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OLDER PERSONS WITH MENTAL DISORDERS

-health, care and health care situations

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*Our time and our temper seem appropriate for a saner and wiser attack upon
this great human problem [of mental disorders] than has yet been made.*

Bentley and Cowdry, 1934

ABSTRACT

Older persons with mental disorders other than dementia disorders represent a vulnerable group in the health care system. Old age brings inevitable changes and the additional impact of newly developed mental disorders may strikingly alter the life situation. The prevalence of mental disorders is likely to increase with the increase in the older population, and as a result of deinstitutionalization the number of older persons remaining in their own homes with extensive and complex needs is increasing. This entails new challenges for their caregivers in Swedish municipal home help services, mainly nursing aides, and the care they provide may greatly benefit from symptomatic stability. However, treatment of older persons with mental disorders entails complex challenges, with drugs constituting the major therapeutic intervention and adequate treatment calls for knowledge in geriatric psychiatry among the prescribers.

This thesis aimed to develop a deeper understanding and enhanced knowledge about the life situation of older persons with mental disorders. Four studies have been included in this thesis (I-IV). Study I aimed to illuminate the meaning of the life situation as experienced by seven dependent older persons with mental disorders and the findings suggest that their life situation involved a struggle for existence. This was understood as a loss of respect and dignity; they longed for a sense of belonging and to be seen as equals with own abilities and knowledge. Study II facilitated an approximation of the prevalence of mental disorders within the older population in Sweden during 2006 to 2008 by estimating their drug use for mental disorders; drug use was thus a proxy for diagnosis. The Swedish Prescribed Drug Register (SPDR) was used for gathering data on anxiety, psychotic and affective disorders, resulting in an estimated prevalence of mental disorders of 6.6% among the older population, lowest among 65 to 69 year olds and increasing with age. Study III illuminated the meaning of caring for older persons with mental disorders as experienced by nine nursing aides. The findings suggest that nursing aides struggle to find the balance between altruistic and egoistic actions, and distancing was used as recourse to prioritize oneself and diminish the value of caring. Study IV also used the SPDR as a data source to evaluate the prescription of drugs for mental disorders to the older population, focusing on the medical specialties held by the prescribing physicians. The findings show primarily that the proportions of prescriptions made by geriatricians and psychiatrists were remarkably low in comparison to other specialties.

In conclusion, the life situation of older persons with mental disorders is complex and the older persons are neglected, struggle with existential issues, and yearn for respect. The extent of persons seeking health care and receiving treatment for plausible mental disorders suggest that mental health issues are common among the old. The older persons exist in a context encompassing several organizations and care providers. Although nursing aides fill an important human function in the care of the old, they are in need of support and guidance to balance their altruistic and egoistic actions. Their sources of support and guidance may be limited by the lack of specialists in geriatrics and psychiatry in health care. The findings contribute with a deeper and extended knowledge about older persons with mental disorders and conclude that all dimensions

of the older persons are in need of acknowledgment to increase health and well-being. In addition, the status of working with geriatric psychiatry should be increased all through the health care system as it may promote work satisfaction and retention, which ultimately would improve the situation for older persons with mental disorders.

Key words: Aged, Epidemiology, Mental disorders, Municipal care of the old, Nursing aides, Old age psychiatry, Phenomenological hermeneutics, Physicians, Register-based, Specialist competence

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LIST OF ABBREVIATIONS

ATC	Anatomical Therapeutic Chemical Classification
CI	Confidence Intervals
GPs	General Practitioners
ICD-10	International Classification of Diseases, version 10
NBHW	National Board of Health and Welfare
SPDR	Swedish Prescribed Drug Register
SSRI	Selective Serotonin Reuptake Inhibitor

1 INTRODUCTION

Like many other Swedish teenagers, I too spent my summers in the municipal care of the old. I once encountered an older person, stricken by several disorders and bound to a wheel chair, decisive but kind. Although I did not realize it at that time, this older person evoked a new way of thinking for me. One day the personnel experienced a challenge in making this person join the rest of the older persons for dinner. I also did my best to get this person to come and join us, but in contrast to previous encounters I met an aggressive and very decisive person trying to run me over with the wheel chair. I went back to my colleagues somewhat defeated and stated that I did not know what to do, and neither did my colleagues. My unsuccessful attempt in making this person join us was not surprising as I lacked the knowledge in how to deal with the disorders the older person suffered from. But how come my colleagues, who had several years of experience and formal education, were equally unsuccessful? How come dinner with the rest of the older persons was an implicit must? What differed from previous days when the older person gladly joined the rest of the group? What was the right thing to do?

