Syndrome Scale (PANSS). The PAC instrument revealed that clients spent, an average of 60.8 per cent of time alone, while only 20 per cent of their daily time was spent with the care providers. Four groups of clients were created based on the GAF scores, high and low, and a PANSS scores, high and low, related factor analysis. The clients in the group judged as having a low level of social functioning in combination with high degrees of psychiatric symptoms, receive less staff attention (18%) and are the clients who spend the most time alone (73.4%). Finally, in **paper VI**, the professional role of care providers in social psychiatry is in the midst of a period of role re-definition towards a recovery, client-focused perspective. In three focus group interviews 13 care providers discussed their views and experiences of their professional role at a social PGD (Psychiatric Group Dwelling) context when caring for clients suffering from severe mental illness. Thematic content analysis was conducted. Four themes were formulated: 'Being a

general human factotum not unlike the role of parents', 'Having a complex and ambiguous view of clients', 'Working in a mainly "strangled" situation', and 'Feeling overwhelming frustration'.

The findings showed that when aspects of the care were related to Kari Martinsen's ontological theory of care, including a practical, relational- and moral dimension, the moral dimension seemed to cause the care providers suffering. Furthermore, a figure is presented to illuminate how the findings contributing to different levels of the features of municipal EGD (Elderly Group Dwelling) and PGD care can be understood and related to each other. There is a hope that the results of this research could be used as a foundation to develop educational- and "contact" programs for care providers and others with the interpretation and the power to decide. This might, in a longer perspective, lead to a positive development for all identified levels, with special focus on a higher degree of experienced quality of life for both elderly and psychiatric clients.

Key words: Care providers, care reform, dementia care, municipality, nursing, psychiatry
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List of publications

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

- I Hellzén, O., Kristiansen, L., & Norbergh, K.G. (2003). Nurses' attitudes towards older residents with long-term schizophrenia. *Journal of Advanced Nursing*, 43(6):616-22.
- II Hellzén, O., Kristiansen, L., & Norbergh, K.G. (2004, a). Being an outsider: nurses' statements about a vignette of an elderly resident with schizophrenia diagnosis and dementia behaviour. *Journal of Psychiatric and Mental Health Nursing*, 11(2):213-20.
- III Kristiansen, L., Hellzén, O., & Asplund, K. (2006). Swedish assistant nurses' experiences of job satisfaction when caring for persons suffering from dementia and behavioural disturbances. An interview study. *The International Journal of Qualitative Studies on Health and Well-being* (in press).
- IV Hellzén, O., Kristiansen, L., & Norbergh, K.G. (2004, b). Living in a group dwelling: how do residents spend their time in a psychiatric group dwelling? *International Journal of Nursing Studies*, 41(6): 651-9.
- V Kristiansen, L., Dahl, A., Asplund, K., & Hellzén, O. (2005). The impact of nurses' opinion of client behaviour and level of social functioning on the amount of time they spend with clients. *Journal of Psychiatric and Mental Health Nursing*, 12, 719-727.
- VI Kristiansen, L., Hellzén, O., & Asplund, K. (2006). Left alone – Swedish nurses' experiences of being a care provider in a social psychiatric dwelling context in the post-health-care restructuring era. A focus group interview study. Submitted for publication.

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LIST OF ABBREVIATIONS

BPSD	<i>behavioural and psychological symptoms of dementia</i>
CCQ	<i>creative climate questionnaire</i>
EE	<i>expressed emotions</i>
EGD	<i>group dwelling for elderly</i>
GAF	<i>global assessment of functioning scale</i>
GD	<i>group dwelling</i>
JS	<i>job satisfaction</i>
MBI	<i>maslach burnout inventory</i>
PAC	<i>patient activity classification</i>
PANSS	<i>the positive and negative syndrome scale</i>
PGD	<i>psychiatric group dwelling</i>
SD	<i>estimated standard deviation</i>
SSA	<i>social services acts</i>

INTRODUCTION

This thesis focuses on features of municipal elderly and PGD care in the post health care reformation era. Approximately 273,100 elderly clients and 43,000–46,000 psychiatric clients are not able to manage living on their own and are dependent to varying degrees on municipal support, some to the extent that they need to live at manned group dwellings (GDs) (The Swedish National Board of Health and Welfare, 2005a,b,c). About 104,800 persons aged 65 years and older, corresponding to 15.2 per cent, spent their lives at “special housing for the elderly” in 2004 (The Swedish National Board of Health & Welfare, 2005b). Approximately 13.5 per cent of them suffer from dementia (The Swedish National Board of Health & Welfare, 2005b, p12). There are different categories of special housing for the elderly, such as GDs, blocks of service apartments, nursing homes, elderly accommodation and homes for the elderly. In spite of this, there are no unequivocal definitions among the municipalities and they use the designations more or less as they please (The Swedish National Board of Health & Welfare, 2005b). GDs and nursing homes are two designations for housing for the elderly, which are estimated as having the highest percentage of elderly people, 80 per cent, with cognitive disabilities, such as lack of memory and orientation, and therefore the highest level of staff dependence (The Swedish National Board of Health & Welfare, 2001). Morally and scientifically, a decent society has a responsibility continuously to explore the living conditions of exposed and most dependent individuals (Martinsen, 1994, pp. 93-94) and, whenever possible, to increase their chances of a good life, because society’s human qualities ought to be measured through the quality of life of its weakest members, as the essence in all morals is the responsibility people take for others’ humanity. This is also a measurement of society’s ethical standards (Bauman, 2002, p. 100). Psychiatry as a scientific and societal institution must always be questioned and re-evaluated (Svensson & Olsson, 1994, pp. 68-69). This examination naturally involves the parties that contribute to the living conditions, which, in this case, include the care providers. For this reason, features of municipal EGD and PGD care in the after the 1990s health care reformations are investigated by examining municipal care providers’ attitudes towards, judgments of and approaches to clients. Moreover, the care providers’ experience of job satisfaction, working climate and burn-out and of being care providers working in community-based psychiatric or dementia services after the implementation of the Care of the Elderly Reform 1992 (SFS, 1991) and Mental Health Reform (SOU 1992:73) adds further information. Further, investigations of the way the clients spend their daily lives, which also includes measurements of mutual time spent together by the care provider-client/user, provide important information.

During my time as a psychiatric nurse working on hospital wards, I occasionally came in contact with patients who normally lived in sheltered accommodation, group dwellings, but who, in an acute phase of psychiatric or dementia disease, were admitted to the ward. In this connection, care meetings to draw up further plans for the care of individual clients were organised between representatives from the county council and

the municipality. I often heard how difficult the municipal health-care providers felt it was to deal with situations at the community-based psychiatric and dementia group dwellings. Through their descriptions, it became clear that the good intentions of transferring responsibility to the municipality, the lowest and nearest public service level through the implementation of the Care of the Elderly Reform in 1992 and Mental Health Reform in 1995, sometimes placed the staff in difficult situations. Sometimes the staff said that they did not know what to do. Due to the specific municipality law, the Social Services Act (SSA) (SSA, 2001:453), the community care providers are not legally entitled, as psychiatric hospital staff sometimes are, to use force to prevent harm. All municipal care must be based on free will and in accordance with the wishes of the clients. Obviously, there were legitimate differences between the municipal and the hospital-based care and services. Further, it seemed that the hospital-based psychiatry, due to its physical location, history, culture of hierarchical traditions (Lindholm, 2005, p. 137) and clearly defined role expectations, was more given and regulated and, in that sense, more comprehensible and predictable for the care providers, compared with that of the municipality. This triggered questions about what the characteristics of care in this specific municipal context actually are. When caring for vulnerable groups of people, like those in dementia and psychiatric care, the fundamental human value that says that we are obligated to each other and entangled in each others' lives, from which the need to take care of each other originates (Lögstrup, 1966, p. 196; Martinsen, 1994, p. 63), becomes even more obvious. Life involves a definite normative dimension, there is something in life that we absolutely must care about and that we cannot violate (Lindseth, 2001). It is not possible to think of care without thinking of caring (Martinsen & Wärness, 1991). Caring means creating bonds and being in relationships through interdependence, according to transcendental anthropology; in this way, a person develops his or her independence (Lögstrup, 1966; Martinsen, 1994, pp. 64-66). Further, according to Martinsen (1989), the concept of care consists of a relational, a practical and a moral dimension. The closely related nursing is logically also seen as a relational profession, where ethical awareness must precede all kinds of care (Peplau, 1952; The Swedish National Board of Health & Welfare, 2005c), and the essence of psychiatric nursing is an interactive process (Peplau, 1952) based on mutual emotional influence (Barker, Reynolds & Stevenson, 1997). Seemingly, the form and quality of the inter-relatedness between the care providers and the clients affect the satisfaction with care and well-being of these two groups. Caring is first and foremost an attitude and the care providers always have to choose either to do or be for the other person, or not to do so. Nevertheless, life preconditions as well as care always exist in a certain time and at a certain place and it is not possible to ignore the historicity and the societal aspects (Mounier, 1952).

Disposition of the thesis

The thesis began with an exploratory study in order to obtain an overview of the dominant carer approach of all the mental health-care providers from seven different units in one specific municipality (**Paper I**). This paper distinguished care providers

from GDs and care providers from the support group, care providers that visited the clients in their private homes, and examined possible differences in approach. As this was a questionnaire study including (n = 75) respondents with fixed categorical statements, it was both interesting and necessary to allow the participants to develop their answers, in their own written words, relating to the way they reasoned and argued in relation to their own carer approach (**Paper II**). The purpose in **Paper II** was to investigate whether the mental health-care providers' approach could be explained in terms of the clinical picture or the fact that the resident had a diagnosis. Further, it was also of interest to investigate and describe the job satisfaction of nursing staff working at two municipal GDs for people suffering from dementia with behavioural disturbances (**Paper III**). In the following **Paper IV**, the purpose was to investigate how clients spent their time at two municipal GDs, which led to further considerations, such as whether there were connections between the time spent together and the care providers' opinion of client behaviour and social functioning, which was also the purpose of **Paper V**. This generated further questions about what it was like to work in the municipal context and the purpose of **Paper VI** was therefore to obtain an understanding of care providers' views and experiences of being a care provider in the municipal PGD context.

Choice of design strategy

No single method or even combination of methods can capture the whole complex reality (Foss & Ellefsen, 2002). The choice of method was guided by the research question. Due to the complexity and multidimensionality of the studied phenomenon, "features of municipal elderly and PGD care in the post health care reformation", an integrated design with mixed methods was chosen with the aim of describing and capturing some of the innumerable perspectives (*cf.* Benner, Tanner & Chesla., 1996; Creswell, 2003; DePoy & Gitlin, 1999; Foss & Ellefsen, 2002; Polit & Beck, 2004). The specific epistemological position put forward in this thesis views knowledge acquired from quantitative and qualitative approaches not as irreconcilable pools of knowledge but rather as different positions on a continuum of knowledge (Foss & Ellefsen, 2002). This position attempts not to ignore the paradigmatic concerns and tries not to reduce science simply to a matter of following certain methodological rules (Morgan, 1998a). The positional intention in this thesis is that both paradigms and therefore both quantitative and qualitative methods are given equal emphasis (Foss & Ellefsen, 2002). A qualitative design is suitable in fields where no or little knowledge is available. Qualitative designs were chosen in **Papers II, III and VI** in order to obtain a deeper insight, understanding and interpretation of the participants' own perspective on their subjective thinking about care and experiences of being a care provider in the post health care reformation era. This provided a certain kind of in-depth knowledge, which is in accordance with the epistemological assumption of the naturalistic paradigm that the researcher is seen as a co-creator of findings, as these are creations of interactive processes, and it is also possible to acquire knowledge by taking part in peoples' life-world through speech and texts. For this reason, the phenomena under study are

interpreted within their context (Creswell, 2003, pp. 4-16; DePoy & Gitlin, 1999; Polit & Beck, 2004, pp. 13-16).

Behind the epistemological assumptions of the naturalistic paradigm lie the basic ontological assumption that realities are subjective, socially constructed and multiple, which then leads to axiological assumptions that the researcher is value bound and that the researcher has pre-understandings and expectations that influence him/her and have to be raised to consciousness and discussed (Creswell, 2003, pp. 4-16; DePoy & Gitlin, 1999; Kvale, 1996; Lincoln & Guba, 1985; Polit & Beck, 2004, pp. 13-16).

In order to obtain a broad and general view of the surface when it comes to staff attitudes towards an elderly fictitious person suffering from both schizophrenia and dementia and the way psychiatric clients spend their days, together with the connections between their symptoms and time-sharing, quantitative designs were used in **Papers I, IV and V**. The quantitative design rests upon the ontological assumption of the positivistic paradigm that, independently of us, one objective reality exists and the epistemological assumption that it is possible to reveal and discover reality and the researcher is seen as objective and non-influencing and, finally, the axiological assumption that it is possible and desirable to remain value free and biases are to be held in check, while hypothetical-deductive methods are applied (Creswell, 2003, pp. 4-16; DePoy & Gitlin, 1999; Polit & Beck, 2004, pp. 13-16). In spite of this, value-free research is more or less impossible, as it is always based on assumptions, which are per se an expression of value.

BACKGROUND

Developments in psychiatry – a societal perspective

The developments that have taken place in psychiatry, including de-institutionalisation, have previously been widely described in different kinds of publication (Bengtsson-Tops, 2001; Brunt, 2002; Hellzén, 2000; Markström, 2003; Pejler, 2000) and, for this reason, this paper only gives a brief summary, which is thought to be necessary in order to contextualise the municipal care in the post health care reformation. The phenomena that we know as mental diseases differ from somatic diseases in some significant ways; to the extent that the theoretical grounds for the categorisation have been questioned. The creation of mental diseases as a concept and category has been primarily due to social and/or political considerations, rather than a scientific basic, while psychiatry is bound to social and cultural systems of norms and values in ways that makes its functions in society political in an absolutely different way from that of medicine in general (Svensson & Olsson, 1994, p. 69). There has been a shift in the way the segregation and integration of people suffering from mental disease is described (Markström, 2003).

Isolation of the “insane” – a process of segregation

Historically, as leprosy disappeared in the late Middle Ages, the group of “insane” individuals eventually assumed both their place in the asylums and the role of society’s scapegoat (Foucault, 1973). In Sweden in the 17th and 18th centuries, people suffering from mental disease were confined to a life under constant surveillance in large asylums (Foucault, 1973). For security reasons, these self-sufficiency asylums were often situated and isolated outside the cities, in order to protect the people who were ill from inappropriate outside impact (Foucault, 1973; Ottosson, 1995, pp. 21-23; Svensson & Olsson, 1994). It was also considered to be a social responsibility to hide away the morally undesirable “deviants”, “insane” persons or “idiots” from society (Foucault, 1973). Through isolation at institutions, a process of segregation was started by separating them from us. Madness became a specific social category that was made the object of a certain discourse and a certain discursive practice. Psychiatric diseases became a separate area of science and the object of professionalisation and the foundation of huge apparatuses and large institutions. This development mirrors the societal power and control interests (Foucault, 1973).

“Moral treatment”

As an expression of criticism towards the dominant position of the institutional system, and the effectiveness of the institutions, an alternative psychiatric treatment, based on psychological theories, developed outside the traditional institutions in the 18th century (Jones, 1972). William Tukes implemented what was called “moral treatment” in England, highlighting the therapeutic value of kindness when treating persons with

mental illnesses (Shorter 1997, pp. 20-21). “Moral treatment” was determined by what was regarded as correct and normal behaviour and consisted of encouraging and praising the patient when he or she behaved “properly” (Foucault, 1995). Through behaviour modifications, the aim was to “re-teach” the patients to become good citizens with good behaviour adapted to a normal life (Markström, 2003, pp. 86-87). In the health-care context, the application of a Foucauldian perspective saw the introduction of the concept of the “medical gaze” as one way of thinking about the social control functions of the medical profession.

From bathing treatment, through lobotomy to the medicalisation of psychiatry

Increased knowledge about the structures of the brain and functions was the starting point of the nature scientific era in psychiatry in the mid-19th century. Different forms of showering and bathing treatment were used for the purpose of calming patients (Qvarsell, 1981, p. 49-50). At the beginning of the 1930s, the first psychiatric clinic, mental hospital, was established near Lund Hospital and this was followed by a similar development in the rest of Sweden (Ottosson, 1995, p. 21). During the same period, some new somatic therapy methods, such as insulin shock treatment, psychosurgery and electroconvulsive therapy, were utilised (Pejlert, 2000, p. 12). The introduction of psychotropic drugs, and chlorpromazine in particular, in the 1950s, reduced the patients’ psychotic symptoms and made them more adaptive to the social environment (Bengtsson-Tops, 2001). This resulted in shorter periods of hospitalisation, a quieter and more humane ward life, where the rehabilitation generally consisted of ADL (activities of daily life), weaving, pottery, woodwork and painting (Pejlert, 2000, pp. 13-14).