I continued with my studies at the university but these questions remained in the back of my mind. I pursued training in biomedicine and was amazed by the effect of diseases and normal processes on the cellular level of the body. However, my interest for older persons was intact and consequently I applied for a position in the drug industry where the main goal was to develop new drugs for neurodegenerative disorders in the old. After working for some time with cells and life on a molecular level, I felt a desire to learn more about the older persons' present situation and develop knowledge that could improve the situation for older persons here and now.

My experience of my grandmother's journey with the municipal home help service and health care brought still more questions to my attention. In the realization of how challenging the life of a relatively healthy older person could be, I was intrigued to find out how mental disorders, in addition to the regular aging process, would impact the life of older persons. Have you ever encountered or heard about a grandmother or grandfather with severe mental disorders? My guess is that you have not, but how come? How come the picture of a grandmother or grandfather with mental disorders interacting with the grandchildren is so rarely depicted? Do people with mental disorders never get children and consequently never become grandmothers or grandfathers? Or are we, as societal members of the world, intrinsically caught in the stigmatization to such a degree that we do not even consider these persons as equal human beings and consequently disregard their existence?

Somewhere along the winding paths of life I realized that older persons in general and older persons with mental disorders in particular constituted my area of interest and research. Hence I knew, as soon as the advertisement for the Health Care Sciences Postgraduate School and this particular project was announced, that this was my way to find the answers to my questions and possibly improve the situation for older persons with mental disorders.

2 BACKGROUND

2.1 AGING AND OLD AGE

Gerontology, the science of aging and old age, aims at finding the keys to providing older persons with adequate conditions of life and old age (Berg, 2007). In the early 1900s it was concluded that being old implied changing needs and requirements, which led to a need for caregivers to adjust the care given in order to meet the individual needs of the older person (Park, 2008). The process of aging involves biological, psychological and social changes (Tornstam, 2005). Psychologically, aging is a process of development where the emphasis lies on change rather than deterioration; with aging comes the development of the individual's uniqueness (Berg, 2007).

While aging can be described as a molecular process involving changes in function and abilities, old age is experienced by the individual and is socially defined and interpreted from the perspective of previous experiences (Jönsson, 2002). While aging concerns the entire lifespan, from birth to death, old age concerns the later parts of life. Old age is complex and involves as many different definitions and meanings as there are people. The transition into old age is a slow process (Berg, 2007) and depends on changes in physical or functional abilities or in socioeconomic roles (Jönsson, 2002).

In this thesis old age is defined by third and fourth age. The third age is the time where the older person is independent and able to manage on his or her own, while the fourth age implies either being dependent on others to cope with daily life or being deteriorated (Laslett, 1989). In a previous study asking persons 60 years and older in Europe what term they preferred to be called, the majority of the Swedes were in favor of being referred to as "older persons" (Andersson, 1993). More recent studies on older persons' preferred labeling are lacking and this thesis thus uses the term older persons for referral to persons in the third and fourth age.

2.1.1 Demography

The development of society and demographical changes affect the situation for both individuals and groups (Tornstam, 2005). The current prognosis suggests that the Swedish population of almost 9.6 million people will increase by approximately 8% over the next ten years (Statistics Sweden, 2012). The older population (aged 65 years and older) is increasing worldwide (Australian Institute of Health and Welfare, 2007; National Institute on Aging, 2007; United Nations, 2008) and as of the year 2012 it constitutes 19% of the total population in Sweden (Statistics Sweden, 2012). Although estimations on the future population may be affected by unpredicted changes and events, all persons that will be aged 65 years and older in 2076 have already been born. Following the increase in the total population, the proportion of older persons will increase with approximately 18% over the next ten years (Statistics Sweden, 2012). With the changes in life expectancy the demographical transition with an increasing older population may involve an increase of older persons entering the fourth, dependent age. This implies changing needs in the older population and calls for further efforts to be implemented in the health care systems.

2.1.2 Life in old age

Life in old age is characterized by the individual's uniqueness and the meaning of growing old differs among individuals. Wadensten (2007) suggested that whether older persons experience their life in old age as good or bad depends on their previous experiences. Santamäki-Fischer and colleagues (2008) interviewed independent 85 year olds and found that growing old can be understood as trying to maintain one's identity while accepting the changes as they occur. Although societal context and an individual's perception will impact the experience of old age and growing older, the characteristics of positive aging, such as availability of social networks, good health and independence, have been shown to be similar in many parts of the world (Chong et al., 2006). Social networks represent an important part of the older person's life; however, it is the quality of the social interaction rather than the interaction in itself that promotes well-being in old age (Litwin et al., 2006). Old age often involves a shift in focus and increased reflection on life in the past and present (Andersson et al., 2008). Older persons are in need of time and space for contemplative moments and their experience of health and well-being is connected to their ability to adjust to obstacles interfering with their health (From et al., 2007).

People experience transitions throughout life and this does not differ in old age. Transitions in old age involve lifestyle changes associated with both retirement and the move from independence to dependency. Late life relocation has been shown to influence the health of older persons as they may struggle with independence, a lack of autonomy, and feeling powerless and cumbersome (Jungers, 2010). Previous studies have suggested that older persons feel powerless when in need of care and support (Nyström et al., 1994), and when receiving home health care they often try to undertake a position in which they are able to critique the care given or, alternatively, co-care (Öresland et al., 2009). Older persons living in their own homes with formal or informal help are shown to have a low quality of life when struck by disorders, pain or loss of mobility (Hellström et al., 2001). To help older persons retain well-being and render a positive appreciation of the care provided, caregivers in municipal care hold a great responsibility to treat them with respect and encounter them as equals (From et al., 2009).

2.2 OLD AGE AND MENTAL DISORDERS

Mental disorders are debilitating and undoubtedly the biggest threat to good aging and a pleasant old age (Berg, 2007). The National Board of Health and Welfare (NBHW) has on several occasions called attention to the group of older persons with mental disorders and states that the Swedish health care system has failed to implement newly financed strategies to acknowledge them (NBHW, 2008a) and that older persons with psychotic or bipolar disorders do not receive the care and support necessary (NBHW, 2008b). Older persons with mental disorders are not only excluded from social services and health care in Sweden, but are also rare participants in research studies worldwide (Moyle et al., 2007). The concept of mental disorders is in this thesis, unless stated otherwise, referring to psychotic, anxiety and affective disorders, and consequently excludes dementia disorders.

No one can better contribute to the understanding of what it means to live with mental disorders than those actually experiencing it. Studies on young and/or middle-aged persons with early onset mental disorders have focused on their experiences of the recovery process (Bradshaw et al., 2007), loneliness (Nilsson et al., 2008), therapeutic relationships (Shattell et al., 2007), schizophrenia (McCann et al., 2004), and depression (Poslusny, 2000), as well as their family members' experiences (Tryssenaar et al., 2002a; Tryssenaar et al., 2002b). However, the experience of life with mental disorders in old age has been scarcely studied. Early-onset disorders and recurrent depression constitute the primary focuses while studies focusing on the experience of other and late-onset disorders are virtually non-existent. Recurrent depression, as experienced by older women, is viewed as a part of life (Black et al., 2007) or as negatively impacting the self-image, and inducing feelings of failure with a subsequent withdrawal (Allan et al., 2009). In comparison to younger persons, older persons with mental disorders who are living in the community are shown to be socially isolated to a higher extent (Dailey et al., 2000), and whether the spiral of mental health among older women with depression is descending or ascending, depends on whether they feel violated or confirmed (Hedelin et al., 2001; Hedelin et al., 2003).