Anti-psychiatry

In the 1960s, a series of critical investigations started to reveal the negative effects on patients. They included Goffman’s (1973) report on “the total institutions”, including a highly temporal order, which constituted a specific context-bound form of the stigmatisation process and socialisation situation, while the context of stigma is everyday life (Belfrage, 1995, pp. 34-35; Svensson & Olsson, 1994, pp. 99-105). During the 1960s and 1970s, reformist criticism of psychiatry that questioned some of the principal elements in what was understood as a traditional psychiatric world of ideas, where the basic idea was that psychiatric problems must be understood and interpreted in terms of disease, was accepted (Svensson & Olsson, 1994, pp. 63-67). One criticism was that the ruling biological/medical view of man ought to be replaced by another theoretical, non-biological perspective – for example, by a psychoanalytical/psychodynamic or existentialistic perspective. At the same time, the “revolutionary” criticism, anti-psychiatry, was based on the total rejection of the idea that human expressions can be understood as disease (Cullberg, 1999, pp. 403-404; Svensson & Olsson, 1994, pp. 63-67). Existentialistic phenomenology attempts to characterise the way a human being experiences the world and him/herself and this is

primarily a question of linking the individual experiences within the framework of that person's whole life (Laing, 1976, p. 13). The person suffering from schizophrenia is a victim of a destructive climate of communication and of "situations of checkmate" in the family and in the social environment. Psychiatry perpetuates this destructiveness through objectifying positioning towards the so-called psychiatric illnesses (Laing, 1967; 1976). The foundation of the category of psychiatric disease is a giant historical-scientific and social mistake and most of what can be termed psychiatry strives at the state's or society's oppression of individuals (Szasz 1961; 1963; 1970). According to Scheff's (1966; 1970) labelling theory, the medical model's theoretical descriptions and conceptualisations of the so-called mental illnesses ought to be abandoned and should instead be seen as a residual category of crime against the social norms. Jones (1962) points at the risk that increased medicalisation within psychiatry might turn social problems, which are otherwise regarded as political and moral, into medical problems. The medical discipline is tending to become the significant institutional performance of social control, even more important than religion and legislation (Zola, 1975; 1978).

De-institutionalisation – starting a process of integration

De-institutionalisation, which began in the 1960s (Topor, 2001, p. 37), can be seen as both a process of development and a result of development. At the same time, it can be seen as a sociological concept that considers deeply rooted social arrangements, roles and processes, intending to change not only the outer structure of mental health care but also the view of people suffering from long-term mental illness (Meeuwisse, 1997) to a direction in which these persons are expected to be integrated into the surrounding society (Markström, 2003). During the last few decades, psychiatric care in Europe has been de-institutionalised (Markström, 2003). Magnusson (2003) claims that, after the mid-1990s, there have been significant ideological, organisational and economic changes in psychiatric care as a whole. The scientific developments within psychiatry, such as the above-mentioned introduction of psychotropic drugs, are said to be one of the main reasons why mental hospitals were eventually shut down (Markström, 2003, p. 90). In addition, more socially oriented models, such as Maxwell Jones' "the Therapeutic Community" (which is described in more detail below), have been emphasised as accelerating the de-institutionalisation process (Hansson, 1994, p. 83). In connection with de-institutionalisation, more and more patients, who would otherwise have been expected to spend their whole lives within closed mental health care, now had an opportunity to find a way back to the surrounding world and to develop their own lives with the support of other, new institutions that developed to support them (Topor, 2001, p. 152). De-institutionalisation meant that mentally ill people became more visible and started to live in society, which led to a gradual shift from a medical/biological concept to a way of thinking in which the relationship between society and the individual is at the forefront (Markström, 2003, p. 139). The de-institutionalisation of psychiatric care has therefore resulted in a movement away from the segregated approach towards psychiatric disease, which was expressed in the mental

hospitals and institutions (Svensson & Olsson, 1994, pp. 63-64). In 1960, there were approximately 34,000 patients in Swedish mental hospitals (Markström, 2003, p. 112). In 2000, on the other hand, the number of psychiatric in-hospital beds was reduced to 5,565 and the reduction in in-hospital beds is still in progress (The Swedish National Board of Health & Welfare, 2002). A great deal of criticism has been levelled at this process.

The rapid restructuring of mental health care was naïve, the economic costs have been enormous and no single country can state that de-institutionalisation has been implemented in a satisfactory manner (Belfrage, 1995, p. 35). Belfrage adds that the combination of the ideology that mentally ill people must be out in society, standing on their own, and the huge economic downsizing of the public services has also been shown to be devastating, due to the tendency that it will always affect the weakest group the most (Belfrage, 1995, p. 35).

Social psychiatry

The broad concept of social psychiatry can be understood as an area of science, a certain specific way of organising, and certain forms of organisation and some sociological and social-psychological theories impact on psychiatric activity, ideology and approach and, moreover, on the historical tendency to develop (Hansson, 1994, pp. 84-85). In the context of social psychiatry, the way treatment creates a mutual relationship in which the client and the care provider are the creators of each other's life situations becomes obvious (Mosher & Burti, 1995). Internationally, the concept of social psychiatry is often equal to community psychiatry (Hansson, 1994, pp. 86). Maxwell Jones has described social psychiatry and its potential through "the Therapeutic Community" fundamentally to change the preconditions of life for mentally ill persons and the opportunity to find a socially acceptable place in society. The therapeutic community is a socially based model upgrading the significance of daily social living, in which the social community has the opportunity to contribute to positive changes due to the involvement of democratic organisational structures on different levels, so that new humanitarian and equality ideals improve human relationships (Hansson, 1994, pp. 86-97). In other words, it is the total social environment, both the place and the people, that is assumed to have a healing effect on mentally ill persons (Mosher & Burti, 1995, pp. 120- 122).

The 1990s – reformation of elderly and mental health care

Several societal reforms were implemented during the 1990s and this has led to comprehensive changes and re-structuring that have had an impact on both the framework and the content, as well as the costs of health care (Anell & Hjortsberg, 2001). According to March and Olsen (1989), the implementation of a reform in society does not simply consist of an instrumental order, it also implies a moral order.

Responsibility transferred from the county councils to the municipalities

In 1990s, the Swedish government set up a so-called parliamentary commission, under the name of “the 1995 Mental Health Reform” (SOU 1992:73), with the aim of investigating the situation of mentally ill persons in the whole country. It found that these people were regarded as a very under-privileged group, one of the losers in the welfare society that ought to be given priority (SOU 1992:73). It was emphasised that people with long-term mental illness must be seen as active and capable of knowing how they want to live, but that they often experience difficulty speaking on their own behalf (The Swedish National Board of Health and Welfare, 1992). Partly because of their illness and partly because of the way society reacts to their presence, they experience great difficulty getting what they want or need without special assistance (SOU 1992:73). As a result of the Care of the Elderly Reform (1992) and the Mental Health Reform in Sweden (1995), the responsibility for people with dementia and long-term mental illness, whose medical treatment had been completed, was transferred from the county councils to the local authorities (Knutsson & Pettersson 1995).

The local authorities, the municipalities, became responsible for the care up to nurse level, as well as being responsible for adequate forms of living and activities (Knutsson & Pettersson, 1995). Small “homelike” types of accommodation were seen as ideal (Shepherd, Muijen, Dean & Cooney, 1995). The transition from hospital-based to community-based psychiatric services, including professional support and help for persons with severe mental illness both in their own homes and in GDs as clients, was completed (Magnusson, 2003). In the Social Services Acts (SSA) (2001:453). This responsibility is regulated with the explicit goal that, when the services are implemented, this should be done with respect to people’s own decisions and integrity in a way that strengthens democracy and solidarity. The services should also be provided in a way in which normalisation and a holistic approach are upheld. Two of the goals for community-based psychiatry are to work towards normalisation and integration into the surrounding society for the sake of the severely mentally ill persons (Markström, 2003). Approximately 0.7 per cent of the adult population, between 43,000 and 46,000 people, in Sweden suffer from severe mental disease leading to a high level of functional disorder, which creates a need for community services (The Swedish National Board of Health & Welfare, 2005a,c).

From severe mental disease to mental dysfunction – a changed view?

Schizophrenia is a disease that implies suffering both for the individual and for his or her next of kin, which can be expressed in general feelings of lack of control and coherence, a struggle with existential anguish, loneliness, anxiety, doubt and thoughts of being socially rejected (Hansson, 2006; Lauber, Keller, Eichenberger, & Rossler, 2005; Lindström, 1995; Nilsson, 2003; Wright, Gronfein & Owens, 2000). Schizophrenia is the most severe form of psychosis, with a poor prognosis, and it often leads to difficulty performing everyday activities and establishing satisfactory interpersonal relations and,

as a consequence, the patients suffer from social isolation (Brusén & Hydén, 2000; Cullberg 1999; Erdner, Nyström, Severinsson, & Lützén, 2002; The Swedish National Board of Health & Welfare, 2005a). The psychopathology of people suffering from schizophrenia may comprise a lack of energy and motivation, withdrawal and false sensory perceptions (Glynn, 1998).

The risk of developing schizophrenia is approximately one per cent, even if the risk is increased by heredity (Belfrage, 1995, p. 117). The dominant etiological point of view today is that schizophrenia is a form of biologically caused brain damage (Belfrage, 1995). The disease often leads to a “breakdown of the self”, with a loss of awareness of the self and the wholeness of personality, a changed conception of reality, or disorganisation of the psychic functions (Ottosson, 1995, pp. 167-174; SBU, 1997, p. 11). There are four primary symptoms of schizophrenia; autism, disturbances of associations, ambivalence and affective disturbance (Cullberg, 1999, p. 217). The person is often primarily affected by positive symptoms, so called type I, such as hallucinations, delusions, abnormal thought content and bizarre behaviour, or by negative symptoms, so called type II, such as a lack of energy, lack of pleasure and affective flattening (Ottosson, 1995, pp. 175-176). Persons with schizophrenia are often very vulnerable and sensitive, with difficulty handling stress, and the rehabilitation aims to help them regain their abilities and functions (Malm & Rutz, 1996). In Sweden today, the term used to categorise persons with long-term mental illness is mental dysfunction (The Swedish National Board of Health & Welfare, 1999); recognising that the term “mental dysfunction” may not be common in many countries. The change in terms can be interpreted as a change in focus, from illness to (dys)function, but also as an attempt to provide appropriate services that will allow these individuals to live a life that is meaningful and satisfying. In spite of this, Evelius (2003, p. 18) states that the medical-disease perspective still rules, because the municipalities still point out the medical advantages of the individual life situation, which is irrelevant for municipal evaluations, and talk about people with “psychiatric long-term illness” or “persons with mental illnesses”. From this illness perspective, the obvious solution is to get healthy and be cured and this perspective includes a dimension of viewing the individual as an objective, being the object of efforts and not a subject with rights. The actual implementation of dysfunctional thinking within the social services and other organisations is difficult and time consuming (Markström, 2003, pp. 228-229). It is understood that the interests of people with “mental dysfunction” are generally best safeguarded if they can speak for themselves, but this might result in denial that takes this opportunity away from some individuals (The Swedish National Board of Health & Welfare, 2003, pp. 56-57)

Dementia disease

The prevalence of dementia varies substantially in different countries. In the United States, approximately 10% of the population older than sixty-five years of age suffers from dementia. This number should be compared with 6.4% in Europe and 3.49% in China (Alvarado-Esquivel, *et al.*, 2004). Dementia is expressed in three areas: (a)

neuropsychological, or cognitive deficits, such as loss of memory, aphasia, apraxia and agnosia; (b) dementia and behavioural and psychological symptoms of dementia (BPSD); and (c) difficulty carrying out the activities of daily living (De Deyn, Katz, Brodaty, Lyons, Greenspan, & Burns, 2005). BPSD can be clustered into one of five syndromes: psychosis, aggression, psychomotor agitation, depression and apathy (Finkel, Costa e Silva, Cohen, Miller & Sartorius, 1996) and comprise signs and symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia (Verkaik, van Weert, & Francke, 2005). The prevalence of BPSD is described in various studies reporting figures of up to 92.5% of patients at some point during their illness (Robert *et al.*, 2005).

Suffering from dementia means having problems relating to oneself, to others and to the world (Norberg, 1994; McDaniel, Edland, & Heyman, 1995). Moreover, reductions in relation to understanding, interpreting and acting in relation to oneself and others might lead to communication problems (Hallberg, Norberg & Eriksson, 1990).

Development of group dwellings in Sweden – re-institutionalisation

It has been shown that traditional institutional care can contribute to behavioural disturbances, such as confusion, wandering and difficulty adapting to surroundings, for people with dementia. In order to provide an alternative to institutional care, small homelike settings, where people with dementia can experience “at-homeness” (Zingmark, Norberg, & Sandman, 1993), known as GDs, were established in Sweden in the 1980s for people suffering from dementia (Asplund *et al.*, 1988, Wimo *et al.*, 1991). One of the basic ideas of GDs is to offer to the opportunity for social community with each other, which is extremely important for people suffering from dementia (Kitwood, 1997). In psychiatry, this flexible form of group living developed primarily from the demands made by younger groups of mentally dysfunctional people who wanted to live by themselves, but who also had access to competent staff (Markström, 2003, p. 104). GDs can be seen as an intermediate level of care between home care and nursing homes (Wimo, Asplund, Mattsson, Adolfsson, & Lundgren., 1995). The small local alternative units, dwellings, implicitly constitute the treatment in which the environment should be characterised by calm, stability and predictability, as well as consistency, distinctiveness and acceptance (Mosher & Burti, 1995, pp. 122-126), as its primary functions are to support and confirm and, at a later stage, to involve, socialise and co-operate (Gunderson, 1978).

The concept of users/clients

In a political science context, the users of public services are sorted into different concepts, depending on the opportunity for choice and influence the person is assumed to have. As a customer, it is possible to *exit*, meaning that one can choose between several alternatives. The concept of users means that the person does not have an opportunity to choose an alternative product, but that the person can still, in different ways, have an impact on the present product (Möller, 1996). For the users of social

services, the opportunity to *exit* is often limited (The Swedish National Board of Health & Welfare, 2003, pp. 17-19). At the same time, a user has also been defined as a person, who in a personal and close way is affected by a municipal service and who usually continuously utilises the service for a relatively long period of time (Ds 1991:18). Markström (2003, p. 121) claims that, regardless of large ideological and economic differences between the municipality and the county councils, a shift from the traditional patient perspective to a user perspective has taken place.

Aspects of elderly and psychiatric care provision

Caring for somebody and taking care of somebody is an existential prerequisite associated with life itself (Martinsen, 1994). Based on care providers' experience, there appear to be many similarities between dementia care and mental health, as being close to persons with human manifestations of suffering in a challenging and difficult care context is demanding and sometimes frightening for care providers (Graneheim, Isaksson, Ljung & Jansson, 2005; Hallberg & Norberg, 1990; Hellzén, 2000; Rossberg & Friis, 2003; Verkaik *et al.*, 2005). Psychiatric nursing is primarily an interactive and communicative activity (Lützén & Schreiber, 1998; Peplau, 1952) and it often involves relating to people whose lives appear chaotic and lacking meaning (Aanderaa, 1995, pp. 7-11). Working in an environment with severely mentally ill patients, where the staff risk being exposed to violence, humiliation and sexual harassment, the staff might feel tormented, questioned and helpless (Hellzén, 2000). Working as a psychiatric care provider may involve contact with acutely disturbed patients who are violent, suicidal or self-harming. Suicidal behaviour, outer and inner aggression and violence are all demanding actions, which risk being interpreted as manipulation by care providers (Rossberg & Friis, 2003) if they do not recognise and respond to them as communication (Laing, 1976). When it comes to psychiatric clients, who had been violent towards care providers, Carlsson, Dahlberg, Dahlberg and Ekebergh (2006) report that, when the clients are met by "detached impersonal", the encounters are experienced as uncontrolled and insecure and might end in a violent incident. However, if they are met by "authentic personal" in an undisguised, straightforward and open way, and they sense that unrestricted respect which the staff would show to any other human being, the result is not likely to be violent (Carlsson *et al.*, 2006).

Hallberg and Norberg (1990) have described a demanding view of the so-called "screamers" within dementia care. The care of people with BPSD has, for example, been characterised as feeling powerless versus capable and feeling rejected versus accepted (Graneheim, Isakson, Ljung and Jansson, 2005) and this causes tremendous distress both for the patients and for their caregivers (De Deyn *et al.*, 2005, Verkaik *et al.*, 2005). Limited body space and excessive environmental stimuli can trigger aggressive behaviour and so respecting privacy, identity, autonomy and relating to security are central, intertwined phenomena, which often simultaneously conflict with each other and this must be taken into account when interacting with a person with dementia and BPSD (Graneheim, Norberg & Jansson, 2001). By tradition, hostile behaviours by clients against caregivers have been termed "aggressive or problem

behaviour” and have not been regarded as “violent acts”, even though research has shown that many care providers actually regard these incidents as violence (Gates, Fitzwater, & Meyer, 1999; Gates, Fitzwater, & Succop, 2003). Furthermore, care providers who are assaulted experience emotional reactions, such as anger, sadness, frustration, anxiety, irritability, fear, apathy, self-blame and helplessness (Fitzwater & Gates, 2002, Hagen & Sayers, 1995, Pillemer & Hudson, 1993). Moreover, the staff find it difficult to cope with the clients who are aggressive/hostile and display deliberately difficult behaviours (Brodaty, Draper & Low, 2003).

On the other hand, Saveman, Åström, Bucht and Norberg (1999) report that 11 and 40 per cent respectively (Pillemer & Moore, 1989) of interviewed care providers in dementia care knew about abuse towards the elderly living in institutions and two per cent (Saveman *et al.*, 1999) and ten per cent respectively (Pillemer & Moore, 1989) of the care providers acknowledged that they themselves had used physical violence towards the patients.

In order to cope with demanding situations, not only for the clients but also for the care providers themselves, support including confirmation, feedback and supervision was crucial (Skovdahl, Kihlgren & Kihlgren, 2004). The care providers need theoretical as well as tacit knowledge to handle the demanding situations (Martinsen, 1994). Logically, the care providers are not only influenced by the patients, they also affect the patients emotionally (Barker, Reynolds & Stevenson, 1997).

Care providers’ attitudes

By our attitudes to one another, we help to shape one another’s world and we help to determine the scope and hue of people’s world; we make it large or small, bright or drab, rich or dull, threatening or secure (Lögstrup, 1993, pp. 50-51). Our attitudes are often non-conscious and non-reflective, even if they often determine our actions, and they include an affective, a cognitive and an action component (Tornstam, 1984). In dementia care, Norbergh, Helin, Dahl, Hellzén and Asplund (2005) state that the carers’ attitude is a basic concept in the care. Further, they show that the prerequisites for person-centred care improved, as a result of the staff’s positive attitude to people with dementia. In psychiatric care, the concept of Expressed Emotions (EE) is a measure of the psychosocial climate in the family-patient relationship, mainly reflecting the occurrence and degree of the aspects of criticism, hostility, over-involvement and intrusiveness, and it is frequently used to measure the staff’s attitudes within mental health care (Finnema, Louwerens, Slooff & van den Bosch, 1996; Moore & Kuipers, 1999; Vaughn & Leff, 1976). High degrees of care provider EE have been associated with a poorer clinical outcome in schizophrenic patients, such as a higher frequency of relapse (Forster *et al.*, 2003). The psychosocial climate in relationships therefore appears to be important in determining the course of problems in mental health (Moore & Kuipers, 1999). According to Van Humbeeck *et al.* (2002), high levels of care provider EE are associated with the psychiatric clients’ poorer level of social functioning and, with the exception of excitement symptoms, no significant

relationships can be seen between the staff's EE and the clients' symptoms and illness (Tattan & Tarrier, 2000). The emotional involvement of key care givers was found to have a significant association with the quality of life of clients with schizophrenia (Mubarak & Barber, 2003).

Care providers' job satisfaction

According to Herzberg's Dual-Factor Theory of JS and motivation, the achievement of a goal, recognition, advancement, the nature of work in itself and the opportunity for development and responsibility constituted six "motivators" or "satisfiers", which appear to play an essential role in the experience of JS (Stamps, 1997, pp. 9-14). Most of the traditional theoretical views of motivation and JS have had an isolated focus on the work itself, rather than on the person. Nowadays, work represents one of the most central values in a man's life (Agervold, 1998), because identity, self-confidence and well-being are based to a great extent on our experiences from working life (Dahlgren & Dahlgren, 1981). According to Andersson (1997), work – the creative activity – is seen as having two equal purposes for mankind. In the ideal situation, work satisfies a physical need, *i.e.* survival as a biological creature. At the same time, work satisfies a psychological need, *i.e.* the confirmation of man himself as a species (Andersson, 1997, p. 92).

There are different approaches to and no single definition of what JS is (Stamps, 1997, p. 45). Locke (1991) defines JS as "a comfortable or positively emotional state which is the result of the individual's work or work experience", while Lindell (1982) has suggested a somewhat similar definition, "JS was subjective and constituted man's emotional experience of work". Krueger, Brazil, Lohfeld, Edward, Lewis and Tjam (2002) concluded that JS was a multidimensional construction in which some predictors of JS appear to be organisation and context specific. JS is an important part of psychiatric care providers' individual well-being (Thomsen, 2000) and there is a strong relationship between JS and quality of work life for care providers (Blegen, 1993). Further, JS was strongly associated with reduced work stress, organisational commitment, communication with supervisors, autonomy, employee recognition, fairness, locus of control, years of experience, education, professionalism and a sense of being confirmed (Blegen, 1993; Guppy & Gutteridge, 1991; McGowan, 2001; Severinsson & Hallberg, 1996). By influencing the ethical climate of the organisation, hospitals might be able to enhance the JS of care providers (Joseph & Deshpande, 1997). In spite of this, Goodell and Van Ess Coeling (1994) found limited research evidence of the actual benefits of JS for care providers. Increased workload, growing occupational stress and declining JS are major concerns for care provider managers (Sveinsdóttir, Biering & Ramel, 2005), as JS is an important component of care providers' experience of high-quality nursing care (Wallis, 1987; Lucas, 1991; Cavanagh, 1992; Gilloran, McKinley, McGlew, McKee & Robertson, 1994). A quarter of nursing home staff (n=253) felt no JS, while 91% were happy in their jobs when caring for people with dementia (Brodaty, Draper & Low, 2003). In addition, problems associated with caring for people with BPSD impose a great deal of strain on care

providers and make it challenging to achieve and experience JS (Coen, Swanwick, O'Boyle & Coakley, 1997).

A low degree of JS leads to high levels of staff turnover (Cavanagh, 1992; Cohen-Mansfield, 1997; Shader, Broome, Broome, West & Nash, 2001; Shields & Ward, 2001). On the other hand, if the care providers felt that they were valued and that an interest was taken in their career development by the developer, they often tended to stay (Yoder, 1995). Exhaustion and disengagement are both indicators of burn-out and low JS (Demerouti, Bakker, Nachreiner & Schaufele, 2000) and cynicism and a feeling of meaninglessness have been reported among care providers suffering from burn-out (Leiter, Harvie & Frizell, 1998). Furthermore, Ekvall (1996) states that a low level of creativity has a negative impact on JS, well-being, productivity and quality of work and it has been argued that the quality of work is closely related to the experience of burn-out (Åström, Nilsson, Norberg & Sandman, 1991). However, Welander Hansson, Hallberg and Axelsson (1995) found that JS is relatively independent of burn-out and work-related strain among carers working with people with severe dementia. Work-related stress is one of the most critical issues for carers in modern health care (Chalder & Nolan, 2000), because high levels of occupational stress have been found to reduce nursing quality (Tarnow-Mordi, Hau, Warden & Shearer, 2000). The main elements of stress consist of reduced resources, reduced time and lack of appreciation from the employer (McGowan, 2001). Now, we will move on describing different aspects of the care provider-client relationship.

Aspects of the care provider-client relationship

Establishing relationships

All kinds of work involving caring are based on relationships (Aanderaa, 1995, pp. 11-12; Martinsen, 1994, pp. 64-67) and the centrality of the care provider-client relationship is emphasised (O'Brien, 2001). Establishing relationships with persons suffering from dementia is difficult, as interpreting and responding to each other's communicative cues is experienced as problematic (Athlin & Norberg, 1998). This contributes to high professional demands being imposed on the care providers and could result in a feeling that care is meaningless (Norberg & Asplund, 1990).

The importance of the therapeutic use of oneself is emphasised in the patient-care provider relationship and the development of relationships is the core of psychiatric nursing (Geanellos, 1995; O'Brien, 2001; Walsh, 1999). Relationships define and confirm self-worth, identity, acceptance as a human being, a sense of belonging and other essential interpersonal needs (Peplau, 1994). Peplau further states that relationships provide social support and tend to reduce stress and that the quality of interpersonal relationships has a strong bearing on perceptions of quality of life (Peplau, 1994; Yanos, Rosenfield & Horwit, 2001) and satisfaction with health care services (Fosbinder, 1994). On the other hand, negative, non-supportive social interactions were significantly related to poorer quality of life in people with severe mental illness (Yanos *et al.*, 2001).

The characteristics of relationship

The relationship between care providers and clients is unequal and asymmetrical (Lindseth, 1996). The patients appear to be sensitive to staff feelings for them (Barrowclough, Haddock, Lowens, Connor, Pidliswyj & Tracey, 2001; Forster *et al.*, 2003). Due to the vulnerability and dependence a person suffering from dementia experiences, the responsibility for the quality of the patient-care-provider interaction rests almost exclusively on the care provider (Ekman, Norberg, Robins Wahlin & Winblad, 1995). In a review of the literature, Shattell (2004) concluded that care providers in the care provider-patient relationship were found to exert power over patients and that they distanced themselves from patients who were labelled “bad” or “difficult”, thereby reducing the quality of care (Lilja, Ordell, Dahl, & Hellzén, 2004; Shattell, 2004).

The professionals’ preferential right of interpretation appears to be an expression of inequality in the care provider-client relationship. There is a social distance between the professionals and the users, as the staff have difficulty accepting the users’ descriptions of two different worlds and negative care experiences in connection with medication, diagnosis and compliance (Topor, 2001). Furthermore, there was inadequate agreement between the staff and the users about time. In this context, the professionals were guided by the demand for effectiveness through rapid improvements. The personal portrayals in the literature often focus on users’ limitations and failings, while the users’ own narrative brings out different abilities and strengths (Topor, 2001, p. 143). Similar results were found in a focus-group interview study with users and professionals that focused on empowerment (Boehm & Staples, 2002). The term “empowerment” has been conceptualised extensively by theorists. Common literature, however, has largely ignored the user’s and practitioner’s point of view. The users thought that concrete results, such as economic independence and reasonable living conditions, were the most important in order to achieve empowerment, while the professionals emphasised the importance of the individual being more active and taking more responsibility for him/herself (Boehm & Staples, 2002).

The importance of being together – an opportunity for dialogue

The most important issue when it comes to being together is the statement that man first becomes and understands himself as a person through interaction with other persons, which is a basic concept in philosophical personalism (Juul Jensen, 1985; Mounier, 1952), and the closely connected dialogue of philosophy, which emphasises the immediate character of the relationship (Buber, 1994; Marcel, 1999). Somebody becomes a *thou* to *me* and a unit is created in which the other person and I other become a *we* and it is first in this sense that it is possible to talk about a genuine conversation and real dialogue. The dialogue relationship is a precondition for the fact that a self-relationship can be accomplished (Marcel, 1999). Marcel (1999) operated with three basic fundamentals of living – the embodiment, the engagement and the dialogue relationship to the other. The first exists in itself, as the ground condition of the human

reality is the *relationship* in itself, where life is constituted “in between” I and Thou (Buber, 1994). The person is the part of a human being that cannot be understood as an object (Mounier, 1952).

From a constructivistic point of view, Sabat and Harré (1992) state that there are several selves that are constructed when people are together with others and that there exists a more formal self, which is independent of social factors. They state that the formal self is a personal singularity, which is kept alive even for people with severe dementia. However, the public self can be reduced, due to the ways in which the surroundings actually encounter and judge the person, more than the developments that are related to the progression of the dementia disease (Sabat & Harré, 1992; Taft, Fazio, Seman & Stansell, 1997). Connections between the engagement and the historicity of existence are emphasised and a social perspective with more or less anonymous collective structures, such as institutions, at the same time constitute a danger and the necessary support, through the agency of community between persons (Mounier, 1952).

Our time has been called the “era of hedonism” (Habermas, 1989; Reisman, 1985) but also the “era of loneliness” and, of these two inter-related phenomena, the inner disposition for loneliness appears to be becoming more prominent, as society’s means of developing people’s identity are weakened (Nilsson, 2003, p. 245). Loneliness is a phenomenon of major importance in the post-modern age and is of general health-political interest. In the case of severely mentally ill persons, this is expressed in a feeling of “longing for” (Nilsson, 2003, pp. 245- 255). Further, loneliness is the most trying human experience (Jönsson, 1962). In psychiatric care, the patients’ feelings of loneliness are a well-known phenomenon, a feeling that has been found to be strong (Murphy, 2000; McInnis & White, 2001) and never decreasing (Lindström, 1995). Patients have described the actual presence of nurses as the most important aspect of the nurse-patient relationship, as this can mean confirmation of the person (Hellzén, Norberg & Sandman, 1995; Mosher & Burti, 1995, p. 123; O’Brien, 2001). It is also important in order to increase the clients’ ability to be in the “normal world”, *i.e.* offering the clients a place/scene where they can act and minimise their psychiatric symptoms, verbalise their sufferings (Fredriksson, 2003) and thereby increase their sense of mastery (*cf.* Wright, 2000). In spite of this, there is evidence of a low degree of patient accessibility to staff and just sitting down and talking has low priority compared with all the other tasks that must be carried out (Mosher & Burti, 1995, pp. 3-38). Voices have, however, been raised against this. For example, Sandford, Elzinga and Iversen (1990) found that increased levels of staffing increased staff-staff interaction but did not affect staff-patient interactions.

The extension to which the care providers and clients are together

In dementia care, Birchall & Waters (1996) and Nolan, Grant and Nolan (1995) have shown that elderly people living in institutions spend most of their time alone (58.5% and 87% respectively). Similar results were presented by Armstrong-Esther and

Browne (1986), who found that people suffering from dementia in a geriatric hospital ward spent 88.5% of their time in solitude. Norbergh, Asplund, Rasmussen, Nordahl and Sandman (2001) showed that people in a psycho-geriatric unit were alone for 50.3 per cent of the time on a daily basis. This figure was 39 per cent for elderly people in GDs (Norbergh, Hellzén, Sandman & Asplund, 2002). In oncological hospital care, Rasmussen and Sandman (1998) reported figures of 73.7 per cent and, in hospice care, patients spend 44.8 per cent of their time in solitude.

Users/clients and care providers in an environment

It is very important not to overlook the fact that all human beings live in a certain historical time that plays a significant role in their life preconditions (Mounier, 1952). Fontana (1996) has described that the person-environment interaction relationship is. Here, we will focus upon users/clients and care providers on an organisational and societal levels.

An organisational level

From the care-provider perspective, the staff are always bound and work in an organisation with certain cultures. Trollestad (2003) states that healthy organisations are generally characterised by long-term, persevering and continuous strategies and by humility towards the staff as well as the task, plus a trust-filled, open climate characterised by solidarity and very committed, clear leadership. We have become dependent on technical, bureaucratic and efficient ways of functioning (Bauman, 1995; Hilberg, 1961), organisations' and companies' ways of working are often characterised by tremendous economic teleopathy, which means that they are guided by a sick desire to reach goals (*cf.* Goodpaster, 1994). Teleopathy is characterised by negative fixation and short-sighted, poorly reasoned decisions. Another factor affecting the organisation is rationalisation – a habit of denying or re-interpreting reality so that it more easily fits in with uncomfortable decisions and actions, which the staff do not actually like, by referring to the owners or the law. Finally, a third expression of teleopathy is dissociation which, together with the fixation, leads to an emotional insensitivity that results in the separation of thought and emotions (Goodpaster, 1994). In such an organisation, the moral responsibility is easily set aside and compassion, closeness and generosity are replaced by competition, result orientation and the instrumentalisation of the staff (Goodpaster, 1994). It can also lead to the dehumanisation of people, whom we are expected to serve (Bauman, 1995).

From the psychiatric-client perspective, the goals of the reform have clearly not been realised, as the reform is not sufficiently rooted in the leadership at the municipalities and local politicians and leaders lack knowledge of the client group's need for social support services (The Swedish National Board of Health and Welfare, 2005b). Even if an investigation from a smaller Swedish municipality, comprising 377 psychiatric clients, shows that the total sum of unmet needs and unmet needs regarding accommodation and support from social services has decreased, there are no differences

between the level of daily activities and social contact with friends and relatives before and five years after implementing the Mental Health Reform (Arvidsson, 2003).

A societal level

Lögstrup (1997) states that the manifestations of life, such as trust, awaken an ethical demand from the other to be received on a personal level by me, while, on a societal level, this gives rise to the foundation of ideals; for example, the idea of taking care of the weakest in society originates from mercy. In spite of this, in our modern society, the community around the foundation of ideals can no longer be taken for granted and this leads to a lack of solidarity with society (Lögstrup, 1997). Ethics on a societal level are just like the ethics of closeness, a question of power (Lögstrup, 1997). Further, on a societal level, a German study has shown that there is still a substantial stigma attached to mental illness (Angermeyer & Matschinger, 2005) and a reduction in the societal stigma attached to mental illness is needed in order to promote clients' integration into society (Magnusson, Lützén & Severinsson, 2004).

The concept of normality and integration

The Scandinavian principles of normalisation originate from the debate in the 1950s about the mentally retarded, which reflected cultural normative activities (Markström, 2003, pp. 136-137). What is considered normal is characterised by a desirable lifestyle of which people in general have experience, which basically includes having structure and rhythm during the days, the weeks and the years, being met with normal expectations, having sexual relations, good economic standards and good living environments (Ninje, 1980). These ideas of Scandinavian normalisation are based on rights and equality perspectives, while the North-American normalisation ideas are known as social role valorisation, which was introduced by Wolfensberger and is based on creating, supporting and defending valued social roles for people at risk of being devaluated, by working with highly valued others, for example (Markström, 2003, p. 137). The SSA (2001:453) is the legislation governing public services, including the municipal housing and caring services for the elderly and the mentally dysfunctional, where a comprehensive, holistic view, normalisation and flexibility are strongly emphasised (Fahlberg & Magnusson, 1997, pp. 29-32), while building on respect for people's self determination and integrity (SSA, 2001:453). This also means that there is an empowerment perspective (Hermodsson, 1998). However, the way in which the support is organised is of minor concern, compared with the superior goals of quality of life and normalisation (Bank-Mikkelsen, 1980; Sandvin, 1992). Hydén (2000) states that the disabling process of people with long-term mental illness has been a central strategy in implementing the Mental Health Care Reform. It means that individuals must assume power for decisions and actions that affect their lives (Payne, 2002). An effort is made to integrate the users into the surrounding society, even if the normalisation can produce the opposite effect if it is not anchored in practice (Markström, 2003, p. 139). Today, due to the transfer of responsibility, the formal status

of people suffering from psychiatric disease has been changed, as nobody is any longer able to force them to do things they do not want to do (Topor, 2001, p. 153).

THE STUDY

This study primarily focuses on different features of Swedish municipal EGD and PGD care after implementing the health care reforms in the 1990s. Due to the spatial, temporal and emotional-relational inter-relatedness between care providers and clients (Barker *et al.*, 1997; Finnema *et al.*, 1996; Forster *et al.*, 2003; Gilloran, *et al.*, 1994; Lögstrup, 1966; Martinsen, 1994; Moore & Kuipers, 1999; Mosher & Burti, 1995; Peter & Liaschenko, 2004), a care provider perspective will primarily be utilised.

Rationale for the study

The overall aim was to explore aspects of municipal EGD and PGD care in the post health care reformation era as they impact on the clients' lives. Knowledge, understanding and consciousness of this might lead to steps being taken towards focusing specifically on recovery efforts for the clients and, in the long run, better quality of care and better lives for them. Further, it might counteract burn-out and low degrees of JS and contribute to a process in which the care provider matures both as a person and as a professional.

Purpose of the study

The general purpose of this study is to illuminate features of municipal elderly and PGD care in the period following the 1990s health care reforms, in order to create an enlarged understanding of and interest in the lives of the care providers and, first and foremost, the clients. The thesis comprises six papers with the following specific aims.

- Paper I** – to investigate whether the nurses' approach could be explained in terms of the clinical picture or the fact that the patient had a diagnosis of schizophrenia.
- Paper II** – to investigate whether there was a visible pattern in psychiatric nurses' attitudes towards a fictitious elderly person with a diagnosis of long-term schizophrenia.
- Paper III** – to describe the experience of JS among nursing staff working at two group dwellings for people suffering from dementia with behavioural disturbances.
- Paper IV** – to investigate how residents spend their time at psychiatric group dwellings.
- Paper V** – to investigate the connections between the time spent together and the nurses' opinion of client behaviour and social functioning.
- Paper VI** – to obtain an understanding of nurses' and mental health care workers' views and experiences of being a care provider in a municipal context.

METHODS

Participants and procedures

Sampling procedures – general considerations

The sampling procedures used in this study have been guided by the aims of the individual papers. Total investigation has been utilised for **Papers I and II**, and chance has decided the sample for **Papers VI and V**, while the phenomenon of being a care provider, which is believed to show itself much more clearly, when the research is conducted in more extreme settings. In this case, the research has been carried out through interviews with care providers in caring contexts selected by the municipal director of the department of social welfare for **Papers III and VI**.

Settings

Apart from the settings in **Papers I and II**, which only received written information, all the settings were visited and information about the study was given verbally and in writing. Several studies were being conducted during the same period of time, which meant that both the staff and the clients became fairly familiar with the researchers.

Papers I & II

All the care providers working in the field of social psychiatry at seven different units in one municipality in northern Sweden were an integral part of the study. The units were divided into two groups and classified as “dwelling” or “support”. The “dwelling group” was characterised by care providers working at traditional GDs providing care for 10-20 clients. The “support group” consisted of care providers working in small teams and visiting people with long-term mental illness in their homes.

For **Paper I** All the care providers (n = 93) in one municipality working at seven different psychiatric municipal units in Sweden were informed by letter about the investigation. They were informed that participation was voluntary and that the data would be handled confidentially with regard to both individuals and institutions. A questionnaire was attached to the information letter.

After one reminder, the final response rate was 80% (n = 75). Responses were received from 54 women and 21 men, of whom 12 were Registered Nurses (RNs) and 63 were Enrolled Nurses (ENs).

Of the above-mentioned 75 care providers, the majority (n = 66) took advantage of the opportunity to write down their own justification for their choice of approach in connection with the last statement in the above questionnaire for **Paper II**.

Paper III

The settings in this paper were two group municipal dwellings providing care for clients suffering from different types of dementia. There were 16 clients, five males and 11 females (median age 78 years, range 65-85), at GD A. Four clients, three males and one female (median age 68 years, range 64-71), lived at GD B.

Paper IV

This investigation was carried out at two psychiatric municipal GDs providing care for people with severe mental illness. There were 15 clients, five males and 10 females (median age 41 years, range 22-63), at GD A. Twenty clients, 14 males and six females (median age 60 years, range 42-85), lived at GD B.

Twenty-two women and 10 men (n=32) from two municipal PGDs participated. Four of the care providers were “registered nurses”, while 28 were “enrolled nurses” with special training in psychiatry. The respondents’ median age was 47 years (range 34-58). They had been working within care in general for a median of 19 years (range 3-39 years) and within psychiatric care for a median of 17 years (range 3-39 years).

Papers V & VI

This investigations were carried out at two municipal PGDs providing care for people with severe mental illness. There were 18 male and 11 female clients (median age 53 years, range 35-79) divided between the dwellings, which had 13 and 16 clients respectively.

All the staff from two municipal EGDs was invited to participate. Two declined the opportunity. The appointments with the interviewees were arranged in such a way that they took place during the care providers’ working hours. The interviews took place in an undisturbed environment in rooms connected to the wards. The exact time and day of the interview was chosen by the individual participant, often in connection with another interview taking place or by telephone. Nineteen women and one man (n=20) participated. One of the staff was a “registered nurse”, while 18 were support workers, defined as either “assistant nurses” (16) or “nursing assistants” (2). They had completed courses of between eight weeks and two years at upper secondary level. The interviewees’ median age was 45 years (range 27-57). They had been working within care in general for a median of 22 years (range 1.5-33 years) and within dementia care for a median of 17.5 years (range 0.75-33 years).

For **Paper V** twenty-one women and nine men (n=30) from two municipal PGDs participated. Three of the care providers were “registered nurses”, while 27 were “enrolled nurses” with special training in psychiatry. The respondents’ median age was 46 years (range 20-61).

Eleven women and two men (n=13), from two municipal PGDs, participated in **Paper VI**. One of the care providers was a “registered nurse”, while the remainders

were “enrolled nurses” with special training in psychiatry. The interviewees had varied experience of psychiatry and their median age was 40 years (range 20-61)

Table 1. A schematic overview of the papers in this thesis

	Context of study	Number of subjects	Method of data collection	Methods of analysis and interpretation
Paper I	Seven social psychiatric units in one municipality	93 care providers	Questionnaire consisting of 13 pairs of categorical statements	Spearman’s rho correlation Mann-Whitney U-test independent-sample t-tests Gamma coefficient ‘Monte Carlo’ version
Paper II	Seven social psychiatric units in one municipality	75 care providers	Written answers to an open-ended question	Qualitative interpretative content analysis
Paper III	Two municipal EGDs	20 care providers	Audio-taped individual, narrative interviews	Thematic content analysis
Paper IV	Two municipal PGDs	35 clients 32 care providers	GAF PANSS PAC CCQ MBI	Chi-square, Spearman’s rho correlation, Mann-Whitney U-test, Multiple linear regression
Paper V	Two municipal PGDs	29 clients	GAF PANSS PAC	Spearman’s rho factor analysis Varimax method with Kaiser’s normalisation Pearson correlation, Multiple linear regression
Paper VI	Two municipal PGDs	13 care providers	Three focus-group interviews (4-5 participants in each group)	Thematic content analysis

Methods of data collection

In this thesis numeral methods and instruments have been used. The data collection will be presented in a more comprehensive manner.

Questionnaires

Normann’s case questionnaire

When investigating care providers’ approaches towards a fictitious elderly woman (**Paper I**), a questionnaire designed by Normann, Asplund and Norberg (1999), which had been translated from Norwegian into Swedish using a back-translation technique (White & Elander 1992), was used. The questionnaire, which was constructed using a case description of an 84-year-old woman with severe dementia and problematic behaviour, was used after a small number of modifications had been made. In **Paper I**, the woman’s age in the case description was changed from 84 to 68 and the diagnosis

was changed from severe dementia to long-term schizophrenia; in all other respects, the description was the same as in the original case (please see Appendix 1). The questionnaire consists of 13 pairs of categorical statements from which care providers were asked to choose the standpoint describing the way they should think and act towards the resident in the vignette by rating their decisions on a two-degree scale. Each pair of statements refers to (1) a personhood-focused approach or (2) a symptom-oriented approach. The statements were then grouped into five different indices (Normann *et al.*, 1999):

Index I: Orientation in terms of time, place and situation

Index II: Correction of behaviour

Index III: Emphasis on the past or the present

Index IV: Aim of the care providers' communication with the woman described

Index V: The meaning of confusion for the resident

Finally, by calculating the score for each index, it was possible to make statistical comparisons of the care providers' assessments.

Creative climate questionnaire (CCQ)

In order to measure the creative climate at the two psychiatric GDs (Paper IV), the CCQ (Ekvall, Arvonen & Waldenström-Lindström., 1983) was utilised. It is based on 50 statements covering 10 dimensions of working climate: challenge (*engagement and feeling for the work and its goal among the organisation members*), freedom (*behavioural independence exercised by the members of the organisation*), idea-support (*way in which new ideas are received*), trust (*organisational members' emotional confidence in the relationships*), dynamism (existing dynamics in the organisation), playfulness (*existing playfulness and humour among the members*), debates (*extent to which there are agreements and disagreements between members, their ideas and various experiences and skills*), conflicts (*counter-indicative; existence of emotional tensions among the members*), risk-taking (*organisation's willingness to tolerate uncertainty*) and idea-time (*time one can use to work out new ideas*). The statements were geared to the organisation's capacity for change and innovation (Ekvall & Tageberg-Andersson, 1986). Each dimension was measured using five statements, each of which used a four-point scale: "strongly disagree" (0), "agree up to a point" (1), "agree" (2), or "strongly agree" (3).

The CCQ has been found to have good validity and reliability. Internal consistency reliability with a Cronbach's alpha coefficient of 0.88 has been reported (Berg, Welander Hansson, & Hallberg, 1994).

Maslach burnout inventory (MBI)

The MBI instrument (Maslach & Jackson, 1981) was used when exploring the extent and intensity of burn-out at the two psychiatric GDs (**Paper IV**). It has been

translated into Swedish by Hallsten (1985) and consists of 25 items, 22 of which were used in this study. The inventory measures three aspects: emotional exhaustion, which contains nine items, depersonalisation, five items, and personal accomplishment, eight items. The respondents were instructed to comment on each statement – frequency and intensity. The frequency scale ranges from “never” (0) to “every day” (6) and the intensity scale ranges from “never” (0) to “very strong” (6). Carers with a high degree of emotional exhaustion and depersonalisation and a low degree of personal accomplishment are believed to be more burnt out (Maslach & Jackson, 1981).

Scales

Global Assessment of Functioning Scale (GAF)

In order to depict the care providers’ global evaluation of a patient’s psychological, social and working level of functioning and ability, as well as psychiatric symptoms, the GAF scale (Valliant & Schnurr, 1988) was used (**Papers IV & V**). The GAF scale assessment is based on the care providers’ clinical evaluation of the resident during the last three-month period. The scale depicts the severity of the symptoms or the yield of functioning, which means that the same score is possible for two clients with different clinical pictures. The GAF scale is regarded as a hypothetical continuum, where psychiatric health and psychiatric illness respectively construct the two opposite poles, ranging from “inadequate information” (0) to “exceedingly good functional ability within different areas, where the problems in life never appear to be unmanageable” (100).

The Positive and Negative Syndrome Scale (PANSS)

To measure the care providers’ evaluation of the clients’ psychiatric symptoms, the PANSS scale (Kay, Fiszbein, & Opler, 1987) was applied (**Papers IV & V**). It has been translated into Swedish by von Knorring and Lindstrom (1992). The scale includes 30 items, a seven-item subscale for positive symptoms, a seven-item subscale for negative symptoms and a 16-item subscale covering general psychopathology. It measures the respondent’s valuation, in a seven-point format ranging from 1=absent to 7=extreme, of the psychiatric client’s symptoms. In these studies, the PANSS assessment is based on the carers’ clinical evaluation (observations and interviews) of the resident during the past week. The scale concentrates on the severity of the symptoms and the estimator’s opinion based on his/her clinical judgement with help from a complete definition and detailed anchoring criteria for each item in the instrument.

Non-participant observations

Patient Activity Classification (PAC)

In both **Paper IV** and **Paper V**, the psychiatric clients' activities were observed and classified using an instrument (PAC) developed by Rasmussen and Sandman (1998). The construction of the instrument is hierarchical and implies three levels of abstraction, *i.e.* six domains, 34 categories and 152 sub-categories. The term "hierarchical" means that, if, for instance, a client was observed with a relative and a care provider, the observation was subsumed under the domain of "patient and care provider". The same course of action was used if the client was with a fellow resident and a relative was also present, when the observation was subsumed under the domain of "patient and relative".

Research interviews

The data collection was carried out using personal narrative interviews with 20 care providers at two different GDs for people with dementia (**Paper III**) and focus-group interviews were carried out three times (**Paper IV**). An interview is an interaction between two people, where mutuality and respect are important characteristics (Kvale, 1996). Interviews are a way of obtaining subjective descriptions of the interviewee and identifying and defining the richness and complexity of human experience, thereby obtaining a deeper understanding of them than a questionnaire is usually able to provide (Kvale, 1996; Polit & Beck, 2004). The interview guides featured a few general questions or subject areas that were composed to help realise the aim of the study. All the interviews were carried out by the present author. The interviews were conducted in a normal conversational language tone in the form of dialogues (Benner, 1994, p. 108). During the interviews in **Paper III**, the participants were asked four open questions; (1) about the JS they experienced when working with clients suffering from BPSD; (2) they were also asked to reflect on their own involvement in nursing care; (3) to describe what was "good" and "not so good" about working at the particular GD; and (4) whether they intended to continue working at the GD and why or why not? The discussion questions in **Paper VI** focused on what it means to be a care provider in a municipal PGD context, what the characteristics of this kind of care are and what the most important tasks are considered to be. Clarifying and encouraging supplementary questions were also asked when appropriate, in order to understand, specify and deepen the answers.

Narrative interviews

In order to describe JS, narrative interviews, which are based on the assumption that people give meaning to events by telling stories, were used (**Paper III**) (Viney & Bousfield, 1991). Due to the highly strained working situation, the questions were constructed in order to obtain an understanding of what made the care providers stay at the GDs. Often, narrative interviews have one question at the starting point, though here is no binding prescriptive theory concerning narratives (Riessman, 1993, pp 16-17) and no one method for analysis (ditto, p 5). The use of narrative interviews has many

advantages that need to be taken into consideration. Meaning is constructed through a mutual understanding between the interviewer and the interviewee and it is contextual and value bound (Lincoln & Guba, 1985; Mishler, 1986, pp 6-7). The interviews were conducted with as little interruption as possible, on the part of the interviewer, to encourage the interviewees to generate narrative in their own “voices”. The interviews lasted between 25-65 minutes.

Focus-group interviews

In **Paper VI**, the aim was to obtain an understanding of care providers’ and mental health workers’ views and experiences of being care providers in a municipal PGD context and the dynamics of group interactions were used to produce data in the focus-group interviews (Morgan, 1997; Kitzinger, 1996). The aim of focus-group interviews is to investigate how human beings think, feel and act in relation to phenomena that have been defined by the researcher in advance (Morgan, 1998b). When investigating professional roles, which are per se a social construction, focus-group methodology was chosen as suitable, to allow the participants to verbalise experiences and consider their own thoughts and views in the context of other people’s views, which may enhance data quality and produce deeper and richer data more rapidly than individual interviews (Kitzinger, 1996). Psychiatric nursing is primarily an interactive and communicative activity where problems relating to client care are often discussed in formal or informal group settings. The interactive process of a focus group might shed more light on the topics compared with individual interviews (Lützén & Schreiber, 1998). The research questions are examined from the research participants’ own perspective, the data must be as specific as possible and the group interaction must be supported by the moderator who, as in this study, is also often the primary researcher (Morgan, 1998b). Normally, the size of the focus groups ranges between four and 15 participants and the number of group sessions usually ranges between three and five, depending on when “theoretical saturation” is achieved (Morgan, 1998b). The interviews lasted between 80-100 minutes.

Methods of data analysis

Statistical analysis

All the data in **Papers I, IV** and **V** were entered and analysed using 11.0 or 12.0 SPSS software packages (SPSS, 2004). Due to the nature of the data, non-parametric statistics were most frequently used. In **Paper I**, the five indices from the questionnaire manual were used. In order to explore differences between groups, Chi-square test, the Mann-Whitney U-test and independent-sample t-tests were used. Spearman’s rho and gamma-coefficient were calculated to check for correlations between the five indices and the years of work experience. In **Paper IV**, chi-square test was used to calculate significance on categorical variables, while the Mann-Whitney U-test was used for differences between the two GDs for the different scales and questionnaires. In order to calculate correlations between the two questionnaires, CCQ and MBI, Pearson’s

correlation was calculated. In order to examine whether something client bound could explain the time spent together with staff and the time spent alone respectively, correlations between PANSS, GAF and PAC and, when appropriate, multiple regression analysis were calculated.

In **Paper V**, Spearman's rho was used to test correlations between PAC, PANSS and GAF. To elucidate the relationships within the PANSS items, symptom groups (factors) were created through factor analysis, using the rotated Varimax method with Kaiser's normalisation. To explore relationships between the symptom indices and the dimensions of PAC, Spearman's rho was calculated. Pearson's correlation was calculated for GAF and the symptom indices and multiple regression analyses were also calculated. Furthermore, four groups were created. Thresholds in the indices corresponding to a PANSS score below or equal to 4 were chosen with reference to the moderate presence of symptoms and a GAF score below or equal to 40 indicating "severe functional difficulties" was set (APA, 1994). Four small groups of clients were created. Finally, the average time for the PAC dimensions "client and care provider" and "client alone" were calculated for the four groups of clients.

A *p*-value of 0.05 or less was considered statistically significant.

Content analysis

In **Paper II**, qualitative interpretative content analysis was used (Morgan, 1993), in order to understand the sense of messages in the respondents' answers where they elucidated and justified what the consequences for the elderly woman could be if they did not act in the way they did. In order to uncover the underlying meaning in the texts in **Papers III** and **VI**, they were analysed using thematic content analysis (Baxter, 1991), which is an interpretative process in which the researchers take the whole context into consideration. In latent content analysis, there is a deepened level of inference and in this case the latent message in the text is interpreted and more attention is focused on *how* the message is communicated (Graneheim & Lundman, 2004). Further, Baxter (1991) states that a theme is threads of meaning that recur in domain after domain. Graneheim and Lundman (2004) consider a theme to be a thread of an underlying meaning through the condensed meaning units, codes or categories, on an interpretative level. The tape-recorded interviews were transcribed verbatim (**Papers III** & **VI**). The interviews (**Papers III** & **VI**) and the statements (**Paper II**) were read several times by the author until it was felt that a sense of the whole had been captured (Sandelowski, 1995). In **Paper II**, topics, domains of content, were identified, when the whole text was re-read in order to define how care providers reasoned in connection with these topics and meaning units were then identified on the basis of this process. They were then transformed and interpreted and sorted into sub-categories. The sub-categories were abstracted and understood in relation to the text, resulting in categories. Graneheim and Lundman (2004) state that creating categories is the core feature of content analysis. The text in **Papers III** and **VI** was also divided into meaning units. They could consist of either some words in a sentence or several sentences bound

together by their content. They were condensed into shorter sentences, while keeping the original essence of the text (Downe-Wamboldt, 1992; *cf.* Graneheim & Lundman, 2004). In **Paper III**, the condensed meaning units were labelled with a code, simply stating the content of each. The condensed statements were coded using an open coding method in order to find similarities. The codes represent conceptual labels of the content of the meaning units that must be contextually understood when considering the meaning units (*cf.* Graneheim & Lundman, 2004). In order to find similarities and differences, the various codes were compared and sorted into sub-themes. The sub-themes were then compared and sorted into themes, which were not necessarily mutually exclusive. Hereafter, the themes were formulated into a core theme illustrating the core or central interpreted meaning of the assistant nurses' narratives of JS (Please see Table 1). The themes and the core themes were formulated as a descriptive aspect of a structure of an experience, because, according to van Manen (1990), a theme cannot be a thing. In **Paper VI**, depending on the logical content of the condensed meaning units, they were sorted into sub-themes, which again were interpreted, abstracted and sorted into the themes (Please see Table 2).

Table 2 Examples of the thematic content analysis with condensed statements, codes, sub-themes, themes and core theme.

<i>Condensed statements</i>	<i>Codes</i>	<i>Sub-themes</i>	<i>Themes</i>	<i>Core theme</i>
We don't have time for the elderly, you see. Nowadays it's like storage. It used to be care	Lack of "good" nursing time	Having a bad conscience	Being insufficient	Destructive aspects
The patients' behaviour affects you so that you feel that you can't really trust yourself. After three and a half years, you start to feel insecure about your own reactions. Will you "pinch back"?	Unpleasant nursing experience	Feeling uncertain	Doubting oneself and others	
My workmates are the most positive thing about working here; you are never alone	Community with the staff	Feeling confident with and supported by co-workers	Respected and valued	Nourishing aspects
"It feels as if the elderly clients are my 'own'. Maybe I feel too much about them?"	A familiar relationship with the clients	Being fond of the clients	Being devoted to the clients	

Table 3 Example of meaning unit, condensed meaning unit, sub-theme and theme

<i>Meaning unit</i>	<i>Condensed meaning unit</i>	<i>Sub-theme</i>	<i>Theme</i>
You get angry when you enter his apartment and then see that he has cut the lampshade to pieces... tiny, tiny pieces everywhere, eaten all the advertising circulars and spat them out so that there are small lumps everywhere... There are faeces all over the apartment, smashed glass, toilet paper... of course you get furious and sometimes you get this feeling of well I don't know... he's violating himself... sometimes it feels as if... these are conscious acts on his part.	The staffs get angry with a particular resident because he has littered the whole apartment with paper, faeces, smashed glass and toilet paper. The staffs feel that the resident is violating himself and they are uncertain about whether these acts are performed on purpose.	Occasionally non-trustworthy persons	Having a complex and ambiguous view of the clients

Ethical considerations

When interviewing people, it is very important that the interviewer is conscious about and understands the vulnerability and the potentially exposed situation the interviewee is in. The situation requires sensitivity. There is a risk that talking about JS could cause the interviewees pain through thoughts of a more existential nature, for example: How do I do my job?, How good am I? or What is the meaning of my work and perhaps even me?. Furthermore, there is a possibility that on-going or old work-related conflicts could pop up, or that difficult memories of unjust treatment, for example, will occur when talking about JS. In reality, I felt that most of the participants had a real need to put the working situation into words and they seemed glad that somebody was paying attention to them. The interviewees in the individual interviews were thoroughly briefed beforehand and guaranteed confidentiality. In connection with the focus-group interviews, the participants were encouraged, both initially and at the end of each focus-group session, to keep quiet and let what was said stay in the room. The guaranteed confidentiality therefore dealt with how the data were going to be treated afterwards. The respondents each gave their informed consent to participate in the study. In connection with the realisation of an observation study, it is essential to make oneself as “invisible” as possible, in order not to disturb or interrupt, or in any other way affect what is going on. On the other hand, the researchers are human beings and, as such, social. When conducting the observation studies, we tried to be like “polite flies on the wall”. Needless to say, observation studies can generate a feeling of inconvenience for both the care providers and the staff, but we did not observe any such signs. Contact was made with the employer, the local authority, who gave permission for the performance of the study. The Ethics Committee at the Medical Faculty, Umea University, approved the study (§ 409/00, No. 00-337).

FINDINGS

Paper I

The first paper presents care providers' (n= 75) view of a caring approach towards a fictitious elderly long-term resident suffering from schizophrenia, investigated by a questionnaire. The results show that there are differences in care providers' approach to the vignette and that a person with a diagnosis of long-term schizophrenia, who also suffers from severe dementia, might be treated not as a person with dementia but as a person with long-term schizophrenia. Furthermore, approximately 70 per cent of the care providers had a symptom-oriented approach, which focuses on the correction of disease-related symptoms in the clients. If the care providers had been working for less than 10 years, they tended to have a more person-centred approach, which indicates that long-term job experience might affect the care providers' attitudes towards the clients negatively. Moreover, the care providers working in the "GD" seemed to be more symptom oriented than the "support group", Index III: emphasis on past or present ($p=0.022$) and Index IV: the meaning of confusion for the resident ($p = 0.047$).

Paper II

The second paper focused on whether there was a visible pattern in psychiatric care providers' attitudes towards a fictitious elderly person with a diagnosis of long-term schizophrenia. The results show that there is a visible pattern of this kind, because forty-eight (73%) of the respondents (n = 66) emphasised the importance of meeting Mrs NN within the framework of reality and the need as a nurse to focus on the present or the "here and now" when they communicate with her, when they chose one of the two statements relating to the vignette. In addition, twenty-seven per cent (n = 18) of the care providers stressed the importance of meeting Mrs NN within the framework of a person-focused approach to the same question. The majority were unable to see the resident as anything other than her diagnosis, the label. Through the interpretative content analysis, five categories were created; "a life-and-death situation", "change leads to deterioration", "structure leads to improvement", "rebuilding the identity", and "nurses' own participation in the process".

Paper III

The third paper presented a description and interpretation of twenty care providers' experiences of JS; their work involves taking care of clients suffering from dementia and elements of "aggressiveness" and "psychomotor agitation". The narratives indicated exposure, insufficiency, a feeling of not being valued and doubt, as well as respect and importance and devotion towards the clients. The interpretation of the narrations revealed an ambiguous and complex core-theme: "JS as a process moving between breaking down and occasionally building up the working person". The care providers felt that they only received support from each other and the positive relationship with colleagues was mentioned as the primary reason for care providers

continuing to work at the GDs. Just a small degree of support was experienced on the part of the organisation. The organisation and clients' behaviours were seen as very negative. Some care providers described insecurity in terms of how long they could continue to take rudeness, being spat at, being scratched or physically hit by clients, without "hitting back".

Paper IV

In the fourth paper, the PAC revealed that the clients spent 8.9% of their time with care providers. On average, the clients received 75 minutes of staff time, i.e. 1 hour and 15 minutes together with the carers each day. The time spent with relatives was 1.6%, i.e. an average of 13 minutes a day, while the corresponding figure for fellow clients was 5.1%, i.e. an average of 43 minutes a day. A multiple regression analysis revealed that 22.3% of the clients' time together with the staff could be explained by one of the items (symptoms) on the PANSS scale's sub-scale of negative symptoms: "passive/apathetic withdrawal –neglecting daily life functions" ($p=0.003$). Similarly, the multiple regression analysis also revealed that the clients' time alone could be explained in 29.5% of cases by three PANSS items, "Withdrawal – lack of engagement and interest" on the negative sub-scale ($p=0.086$) and the general psychopathology sub-scale items of "disorientation" ($p=0.007$) and "self-absorption – emotions with autistic experiences" ($p=0.029$). The GAF scale produced a score for both dwellings together that points to "severe functional difficulties" (4.13; $SD\pm 1.47$). In the sub-scale for positive symptoms, the GDs obtained low PANSS scores for positive symptoms (3.65; $SD\pm 1.13$). The other two sub-scales produced moderate PANSS scores (4.95; $SD\pm 2.32$) for negative symptoms and a minimal PANSS score (2.54; $SD\pm 0.87$) for general psychopathology.

The CCQ questionnaire revealed that both the GDs could be regarded as having a creative work climate. Furthermore, the MBI questionnaire showed that, in overall terms, the frequency and intensity factors indicated that the carers were suffering from a moderate degree of burn-out, a moderate degree of emotional exhaustion with a low frequency (1.46; $SD\pm 0.83$) and a moderate intensity (2.19; $SD\pm 1.07$), a moderate degree of depersonalisation with a moderate frequency (1.46; $SD\pm 0.83$) and intensity (1.46; $SD\pm 0.83$).

Paper V

In the fifth paper, the PAC instrument revealed that clients spent an average of 60.8 per cent (8 hours and 30 minutes) of the time alone, while only 20 per cent (2 hours and 48 minutes) of their daily time was spent with the care providers. "Passive activities", staff being present without any special activity taking place, were observed for an average of 18.5 minutes. The GAF scale produced a score, for the whole group of clients, which indicated the area of "severe functional difficulties" (38.2; $SD\pm 13.3$). In the sub-scale measuring positive symptoms, the results revealed moderate PANSS scores (4.13; $SD\pm 1.31$). The sub-scales for negative symptoms revealed low PANSS scores (3.79; $SD\pm 1.29$). For general psychopathology, a low PANSS score was found

(2.54; SD±0.87). Based on a factor analysis, five indices were created: “being seen as withdrawn”, “being seen as agitated”, “being seen as mad”, “being seen as worried” and “being seen as inhibited”. There were two statistically significant correlations between indices for the PAC dimension of “client alone” and “being seen as withdrawn” ($r_s = 0.512$; $p = 0.005$) and between “client being outside the dwelling” and “being seen as inhibited” ($r_s = -0.504$; $p = 0.006$). By setting threshold points for the PANSS and the GAF scores, four small groups of clients were generated: a relatively high level of social functioning and a low degree of psychiatric symptoms (A), a relatively high level of social functioning and a high degree of psychiatric symptoms (B), a low level of social functioning and a low degree of psychiatric symptoms (C) and, finally, a low level of social functioning and a high degree of psychiatric symptoms (D). When calculating the average time for the four groups in every **index**, it became clear that the clients in group A spent 63.4% of their time alone and 16.6% with the staff, group B spent 69.3% alone and 19.2% with the staff, group C were alone for 69.7% of the time and with staff for 23.7% and, finally, group D, with a high degree of psychiatric symptoms and a low degree of social functioning, were alone for 71.4% of the time and spent 18% with the staff.

Paper VI

The last study focused on care providers’ views and experiences of being a nurse in a municipal PGD context. The findings indicated that the care provider role was quite like the role of parents, but they themselves had to figure out the role on their own. The care providers sensed that they were in a more or less “strangled” working situation, with unclear leadership and a highly economically oriented organisation. Furthermore, they had an ambiguous view of the clients and they mainly responded to the work as a whole with overwhelming frustration, including a sense of being alone. Their views of their task were very comprehensive when it came to their actual work with the clients.

METHODOLOGICAL CONSIDERATIONS

The price of writing a thesis dealing with two contexts and with two perspectives, a client and a care provider perspective, is that the presentation could be split and the knowledge that is generated might not be on a particularly deep level. The triangulation that has been used, defined as the combination of methods in one study of a single phenomenon (Denzin, 1989), has the potential to provide a multifaceted view of this kind, as it denotes the combination of different research strategies (Foss & Ellefsen, 2002). Traditionally, combining quantitative and qualitative methods has proved problematic and contradictory because of the seemingly incompatible epistemological assumptions behind the positivistic and the hermeneutic/naturalistic paradigms, between the “context of verification” and the “context of discovery” (Johansson & Lynøe, 1997, pp. 21-23, 31-49). In spite of this, the use of method triangulation in nursing research has increased and, even if quantitative and qualitative methods are occasionally combined, one method is often regarded as complementary to the other that is given

precedence over the first (Morgan, 1998a). In this thesis, both methods have had equal values.

In overall terms, there are large differences between EGD and PGD care, but there are also several similarities, when it comes to the interviewed staff's descriptions of clients and the organisation, for example. The fact that only one paper relating to elderly care has been produced is naturally a major limitation. The care providers' descriptions of JS in connection with caring for clients with BPSD in **Paper III** and the care providers' experiences of their professional role in **Paper VI** are very similar, but one common feature is that the findings in **Paper VI** are slightly more positive than those in **Paper III**. One obvious difference between the two papers is the method of data collection. Though, I prefer to postulate that the differences are related to the fact that the care providers in dementia care, **Paper III**, had an objective, more strengthened working situation, as many of them experienced physical and mental abuse in their daily work, for example. The work was also physically heavier in **Paper III**.

There is a great deal of confusion when it comes to the content analysis concepts and their different use, which are classified and explained by Graneheim and Lundman (2004). Historically, however, content analysis has its roots in the tradition of journalism and subsequently in propaganda analysis in and after the Second World War, as well as processes of communication, and it is regarded as a way of quantifying qualitative data (Krippendorff, 1980, pp. 9-20). Berelson (1971, p. 18) defines the method in the following way, "Content analysis is a research technique for the objective, systematic, and quantitative description of the manifest content of communication". Content analysis lacks the philosophical foundation that characterises other qualitative traditions, such as phenomenology and hermeneutics (Graneheim & Lundman, 2004). In spite of this, content analysis is systematically used when searching for patterns and themes in people's experiences. Its theoretical assumption can be related to Watzlawick, Beavin and Jacksons' (1967) communication theory (Graneheim & Lundman, 2004). Watzlawick *et al.* (1967, pp. 48-71) pointed out that it is impossible not to communicate. Information is one aspect of communication, while relationship is another. Further, the first message is what we communicate and the second is how we communicate. The manifest content analysis examines and describes the obvious components of communication (Downe-Wamboldt, 1992; Kondracki, Wellman & Amundson, 2002). To a large extent, this analysis answers the question of *what* the text deals with, which is reflected in the construction of categories (Krippendorff, 1980), which are close to the text, with only a small amount of interpretation (Graneheim & Lundman, 2004). Qualitative content analysis is the analysis of the content of narrative data to identify prominent themes and patterns among themes (Polit & Beck, 2004, p. 580). Content analysis can have various aims; describing and quantifying specific phenomena, analysing data consisting of open questions, describing themes and aims in inter-human communication, making reflections on cultural patterns, as well as investigating focus, patterns, meanings, intentions, consequences and contexts for individuals, groups and institutions, for example (Baxter, 1991; Downe-Wamboldt, 1992; Osborne, 1994). It is also concerned with the interpretation of meanings,

intentions and consequences (Baxter, 1991; Morgan, 1993; Weber, 1990). Downe-Wamboldt (1992) underlines the fact that the goal of content analysis is to enhance the inferential quality of the results by relating the categories to the context or in accordance with the environment that produced the data. She says there is no one meaning that can be identified from the data; what you see in the dark depends on where you choose to focus the light (Downe-Wamboldt, 1992).

In qualitative research, trustworthiness is based on credibility – authenticity, on dependability, that deals with the stability, and on transferability, which deals with the extent to which the findings can be transferred to other similar contexts, and it therefore indicates the usefulness of the findings (Lincoln & Guba, 1985; Sandelowski, 1993).

One important aspect of credibility is to present data and processes of analysis in a manner that enables the reader to obtain an insight into and follow the process and to show how well the presented data agree with the aims of the papers. The reason why the presentations include quotations from the original texts, together with further abstractions into the various sub-themes, themes and core themes (**Papers III & VI**) and into sub-categories and categories (**Paper II**), is to help to make an independent assessment of the credibility of the papers possible. The aims of the qualitative papers, investigating nursing approaches towards a resident with a diagnosis of schizophrenia (**II**), describing JS while working with people suffering from BPDS (**III**) and obtaining an understanding of nurses' views and experiences of being a nurse in the municipal PGD context (**VI**), are realised. To deal with credibility, the interview transcripts (**Papers III & VI**) were repeatedly read through, while comparing and validating them against the sub-themes, themes and core theme and the sub-themes and themes respectively (LK), ensuring that no relevant data had been inadvertently or systematically excluded or irrelevant data had been included. One of the authors (KA) read the transcripts while following the path of the analysis. In **Papers II, III & VI**, discussions took place between the authors relating to the dependability and the level of abstraction and how to interpret the messages. The papers represent one possible interpretation of multiple meanings, influenced by the fact that all the authors have long experience of working with demented patients and psychiatry.

In addition, in **Paper III**, six participating assistant nurses confirmed that they recognised the findings. To secure the dependability of this study, for instance, by it being consistent over time, a continuous dialogue also took place with regard to this issue among the authors. To relate to the transferability of the findings, it is up to the reader to make a realistic assessment of whether or not the findings can be transferred to other similar contexts.

It is important to remember that the findings in **Papers I and II** are based on fictitious cases; it cannot simply be taken for granted that the care providers would act in the same way in a real-life situation.

It is important to remember that the nine per cent and 20 per cent respectively in **Papers IV and V** do not actually show how much time the care providers spend with

clients. These figures instead indicate how much time the clients get with the staff. Further, the limitations of **Paper V** include the sample size for the dataset. Usually, the sample size is reported to be at least 100. A sample size of 30 may limit the ability of factor analysis to best explain what is happening with the instrument and people's responses. A sample of 30 individuals limits the number of variables compared with a larger sample size, above 100, where more inter-correlation and perhaps a stronger, more interpretable factor structure might be anticipated. Conclusions relating to client groups A-D must be drawn with great caution, due to their small size and because statistical significance has not been calculated.

Another major limitation in the observation studies in **Papers IV** and **V** is that the PAC instrument that was used only measures the time spent in quantitative terms. There need not be a relationship between the quantity and the quality, but it seems that we sometimes make this unconscious and unarticulated assumption. Even if we cannot define a decent level of being together, the strength is that, to our knowledge, no study of this kind has ever been previously conducted in the PGD context.

REFLECTION

The overall aim of this thesis was to explore features of municipal EGD and PGD care in the post health care reformation era of the 1990s in Sweden. One feature was that being a municipal care provider in this context included a feeling of solitude, an experience of lack of support and that job satisfaction is at risk. Another feature was that the care providers' approaches towards clients rarely included a personhood orientation. While, a third feature was the clients spend the most of their daily lives in solitude, and only a relatively small amount of time together the staff.

The findings are discussed in the light of Kari Martinsen's (1993, p. 149) theory of caring. This theory is influenced by the thinking of Aristotle and K. E. Lögstrup, where the care provider, like the artist, is most reliant on his or her judgement and allows it to dominate the practical knowledge. Martinsen (1993, pp. 75-78) states that knowledge is associated with and bound to the sensuous understanding and that it has nothing to do with science or routine everyday knowledge. According to Martinsen (1989), the foundation of all nursing is the ontological concept of care that is existentially involved with life itself. This care concept consists of a relational, a practical and a moral dimension, where the relational dimension includes an open, close relationship between two individuals. The practical dimension of care, Martinsen (1989) continues, has a situational basis, where the concrete nursing acts rest upon the understanding of what will be of most benefit to the patient. So nursing is also a practical profession (Martinsen, 1994). On the other hand, the moral dimension of care is connected with the fact that human relationships are characterised by power and dependence, but it is bound to the principle of taking responsibility for the "weak" persons. The concept of morals is essential when it comes to the way this power-dependence relationship is administered. In order to act rationally when caring, it is necessary to take the situation and the parties involved, as well as the ethical norms, into consideration (Martinsen, 1984). The moral dimension is stressed as being essential in nursing care, together with relational and practical dimensions; it is of the utmost importance when it comes to providing care (Martinsen, 1989). If any of these ingredients are missing, the moral share will be reduced. Värness (Spri, 1999, p. 53) claims that nursing care for the elderly must have a normative basis and that a relational understanding of the nursing concept ought to result in a way of organising public care, where human dignity is retained.

In the following, aspects of the care providers, from their perspective, will be discussed in relation to the practical, relational and moral care dimensions. Afterwards, the results in term of imaginable consequences for the clients will be debated. Moreover, a discussion of the findings affecting the care provider – client relationship will be presented. Depending on the content and focus, the findings can be sorted into four different levels. Furthermore, due to the fact that nursing care do not take place in a vacuum, the findings also seem to be related to each other, where each level appears to have an impact on the level above. An attempt to visualise the proposed inter-relation of

the findings in the different papers, is present below in figure 1. Three of these levels have been described (*cf.* SIOS, 2004); the individual level, the organisational level including how politics and law are understood and implemented in real life, and the collective level including the law and legal and political ideas in society. In this thesis an interpersonal level is added.

Moral and ethical aspects and nursing care

So, even if caring is always bound in an historical period in certain circumstances, it is first and foremost an attitude in which care providers do or are *for* the other person or not. Juul Jensen (1985, pp. 10-18) states that moral responsibility means acting for *the other* and this responsibility also contains a dimension of power, which emerges as a result of the fact that you tie and make somebody dependent on you. Responsibility implies causal power that includes the ability both to act and to influence (Jonas, 1994, pp. 151-152). The matter becomes mine because the power is mine. However, there is a difference between responsibility to act, when one is held responsible for something one has done, and responsibility for something that must be done. This could be professional caring responsibility that includes caring for sick, weak persons, which is similar to the situation-bound relational ethical responsibility described by Lindseth (1992) and general, looking ahead and continuous, like parenthood (Jonas, 1994, pp. 156-157). Caring responsibility has to be understood from a practical angle and is a moral aspect of health care, where the care provider has the responsibility for using personal judgement when caring for patients and, at the same time, the care provider has a responsibility towards his/her superiors to act. The power may be neutralised or settled if there is mutuality in the relationship and in this way the power can be used in order to create community between the parties (Juul Jensen, 1985, p. 18). We are tied to each other and live in an unbroken and unavoidable interdependence on other human beings (*cf.*, for example, Juul Jensen, 1985; Lögstrup, 1993). It is the human community that makes us who we are, as we cause and maintain the vital necessities together with other human beings (Juul Jensen, 1985, p. 20; Topor, 2001). However, Lögstrup (1994) states that we can either destroy or welcome each other and in that way let life itself be expressed. The expression of life is not imminently dependent on us, due to the fact that life incessantly shows itself in multiple ways. Life comes through us, for instance, when another human being narrates something for us and we can choose to turn it down or welcome and hold this expression of life (Lindseth, 1992). Martinsen (1988) says that the moral dialogue is constituted in practice, but ever since the Renaissance there has been a tendency to eliminate practice in favour of poesis. In a nursing context, the instrumentalisation of both the practice and the poesis activity may have devastating consequences. Martinsen and Wärness (1991, p. 104) state that caring for patients does not improve by academising nursing and they disagree with the thoughts of heightened effectiveness in the area of care and nursing. Martinsen and Wärness (1991) plead for a heightened status for the practice-accented care of sick people, which also entails an implied emphasis on practice-rooted tacit knowledge.

Features of municipal care – from a care provider perspective

The care providers in **Paper VI** feel that their professional role at the PGDs contains practical, relational and emotional parts. The practical part involves teaching by example. Nursing care always takes place in a certain time and place. Their overall experience of the professional role was that they were like a general human factotum not unlike the role of parenthood.

Practical dimension

Almost half the time spent together appears to be characterised by practical activities, like helping the clients in connection with meals or with clothing, medication and surveillance, and it is only characterised to a small degree by simple relationally passive being together (without any other activity taking place) (**Paper IV** and **Paper V**). Task-oriented activities appear to be given priority, which is in line with Martinsen's (1988) description that there might be a risk of instrumentalising the practice.

By making the clients participate in everyday obligations, the care providers attempt to normalise the clients by imitating what they do at home and by maintaining a temporal structure through the days and weeks (**Papers II & VI**). As is shown in **Paper VI**, the staff sometimes think of the clients as annoying and difficult, because the care providers find it difficult to motivate and make the clients participate in activities due to their lack of energy (Pejlert, 2000). They are afraid that, if they do not maintain the structure, this will stand in the way of improvements that will benefit the clients, while changes will lead to deterioration for the clients (**Paper II**). In this context, it is possible to observe traces of the Scandinavian idea of normalisation from the 1950s (Markström, 2003), where the care providers appear to have the preferential right of interpreting what normalisation is. It appears that the concept of normalisation is ruled by social conventions and to some extent this points to the level of ability to imitate the majority. Social conventions – conventional forms, Lögstrup (1993, p. 51) states, have a twofold function; the effect of reducing both the trust that we show and the demand that we take care of the other person's life. This means that they facilitate our relationship with one another, making it smooth and effortless, not least because they protect us from psychic exposure. Without the protection of the conventional norms, associating with other people would be intolerable (Lögstrup, 1993).

Relational dimension

In **Paper VI**, the staff stated that creating and maintaining a relationship with clients was the basic prerequisite for achieving positive changes for the sake of the clients, which was described as a major challenge and a very demanding and trying task. The central feature of caring is the interpersonal relationship (Aanderaa, 1995; O'Brien,

2001). The care providers also sensed a desire from the clients to be relationally accessible. The care providers sensed that they were role models for normalisation, a guarantee of security and stabilisation, and this was the reason why many of the clients just wanted to check that the staff were around, which also feels good for the care providers (**Papers II and VI**). On the relational level, only a few care providers in **Paper II** claimed that it was important to let oneself be emotionally touched by the client, which is the same as Lindström's (1995, p. 42) description of a true caring relationship. She states that the care provider offers his/her I to a Thou in a relationship that breeds trust and tenderness with the opportunity for both fellowship and separateness and where the care provider lets his/her inner be touched by the longing of the client/patient so that the first beam may shine through the mist of loneliness (Lindström, 1995, p. 42). A caring relationship creates a foundation for 'understanding and being understood' (Sundin, 2001). This is also a way of welcoming and holding this expression of life (Lindseth, 1992, Lögstrup, 1956). Obviously, the majority do not reason in this way. It seems as though the clients were rarely related to as persons by the care providers. Instead, the care providers appear to be guided by the medical diagnosis in their way of approaching and relating to the client and this includes a risk of not being seen as a whole, capable person (**Paper I**).

Moreover, the care providers appeared to become more and more insensitive as their years of working experience increased. It is therefore not particularly surprising that the care providers are less sensitive to their relationship with a person with a large number of psychiatric symptoms (**Paper V**). Some of the features of municipal EGD and PGD care in the post health care reformation era are feelings and experiences of contradiction, which is the mutual feature care providers in both dementia (**Paper III**) and psychiatric care (**Paper VI**) express on a relational level. On the one hand, the care providers feel that they are exposed to the clients, because the clients are the reason why they experience being tired and drained of energy, feeling overwhelmed by noise, being abused and feeling humiliated (**Paper III**). In **Paper VI**, the clients are occasionally seen as non-trustworthy persons and lazy, annoying persons, who are difficult to handle. On the other hand, the care providers feel that they really like the clients and, in some cases, view them as their own relatives (**Paper III**) and as mature, competent and significant persons (**Paper VI**). In this way, because of the temporal and spatial proximity to the clients, the relational dimension of caring generates both feelings of suffering and feelings that the relationship is rewarding for the care providers (Peter & Liaschenko, 2004).

Moral dimension

Martinsen (1994, p. 62) states that the moral dimension shows in the way that the work is preformed. So even if, the care providers in **paper VI** sometimes experience the clients as annoying and difficult to handle, they are strongly occupied with thoughts about how to act right towards the client. In **Paper V**, it appears that the clients with a high degree of psychiatric symptoms and a low level of social functioning are also the ones that are most left to themselves. This might not be in line with Martinsen's (1989)

idea that the moral dimension of care is bound to the principle of taking responsibility for the “weakest”, which demands a consciousness about how the care provider-client power-dependence relationship is administered. The care providers may not always do good, but as Bauman (1997, p. 113) states it is not possible to draw an unambiguous line between what are morally good or bad actions. The care providers may not always do good. The moral dimension shows itself in **paper III** and to some extent in **paper VI** through the care providers’ feelings of not doing enough and not feeling sufficient, which generate a feeling of uncertainty (*cf.* Bauman, 2001, p. 19). When performing the work as expressed in **Papers III** and **VI**, the care providers occasionally experience the feelings ambiguity and uncertainty related to themselves. According to Bauman (2001, p. 18-19) human beings are morally ambiguous, the ambiguity creates the core in the primary scene of human encounters. Together with the experience described in **paper III** of being forced towards a limit where they care providers might “hit back”, this causes the care providers an experience doubt about themselves and their own abilities. They feel a lack of confidence in themselves and their own reactions (Hellzén, Asplund, Sandman & Norberg, 1999). In **Paper IV**, the care providers experience “being a failure”, because they fail to stick to their own beliefs; they suffer from a bad conscience and indicate that they feel ashamed. The care providers were conscious of this and it caused them a kind of suffering, in relation to both their own ideals and the “Other”, the clients. This could be understood as failing in one’s obligation to answer, *i.e.* violating the prohibition to kill the Other, which is written in the naked face of the Other (Lévinas, 1988).

The care providers wish to do good and care for the clients (**Papers III & VI**), which they also argue for when they say that acting differently would result in confusion and justify this by quoting their own approaches to care (**Paper II**). Further, in **Paper VI**, the carers explain that they strive for humanistic attitudes and a desire for being and wanting good for the sake of the clients (**Paper III**). They sensed and suffered morally because they felt they were in a gap between what actually is and what ought to be.

Features of municipal PGD care – from a client perspective

From a client perspective, the findings in **Paper IV** show that the staffs are more or less invisible, with an average of nearly nine per cent shared time. Even if the findings in **Paper V** indicate that the rate is more than doubled to 20 per cent, the clients still spend a substantial part of the time alone. According to Denhov (2000) social psychiatric users say that the method that is used to contribute to the process of recovery, or the type of profession, is of minor importance. The central act that is experienced as helping is the time spent together, as well as the relationship between the patient and the professional, where the professionals are around for a long time through different phases of the recovery (Denhov, 2000). In **Paper V**, it is observed that, on

average, the clients are together with the care providers for eight per cent of the time, with the focus on mental, spiritual and social needs. This means being asked and making conversations about how they feel. We have no knowledge about the quality of the relationship, but Topor (2001) claims that the care providers' curiosity and authenticity play an important role. In its fundamental sense, (Lögstrup, 1993, pp. 46-47) trust is essential to every conversation; because in conversation we deliver ourselves into the hands of another and by this very act of addressing a person we make a certain demand on him or her. There is probably no doubt that the staff in **Papers III** and **VI** are emotionally involved with the clients, which is important due to the fact that the emotional involvement of key care givers is significantly associated with the quality of life of clients with schizophrenia (Mubarak & Barber, 2003, Topor, 2001). Bearing in mind that the care providers in **Paper I** appear to relate to the diagnosis, rather than to the person, the question is what kind of tone there is in the engagement and what the psychosocial climate in the relationships is, as this appears to be important in determining the course and clinical outcome of problems in mental health (Forster *et al.*, 2003; Moore & Kuipers, 1999). With reference to the frustration the care providers express in **Papers III** & **VI** and their thoughts of doing wrong things, it might not be too daring to state that there is a risk of a high degree of EE among the staff. According to the Aristotelian (1988) idea, this can be seen as being the equivalent of not having found the mesothesis in a good care provider character, responding too heavily to the clients. Topor (2001, pp. 137-148) states that the feeling of being given special attention, given time and something unexpected from the side of the care provider, is experienced as promoting the recovery process by the clients. From **Paper II**, it is known that the majority of the care providers saw it as their duty to focus on the orientation and correction of the client, which may contribute to a feeling of being stupid and not being able to achieve anything (Tooth, Kalyanansundaram & Glover, 1997) and the clients may therefore experience the support as being inadequate or misdirected. In addition, negative, non-supportive social interactions are significantly related to poorer quality of life in people with severe mental illness (Yanos *et al.*, 2001).

For the clients, the results show that they spend time with the staff for almost ten per cent of the time when something practical is about to happen, mostly in connection with meals, getting into or out of bed, being helped with dressing and hygiene, receiving medication or if the clients check on the staff, are monitored or are walking around (**Paper IV** and **Paper V**). These are normal everyday situations that demand the co-operation of the involved parties to some extent. Normann and Asplund (2002) have shown that demands may cause a higher degree of confusion for people with dementia. Abuse towards the care providers often takes place in connection with the daily co-operative situations associated with basic care activities (Gage & Kingdom, 1995; Hagen & Sayers, 1995).

Features of municipal care – the care provider-client relationship

In **Paper I**, it is obvious that the care providers choose a spectator role in which they deal with the resident by making him/her a psychiatric case, i.e. through a symptom-oriented approach (Normann *et al.*, 1999). This could give rise to thoughts that it is perhaps acceptable to have a large number of symptoms, because people will then relate even more closely to the clients. There appears to be a correlation between the amount and severity of psychiatric symptoms and the care providers' judgements of the social level of functioning, showing that those patients with the most symptoms are also the ones who are most alone (**Paper V**). The care providers' judgements of and attitudes towards the clients, measured here in terms of estimations of PANSS, play a role when it comes to the degree of physical solitude. In **Paper V**, a statistically significant correlation between indices for the PAC dimension of "client alone" and "being seen as withdrawn" was detected, meaning that, the more the client was regarded as "being seen as withdrawn", the more he or she was physically alone. However, the fact that patients appear to be judged according to the degree of symptoms and are not related to as people also creates a risk that the other person will not be allowed to come into his own through words, deeds and conduct; instead, the client might be hindered by the staffs' suspicion and by the picture they may have formed of the client as a result of an antipathy towards him/her. This is then a denial of life, his/her life and the care providers' own life (Lögstrup, 1993, pp. 46-47). By primarily using a care approach in which the clients should be oriented towards "our reality" (**Paper II**), the care provider does not appear to confirm the clients' Otherness (Lévinas, 1988). Lögstrup (1993) states that it is in the very nature of human existence that it does not want to be reduced to reactions which are determined solely by what has transpired. Further, the very nature of the human existence dictates that it wants to be just as new as the other person's new words, new deeds and new conducts. We assume, as it were, that, because they are contemporary, they are new, so we insist upon taking a similarly new attitude to them; we might call this trust in life itself, in an ongoing renewal of life (Lögstrup, 1993, p. 46).

It appears that the majority of the care providers, by using this traditional medical perspective in their approach towards the clients and by showing signs of being depersonalised (**Paper IV**), distance themselves from the humanity of the clients and thereby minimise a fundamental human normative part of themselves, their moral duty to see and take care of the clients (Martinsen, 1993). The interesting question is why this is possible. One suggestion is that it is a consequence of the lack of employer support and above all the lack of knowledge and willingness to guide and lead. This is stated in full awareness of the fact that the moral dimension of care is bound to the principle of taking responsibility for the "weak" (Martinsen, 1989) and that it is an individual's responsibility to act if the power is also the individual's (Juul Jensen, 1985; Jonas, 1994). It is important to remember that nursing care always takes place in a context in a certain time and place.

Features of municipal care – organisation

The care providers feel that they are working in what can primarily be described as a “strangled” situation (**Paper VI**). One mutual feature for EGD and PDG- care is the care providers’ (**Papers III & VI**) experiences of being alone without the support of their employers and feeling insufficient and dissatisfied, which generates a cry for support and confirmation but also demands for guidelines and clarity on the part of the leaders. This is, for instance, seen in one of the themes; being part of a non-rewarding organisational style (**Paper VI**) that bears some similarities to the experience of “not being valued” (**Paper III**), which includes a feeling of being unwanted and defining oneself as an economic burden to the organisation/society. This might be equivalent to Goodpaster’s (1994) and Trollestad’s (2003) descriptions of an unhealthy organisation. They states that the employer’s moral responsibility is easily set aside and compassion, closeness and generosity are replaced by competition, result orientation and a process in which the staff are instrumentalised (Goodpaster, 1994; Trollestad, 2003). Moreover, it is possible that the municipal organisation is a victim of bureaucracy and dependence on techniques, which make it insensitive to the human beings it is serving (Bauman, 1995; Hilberg, 1961). Anyhow, Nyberg, Bermin and Theorell (2005) claim that it is the nearest leader’s leadership that predestines the employees’ experiences of thoughtfulness and support and in reality determines the degrees of freedom and restriction. Furthermore, Lindholm (2005, pp. 128-129) describes how the headship is linked to the outer formal authority that has to make decisions within the framework of the task in order to create the foundations for the work. The headship is surrounded by many circumstances that might lead to problems in the daily working situation; lack of information, changes within and outside the organisation and conflicts that affect the working environment (Lindholm, 2005, p 129). Lindholm (2005, p. 129) adds that transformative leadership knows the needs of its attendants and tries in interaction to satisfy the employees’ higher needs and thereby involve the employee as a person.

The over-riding experience of the clients’ negative behaviours leads to the care providers experiencing their job as negative and feeling that meaning and energy do not originate from the relationship with the clients; instead, it is primarily generated by their colleagues (**Paper III** and **Paper VI** to some extent). The care providers also feel unsafe and insecure in relation to both the clients and the employers. A feeling of insufficiency and dissatisfaction with one’s work could be explained by the fact that the three care dimensions, practical-relational-moral, are not integrated into a whole and, moreover, that, when the focus of the papers is sometimes dominated by practical and sometimes relational aspects, this often takes place in a negatively charged atmosphere. In opposition to this, Argyris (1990) has seen that, if the leadership and the subordinates experience a high degree of JS and a good psychosocial working environment, this will affect the organisation positively. The individual potential resources cannot be developed and result in a positive work engagement if the work organisation is not in harmony with the needs of the individuals (Argyris, 1990). Further, research has shown a mutual dependence between an organisation’s economic profitability and efficiency

and the employees' quality of working life (Argyris, 1990; The Swedish National Board of Health & Welfare, 2006).

The care providers in **Paper VI** even experience fear of doing something wrong and they feel that their employer is nonchalant and lacks knowledge of the target group. On the other hand, they feel supported by each other in the working group, especially in **Paper III** but also in **Paper IV**, where this is expressed in terms of a good and creative working climate. In **Paper III**, the care providers experience an ambivalent JS as a process of moving between breaking down and occasionally building up the working person – destructive aspects. Moreover, the fact that virtually the only support they experience comes from their co-workers is a sign of a poor organisation. Lützén, Cronquist, Magnusson and Andersson. (2003) have identified and described this as preconditions to moral stress, when care providers experience external factors preventing them from what they think is best for the patients and, further, they do not have any control over the situation.

Features of municipal care – society

Both the Mental Health Reform and the Elderly Care Reform are examples of documents with ideological and moral objectives, as they aim to change norms and values in relation to the target groups (March & Olsen, 1989; Markström, 2003). They were also introduced in society during a period of economic restraint and down-sizing (Anell & Hjortsberg, 2001; Hertting, Nilsson, Therorell & Sätterlund Larsson, 2004). The Mental Health Reform does not provide suggestions about how integration and normalisation should be implemented in practical work. It might be helpful further to articulate the assumptions behind the ideas of normalisation, so that the features from earlier steps in the development of psychiatry, such as the medical perspective, are not given the same position. After 50 years of moving patients out of state hospitals and putting them somewhere else, mental health policy-makers and practitioners remain too myopically focused on the locus of care and treatment instead of on the humaneness, effectiveness and quality of care (Geller, 2000). This also characterises the Mental Health Care Reform.

Proposed inter-relatedness between the levels – a figure

At the base of Figure 1, the first horizontal line illustrates the political level, designated the collective-societal level in this thesis. The reforms are diffuse, they are implemented in a period of economic restraint and they signal that certain groups must be given precedence. This means that the recommendations to the organisational-municipal level, the second horizontal line in this case, are indistinct and this leads to the possibility of different interpretations. When care is provided, the care providers, on the third horizontal line, are left alone to work out how this should be done.

Figure 1 illustrates the basic idea that the preconditions at a collective-societal level have an impact on the levels above. The first vertical column in Figure 1 constitutes one feature of the municipal EGD and PGD care, interpreted as abandonment and solitude. On the collective-societal level, a combination of the fact that both the reforms are solely ideological and moral documents (*cf.* March & Olsen, 1989; Markström, 2003) and a Swedish tradition of a relatively high degree of the local right of determination and flat organisations results in a situation in which the reforms provide no concrete directions about the specific content. This means that, when the next level, the organisational-municipal level, implements the reforms into practical work, it more or less has to interpret how to implement them. In relation to the organisational level, the care providers feel that the employer has a lack of knowledge about the clients, the working situation and clarity in leadership and they say that they do not receive support from their superiors (**Papers III and VI**). This is equivalent to the final report of the national overhaul of the municipalities' effects on the social psychiatry of people with long-term mental illness (The Swedish National Board of Health & Welfare, 2005d), which concluded that the reform is not sufficiently rooted in the leadership at the municipalities. This indicates that the local politicians and leaders lack knowledge about caring for the client group (The Swedish National Board of Health & Welfare, 2005d). At individual level, solitude has been seen both from the angle of the client in **Papers IV and V** and from the angle of the care providers in **Papers III and VI**. There appears to be a parallel situation between the status of the care providers and the clients. The clients are actually alone and this is particularly obvious in **Paper IV** and to some extent in **Paper V**. The care providers feel alone (**Papers III & VI**). Lévinas (1992) claims that solitude appears to be an indissoluble unit between the existing person and his/her mission/task to exist. The fact that I exist is the absolutely intransitive element, which is something without intentionality, without relationship and it is possible to exchange everything between people except existence (Lévinas, 1992, p. 35). This goes for all human beings; both clients and staff are alone in the self-realisation of their being. In opposition to the care providers' experiences in **Papers III and VI**, Lévinas (1992, pp. 33- 53) states that the solitude the subject experiences does not originally depend on the lack of support, rather on the fact that it must nourish itself, that it is caught in itself. Solitude is not only despair and abandonment; it is also virility, pride and sovereignty (Lévinas, 1992, p. 53). Moreover, Lévinas (1992, pp. 31-52) states that knowledge will never overcome solitude, because through knowledge the object will be absorbed by the subject and this leads to the destruction of duality, which is incompatible with the ethical idea of confirming the Other's otherness (Lévinas, 1988). On the other hand, however, when investigating the significance of loneliness for persons suffering from severe mental illness and living alone, Nilsson (2003) found that the most clearly distinguished mutual and unvarying feature was "longing" – longing to connect and socialise (Nilsson, 2003; Pejler, 2000). It might be reasonable to assume that, in order to bear the existential anxiety connected with the endless loneliness (Nilsson, 2003), as well as the existential opportunity and responsibility to choose (Kierkegaard, 1994, pp. 73-75) and to reduce the social and existential alienation (Erdner, Magnusson, Nyström & Lützén, 2005), clients must be offered the opportunity

to connect and be together to increase the opportunity for maturity and growth (Mounier, 1952; Marcel, 1999). As a result, there appear to be many reasons why we must take steps to change the situation for the clients.

The second vertical column in Figure 1 represents another feature of the municipal EGD and PGD care, which is understood as an economic situation characterised by restraint. The figure suggests that it might not be a coincidence that an obvious decline in the economic situation, in the post health care reformation era, at the collective-societal level has an impact on the other levels. Martinsen (1994, p. 93) claims that, in times when the economic resources are limited, we have to prioritise caring for those in the worst situation. Otherwise, the disdain for the “weak” will guide our way of organising society (Lögstrup, 1987, pp. 18). On the level above, the organisational-municipal level, an attempt is made to adapt to a new and stronger economic situation (*cf.* Anell & Hjortsberg, 2001; Hertting, *et al.*, 2004). It is proposed that an inherent part of this attempt might involve a risk of instrumentalising and dehumanising the care providers, as can be seen to some extent in **Papers VI** and **V**. At individual level, there also appears to be a parallel situation between the ways in which the persons on the individual levels relate to each other. There is a risk that, if the care providers do not feel that they are related to as persons due to the start of their dehumanisation and instrumentalisation on the part of the employers, at the organisational-municipal level (Goodpaster, 1994; Trollestad, 2003), and partly due to the lack of support and guidance (**Papers III & VI**), they may generally apply an approach based on a symptom orientation and rarely a person orientation towards the clients (**Papers I & II**).

The third vertical column illuminates one positive aspect contributing to the features of municipal EGD and PGD care. This vertical moral-nursing column is interpreted as the moral dimension of care, expressed in goodwill and caring efforts. At the collective-societal level, the reforms are expressions of moral efforts because they want to give priority to the “losers in the welfare society” and enhance the conditions of life for both elderly and psychiatric clients (*cf.* March & Olsen, 1989; Markström, 2003). At the organisational-municipal level, resources are given to realise the reform goals. One positive effect of not giving directions is that the care providers experience the freedom to perform the work as they please (**Papers III & VI**). At the individual-care provider level, this results in generally positive CCQ scores, experiences of occasionally positive JS and support from fellow workers (**Papers III, IV & VI**). So, even if being *for* the other comes through a person, it is a manifestation of life (Lögstrup, 1993) and, even if the first moral reality of the ego is *being-for-the-other* before *being-with-the-other* (*cf.* Bauman, 2001, pp. 21-22; Watson, 2003), which is a starting point rather than a product of society, the reason for moral responsibility cannot and need not be motivated, as the effect of the support within the group of care providers affects the individual-client level positively.

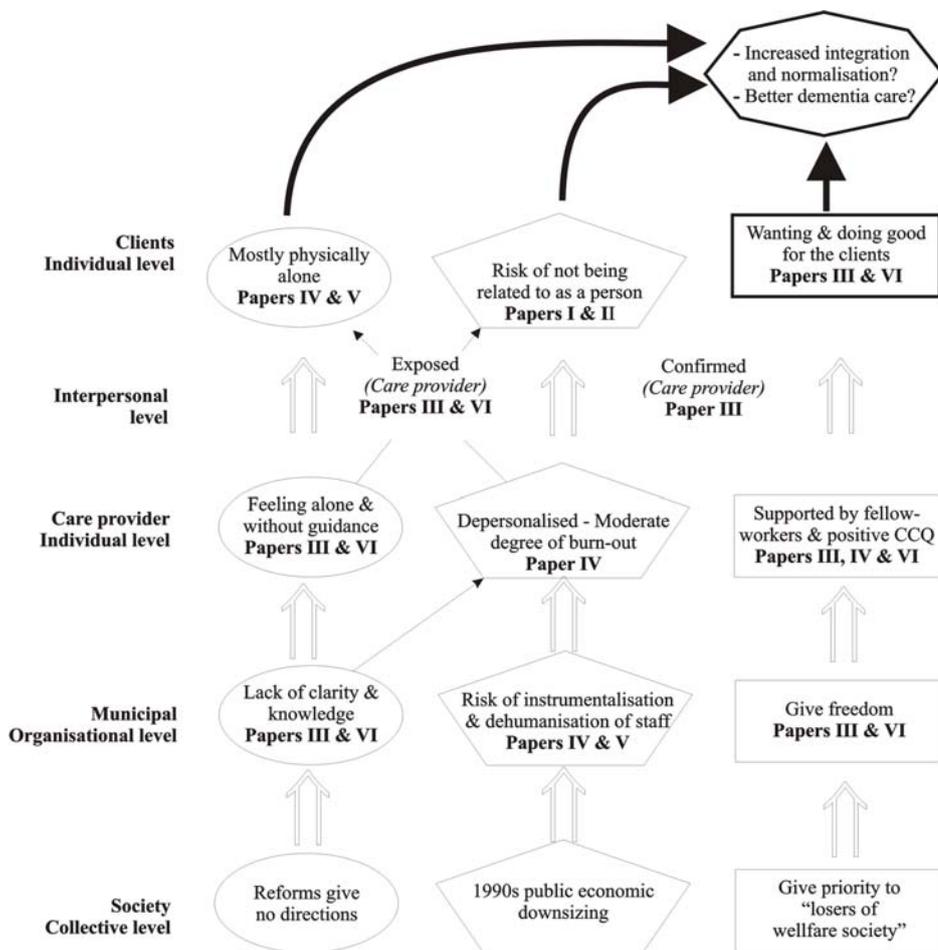


Figure 1

Comprehensive interpretation of the findings. A summary of the identified features of municipal EGD and PGD care in the post health care reformation era.

Conclusions

This thesis has shown that, in order to stimulate a lasting positive contribution towards a heightened quality of services and certainty for the clients, the care provider level, the interactive care provider and client level, the local municipal leadership and headship and the societal levels must all be acknowledged as parts of the caring reality. The purpose has been to lay the foundations for future improvements in care and research by describing different perspectives of caring for persons with psychiatric dysfunctions.

Even though the features of our postmodernist era are ambiguous and characterised by loneliness and hedonism, where everyone tries to find his/her own way without guidance (Bauman, 1995; Habermas, 1989; Reisman, 1985), this does not appear to be the right way to care for the “weakest”. In conformity with the fact that we cannot totally destroy the utterances of life, as they exist independently of humanity (Lindseth, 1992; Lögstrup, 1993), we cannot create a moral reality. Värness (Spri, 1999, p. 53) claims that nursing care for the elderly must have a normative basis and that a relational understanding of the nursing concept ought to result in a way of organising public care, where human dignity is retained. However, we might need to find other ways of further developing psychiatry in elderly care as well, because the postmodernists remind us that what is written about psychiatry and illnesses is culture, while the anthropologists have long argued that psychiatric theory and practice are best understood using the same interpretative tools as are applied to other areas of cultural life, such as religion (Skultán, 2006). More knowledge is needed. We must therefore further explore the situation of the clients from their perspective, by conducting interviews with them, for example, to obtain an enhanced understanding. Efforts to improve the subjective quality of life in people with severe mental illness should include the careful monitoring of depressive and anxiety symptoms and particular attention should be paid to assessments of and interventions against unmet needs. Further, such interventions should stress the strengthening of the social support of clients. It is also important to pay attention to mediators of changes in subjective quality (Hansson, 2006).

However, it appears to be far more important to involve the “dependent” clients themselves in future research, because, as Corrigan and Gelb (2006) state, stigma still impedes the life opportunities of people with mental illness and research therefore suggests that stigma may be reduced by three approaches: protest, education and contact. Even though, Erdner *et al.* (2005) have shown that people with psychical dysfunction consider their own thoughts of themselves as contributing to the stigmatisation.

Implications for nursing

To promote nursing, there needs to be an acknowledgement of the fact that the local nursing cultures are influenced by the social, political, economic workplace and historical environments in which they exist (Goopy, 2005). To secure a balance and

further development, measures must be consciously taken by municipal administrators, for example, to support and direct developments towards a situation in which the shown levels are dominated in far greater congruence. Moreover, further knowledge related to how these levels can be developed to support the clients must be acquired. In order to continue being *for* the clients (*cf.* Norbergh *et al.*, 2005) and to cope with demanding situations, on the individual-care provider level, it is crucial that the organisational-municipal level offers support, including confirmation, feedback and supervision (Severinsson, 1999; Severinsson, 2003; Skovdahl, *et al.*, 2004). This is important as the parallel process of giving supervision and support to the staff that in turn support and help the clients (Playle & Mullarkey, 1998). It also appears to be important to guide the care providers more distinctly, both in stating what is good and proper care behaviour and in not leaving them alone to figure out and define their work role in municipal psychiatry. It is reasonable to assume that they both need a headship and a leadership. Good leaders in care must be able to exhibit care and understand caregivers at the same time.

Future research

To paraphrase Peters and Laischenko (2004), the politicians must come closer to the bedside of the clients in order to understand. This means that, through a changed perspective, there might be a hope of and possibility to understand the Other, because it is then no longer possible to distance oneself from him or her. How can we, in real life, create a shift in perspective? Schützenberger (1998) states that the best way of increasing the consciousness of one's own opinions and attitudes and in the long run accomplishing a change in attitudes is through forming and dramatising different positions and points of view. Moreover, Blatner (1984, pp. 23-136) says that the use of role play as a pedagogic method is well described in the literature and this technique is particularly applicable within industry and school and for everyone involved in the nursing and caring professions. Drama goes beyond the use of words and may extend the embodied knowledge of the participants. Research involving drama must be conducted with a high degree of sensitivity and ethical responsiveness from the side of the researchers as described by Bagshaw and Lepp (2005). Based on the findings in this thesis, it would be interesting to investigate whether the systematic use of drama can have an impact on the attitudes of persons with the preferential right of interpretation and the power to decide, which might, in a longer perspective, lead to a higher degree of experienced quality of life for both elderly and psychiatric clients. This could be explored in the form of both education and "played" contact intervention (*cf.* Corrigan & Gelb, 2006).

A good working environment for both the human resources managers and the employees should always be profitable and lead to a high level of efficiency, productivity and quality (The Swedish National Board of Health & Welfare, 2006), keeping in mind that JS is an important component of care providers' experience of

high-quality nursing care (Wallis, 1987; Lucas, 1991; Cavanagh, 1992; Gilloran *et al.*, 1994). Even though it is of the utmost importance, we should not allow ourselves to be blinded merely by the interpersonal relationship in nursing. Instead, we must at the same time both carefully consider the practical, relational and moral dimensions of care and raise our sights and accept the existence and relatedness of the four parts; the individual client and care provider level, the interpersonal level, the organisational and the collective levels. The studies in this thesis have indicated that the next step in research would benefit from using process-oriented research methods and intervention studies.

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SUMMARY IN SWEDISH (Sammanfattning på svenska)

Genomförandet av äldre- och psykiatrireformen år 1992 respektive år 1995 syftade till förbättrad livskvalitet, på trots av sjukdom eller funktionshinder, för tidigare ej lika prioriterade grupper av brukare/klienter. Intentionen var samtidigt att den samhälleliga omsorgen om dessa grupper av människor i stor utsträckning skulle ledsagas av ett icke-medicinskt perspektiv. Några direkta anvisningar till hur vårdare och andra skulle tillse att reformerna realiserats har inte funnits. Gruppboendekonstruktionen har inom äldreomsorgen setts som ett försök att individualisera och göra boendemiljön hemlik samt överskådlig. Samma boendeform har inom den kommunala socialpsykiatriska verksamheten betraktas som ett mellansteg från institutionsboende till eget boende.

Det övergripande syftet med denna avhandling är att undersöka och beskriva karakteristika vid den svenska kommunala gruppboendeverksamheten för äldre brukare med demens eller för brukare med psykisk funktionsnedsättning efter 1990 talets vårdreform, eftersom dessa påverkar brukarnas/klienternas liv. Detta är dessutom viktigt därför att ett anständigt samhälle utmärks av sitt moraliska och vetenskapliga ansvar att kontinuerligt undersöka livsvillkoren för de sämst ställda. Av detta följer också, om möjligt att förbättra dessa möjligheter. Det är således viktigt att skapa en större förståelse och intresse främst för brukarna/klienterna men även för vårdarna. Att undersöka vårdarnas perspektiv ingår som en naturlig del av den kommunala gruppboende vården, eftersom vårdarna har en rumslig, tidslig och relationell närhet till brukarna/klienterna. I avhandlingen har därför även ingått att undersöka vad det kan innebära att vara vårdare med avseende på attityder, bemötande och arbetstillfredsställelse samt dess möjliga konsekvenser för det dagliga livet och för samvaron vårdare – brukare/klient inom den socialpsykiatriska eller den kommunala äldreomsorgen efter införandet av äldre- och psykiatrireformen. Beroende på forskningsfrågans karaktär har metod valts.

Delstudie I

Ett personorienterat förhållningssätt är mindre förvirrande för personer som lider av demens än vad ett symtomorienterat förhållningssätt är, som är inriktat på att korrigera de sjukdomsrelaterade symtomen. Ett symtomorienterat förhållningssätt är också vanligt vid bemötandet av personer med schizofreni. Syftet med denna enkätstudie var att undersöka huruvida det är möjligt att förklara social psykiatriska sjuksköterskors/vårdares sätt att relatera till äldre brukare/klienter med långvarig schizofreni diagnos utifrån den kliniska bilden eller utifrån det faktum att brukaren/klienten hade en schizofrenidiagnos. Hela vårdargruppen (n=90) inom en kommuns socialpsykiatriska verksamhet fick enkäten tillsänd. Den innehöll en fallbeskrivning av en fiktiv kvinna som led av såväl långvarig schizofreni som allvarlig demens. Vårdaren fick välja mellan två olika ståndpunkter, som bäst beskrev deras tankar och handlande gentemot den fingerade brukaren/klienten. Dessa ståndpunkter var organiserade i 13 par av kategoriska påståenden som antingen speglade en

realitets/symtomorienterat- eller ett personorienterat förhållningssätt. Svansfrekvensen var 80,6 % (n = 75) och dessa var fördelade i en gruppen boendepersonal (n = 57) och en grupp stödverksamhet (n = 18). Data analyserade med hjälp av deskriptiv statistisk och statistisk inferens. Resultatet visade att man inom den socialpsykiatriska vårdaregruppen (n = 75) i ca 70 % av fallen hade ett realitets-/symtomorienterat förhållningssätt till brukare/ klienter. Detta indikerade att en brukare/klient med långvarig schizofreni och samtidig demenssjukdom hade en tendens att förbli bemött med ett korrigerande förhållningssätt, som kan vara kontraproduktiv eftersom det hellre ökar än minskar graden av förvirring. Om man hade arbetet mindre än 10 år inom vården hade man än större grad av personorienterad förhållningssätt, vilket kan tyda på långvarig arbetserfarenhet kan ha en negativ effekt på vårdarens attityder. Vårdare som arbetade inom "stödverksamheterna" hade i mindre utsträckning ett korrigerande förhållningssätt i jämförelse med vårdare från gruppboenden.

Delstudie II

Denna studie syftade till att undersöka om det fanns mönster i social psykiatriska sjuksköterskors/vårdarens attityder till ett fingerat fall och sätt att bemöta en person schizofreni som uppvisar symptom på demens sjukdom. Studien bestod av en kvalitativ öppen fråga i anslutning till det fingerade fallet i **delstudie II**. Den social psykiatriska personalen fick i skriften text motivera hur man resonerade och försvarade det ena respektive det realitets/symtomorienterade - eller det andra personorienterade förhållningssätten med hänvisning till vilka tänkbara konsekvenser det kunde få för brukaren/klienter. Flertalet (n = 66) av personalen svarade. Data analyserades med hjälp av kvalitativ tolkande innehållsanalys. 5 kategorier identifierades; "En situation på liv och död", "Förändringar leder till försämringar", "Struktur leder till förbättringar", "Återbyggnad av identiteten", "Vårdarnas egen deltagande i processen". I resultaten framkom vidare att det till synes fanns ett synligt mönster i vårdarattityderna, där 27 % (n = 18) hade ett personorienterat bemötande och 73 % (n = 48) hade ett realitetsanpassande bemötande, vilket innebar att vårdarna hade svårt att se klienten som annat än vad den medicinska diagnosen sade och därmed personen bakom diagnosen.

Delstudie III

Demensrelaterade beteendemässiga eller psykiatriska störningar ses som en av de mest belastande och stressande aspekter i samband med omvårdnaden av demensdrabbade personer. Syftet med denna studie var att beskriva beskaffenheten av och få en förståelse för upplevelsen av arbetstillfredsställelsen hos vårdare på två gruppboenden som arbetar med brukare/klienter som lider av demens och demensrelaterade beteendemässiga eller psykiatriska störningar. Detta var en kvalitativ studie med narrativa intervjuer med vårdare (n = 20) inom den kommunala gruppboende vården för brukare/klienter som lider av demens. Data analyserades med hjälp av tematisk innehållsanalys. Vårdarnas berättelser indikerade utsatthet, otillräcklighet, en känsla av att inte bli värdesatt samt tvivel. Samtidigt som berättelserna pekade på känsla av betydelsefullhet och respekt för, samthängenhet

gentemot brukarna. Ett sammansatt och ambivalent huvudtema framtolkades: ”Arbetsstillfredsställelse som en process som rör sig mellan att bryta och emellanåt bygga upp den arbetande personen”. Fynden visade på att vårdarna enbart upplevde att de hade stöd från varandra. Vidare upplevdes endast en liten grad av stöd från organisationen. Organisationen och brukare/klienter verkade i stor utsträckning som en belastning och nedbrytande för vårdarna. Kollegor och i viss mån även brukare/klienter upplevdes som varande konstruktiva för vårdarna.

Delstudie IV

I denna studie var syftet att undersöka hur klienter med allvarlig psykisk störning tillbringar sin dagliga tid, när de bor på psykiatriska gruppboenden. Data analyserade med hjälp av deskriptiv statistisk och statistisk inferens. Resultaten från en enkät- och icke-deltagandeobservationsstudie (n=14400) visade enligt Creative Climate Questionnaire (CCQ) på ett gott kreativt arbetsklimat i båda socialpsykiatriska gruppboenden. Maslach Burnout Inventory (MBI) pekade på en moderat förekomst och intensitet av känslomässig utmattning samt en moderat förekomst och intensitet av depersonalisering hos vårdarna. Dessutom fanns en moderat förekomst med hög intensitet av nedvärdering av den egna professionella förmågan. Enligt Global Assessment of Functioning Scale (GAF) bedömdes brukarna/klienterna att ha svåra sociala funktionsnedsättningar. Resultatet av The Positive and Negative Syndrome Scale (PANSS) skattningar av brukarna/klienterna gav vid handen att det förelåg en låg grad av positiva symtom, en moderat grad av negativa symtom samt att de allmänt psykiatriska symtomen bedömdes som varande minimala. Patient Activity Classification (PAC) visade att klienter tillbringade 70.3 % (9 timmar och 51 min) av den dagliga tiden i ensamhet och 1.5 % (43 min) av tiden med andra brukare/klienter. Regressionsanalysen visade att 22.3 % av den tid vårdarna tillbringade tillsammans med brukare/klienter och 29,5 % av tiden som brukare/klienter var ensamma kunde förklaras utifrån brukarnas/klienternas psykiska symtom. Resterande 77.7% respektive 71.5% av tiden kunde inte förklaras utifrån sjukdomen.

Delstudie V

Denna studie syftade till att undersöka om och i så fall på vilket sätt tiden som socialpsykiatriska vårdare och brukare/klienter tillbringar tillsammans är påverkade av vårdarnas uppfattningar om klienters beteenden och social funktionsförmåga. Studien bestod av en enkät- och icke-deltagandeobservationer (n=11200), som analyserades med hjälp av deskriptiv statistisk och statistisk inferens. Det framkom att brukarna/klienterna enligt GAF bedömdes ha svåra funktionsnedsättningar. PANSS skattningarna visade på en moderat grad av positiva symtom, en låg grad av negativa symtom samt en låg grad av allmänt psykiatriska symtomen. PAC visade att brukare/klienter tillbringade 60.8 % (8 timmar och 30 min) av den dagliga tiden i ensamhet och 20.0% (2 timmar och 48 min) av tiden med vårdare. Det fanns endast en korrelation mellan PAC dimensionen 'brukare/ klient ensam' och PANSS underskala för negativa symtom. En faktoranalys av PANSS resulterade i 5 symtomkluster/index: 1

'Blir betraktat som tillbakadragen', 2 'Blir betraktat som agiterad', 3 'Blir betraktat som galen', 4 'Blir betraktat som oroad' och 5 'Blir betraktat som hämmad'. Statistiskt signifikanta korrelationer fanns mellan PAC dimensionerna 'brukare/klient ensam' och 'Blir betraktat som tillbakadragen' ($r_s = 0.512$; $p = 0.005$) samt mellan 'brukare/ klient ensam utanför gruppboendet' och 'Blir betraktat som hämmad' ($r_s = -0.504$; $p = 0.006$). På basis av cut-off värden för PANSS och GAF skapades 4 små grupper av brukare/klienter. Grupp A hade en relativ hög grad av social förmåga samt låg grad av psykiatriska symtom och var ensamma 69.3 % och tillsammans med vårdare i 16.6 % av tiden. Grupp B hade en relativ hög grad av social förmåga samt en hög grad av psykiatriska symtom och var ensamma 69.3 % och tillsammans med vårdare i 19.2 % av tiden. Grupp C en relativ låg grad av social förmåga samt låg grad av psykiatriska symtom och var ensamma i 69.7 % och tillsammans med vårdare i 23.7 % av tiden. Den mest sårbara gruppen D hade en relativ låg grad av social förmåga samt hög grad av psykiatriska symptom och var ensamma i 71.4 % och tillsammans med vårdare i 18 % av tiden.

Delstudie VI

Som en del i roll - omdefinitionen för sjuksköterska/vårdare i socialpsykiatriskt sammanhang, är det viktigt att studera och uppnå en förståelse av uppfattningar och upplevelser av att vara i vårdare i socialpsykiatriskt gruppboendesammanhang. Denna kvalitativa studie bestod av tre fokusgruppsintervjuer med vårdare (n=12) på två gruppboende, där man diskuterade hur det var att vara vårdare i detta sammanhang. Data analyserades med hjälp av tematisk innehållsanalys. Resultaten visade att vårdarna själva fick prova sig fram i yrkesrollen, de upplevde ett otydligt ledarskap samt en höggradigt ekonomiskt styrd organisation och att de kände sig mycket ensamma. Fyra teman tolkades fram: "En omfattande mänsklig alltiallo – inte olik föräldraskapet", "Verkande i en i huvudsak strangulerat situation", "En komplex och ambivalent syn på brukare/ klienter" samt "Känslan av överväldigande frustration".

Reflektion

Avhandlingen är tolkat utifrån Kari Martinsens omsorgsteori. Vården äger dessutom alltid rum i en bestämd historisk tid och är bunden till en viss plats. I avhandlingen presenteras ett försök att påvisa hur beslut fattade på samhälls nivå tillsynes kan tänkas påverka nästa nivå, vilket i slutändan kan få konsekvenser på brukarnas/klienternas liv. De presenterade nivåerna är; brukare/klient-vårdare-individ, interpersonell-, kommun-organisatoriska och samhälls-kollektiva nivå.

När hälsoreformerna genomfördes skedde det utan specifika direktiv om hur man på kommunnivå i praktisk handling skulle omsätta lagstiftningen. Avhandlingen visar att vårdare upplever att den kommun-organisatoriska nivån inte har tillräckligt med kunskap när det gäller såväl brukare/klienter som personal. Man upplever inte att man har någon/något att falla tillbaka på och därmed brist på stöd såväl uppifrån. Detta leder till en känsla av ensamhet på vårdare- individuella nivå. Vidare kan det eventuellt vara

en av förklaringarna till varför brukare/klienter på de psykiatriska gruppboenden är relativt mycket fysiskt ensamma.

Det finns även en risk för att den kommun-organisatoriska nivån, pgr a 1990 talets stora omfattande ekonomiska nedskärningar kan dela till en instrumentalisering och dehumanisering af den kommunala vårdpersonalen. I avhandlingen ses att vårdarna, på den individuella nivån, lider av moderat grad av depersonalisering och utbrändhet. Detta kan eventuellt leda till att vårdarna i större utsträckning är symtomorientering snarare än personorientering i sitt förhållningssätt till brukare/klienter.

På samhällsnivå kan man tolka att hälsoreformerna håller moraliska värden högt i och med att man från lagstiftarens sida vill prioritera "välfärdens förlorare". I avhandlingen ses hur den kommun-organisatoriska nivån ger ett ganska stort mått av frihet. Vårdarna upplever sina arbeten som relativa fria, där man inom ramen för sina befogenheter i stor grad får organisera arbetet som man önskar utan att "någon" lägger sig i. På den vårdare- individuella nivån ses hur man upplever sina arbetskamrater som stöttande och dessutom finns det ett positivt kreativt arbetsklimat. På den brukare/klient- individuella nivån ses en moraliskt önskan om att vilja och göra det allra bästa för sina respektive brukare/klienter.

Den interpersonella relationen mellan brukare/klient och vårdare är av avgörande betydning för rehabilitering för psykiskt funktionshindrade, även om det är viktigt att förstå att vården även har en praktisk och moralisk sida. I avhandlingen presenteras ett försök att påvisa hur innehållet på en nivå tillsynes kan tänkas påverka nästa nivå, vilket i slutändan kan få konsekvenser på brukarnas/klienternas liv. En konklusion är därför att existensen och betydelsen av de identifierade brukare/klient-vårdare-individ, interpersonell-, kommun-organisatoriska och samhälls-kollektiva nivåerna måste accepteras och beaktas, om en hållbar och långsiktig förbättring av reformernas målgrupper och de kommunala vårdarna ska komma till stånd.

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APPENDIX 1

Mrs NN is 84 years old. She became a patient on the ward where you work about two years ago. She was then mildly confused, partly orientated as to time, place and situation but quite unclear about other matters, e.g. she often thought people stole things from her. During the two years since Mrs NN entered the ward, her mental condition has deteriorated more and more. She has now been given the diagnosis of dementia and is no longer orientated as to time, place and situation. Her behaviour is characterized by frequently repeated restless movements such as picking at objects or her own clothes, tablecloths, etc. She sometimes sits continuously wringing her hands. At other times she sits rocking her upper body or banging her right hand rhythmically on the table or on the arm of the chair where she sits. She also often wanders back and forth in the ward. Now and then she moans and groans. She seldom communicates with words and when she uses words they can hardly be understood.