2.2.1 Stigma and agism

Persons with mental disorders are, regardless of the country and cultural setting, commonly discriminated against as a result of stigma (Beldie et al., 2012). Stigma involves the ascription of negative characteristics (Goffman, 2011), and stigmatizing behavior can be understood as rejecting individuals from a group or social interactions because they hold a certain characteristic (e.g. diagnose or label) that implies unworthiness (Andersson, 2008). A previous study has shown that in the society, persons with mental disorders are considered to be a danger to others and should be avoided (Kermode et al., 2009). Stigma and discrimination against older persons with mental disorders occur both in the public and in the health care sectors (de Mendonca Lima et al., 2003). Caregivers working in inpatient and outpatient mental health care are shown to hold negative attitudes towards persons with mental disorders, and these negative attitudes may increase the patients' pessimistic outlook on life as well as feelings of hopelessness (Hansson et al., 2011). Interestingly, a person's own negative attitude towards mental health care has been shown to hinder help-seeking to a higher extent than the anticipated stigma from their surroundings (Schomerus et al., 2009). Besides being stigmatized, older persons with mental disorders are exposed to agism. The phenomenon of agism has developed in the context of a society that enhances productivity and independence (Tornstam, 2005) and is implemented by younger persons considering their own aged self as fundamentally different from the older persons about whom they express their ageist views (Jönson, 2012). Older persons are portrayed as a homogenous group of people and mostly portrayed negatively in ageist media (Wilińska et al., 2010). Agism or age-dependent care is shown to be a feature in all instances when it comes to treating and acknowledging older persons (Peake et al., 2003). The stigma and agism may result in a situation in which older persons with mental disorders remain under treated and not cared for.

2.2.2 Prevalence and incidence

Older persons in general and older persons with mental disorders in particular are at constant risk for being either over- or under-diagnosed. Mental disorders such as depression are often considered part of primary (normal) aging, and consequently older persons are not diagnosed with depression to the extent necessary to provide them with adequate support and treatment (Berg, 2007). When comparing younger and older persons, it has been concluded that older persons' major depression has a more somatic presentation (Hegeman et al., 2012), which may increase the likelihood of considering depressive disorders as part of primary aging. Estimates of the prevalence of mental disorders among older persons vary between 1% and 46.2% depending on the sample size, selection criteria and setting, as well as on the inclusion of symptoms (Kvaal et al., 2001; Wada et al., 2004; Östling et al., 2007; Olivera et al., 2008; Sigström et al., 2009) and/or diagnosed disorders (Jongeneelis et al., 2004; Mechakra-Tahiri et al., 2009; Bunting et al., 2011; Prina et al., 2011; Meesters et al., 2012). The wide range of estimates makes comparisons among studies difficult.

Studies estimating the incidence of mental disorders among the old are scarce and a first-onset of a mental disorder in an older person is in general considered rare. However, a population-based study in Sweden showed that the incidence of first-onset depression increases from 1.7% among 70-79 year olds to 4.4% among 79-85 year olds (Palsson et al., 2001), and an American study on community-dwelling older persons showed that the incidence for depression is approximately 3% and for anxiety more than 1% (Chou et al., 2011). Thus, first-onset mental disorders are relatively common among older persons. The incidence rates may also be impacted by contextual factors such as living alone, in a nursing home or an institution; these factors have been shown to increase the risk of depression among the old (Xiu-Ying et al., 2012).

2.3 CARING FOR OLDER PERSONS IN ORDINARY HOUSING

The home is important to older persons as it contributes to their autonomy and independence (de Jonge et al., 2011) and with its close link to feeling safe and secure, it is regarded as important to both young and old persons with mental disorders (Granerud et al., 2003). There have been very few studies exploring the meaning of caring for older persons in ordinary housing, but a previous study on registered nurses showed that they adopt and differ between the role as an equal and professional when caring for persons in their own homes (Öresland et al., 2008). Interestingly, caregivers caring for persons with mental disabilities in their own homes are more likely to assess their services as inadequate than those caring for persons with physical disabilities (Vecchio et al., 2008), suggesting that the caring for persons with mental disorders is complex and challenging. One study exploring the meaning of work as experienced by enrolled nurses in American nursing homes reported a sense of closeness to the residents and a sense of pride, control and purpose (Secrest et al., 2005). In addition, in contrast to physicians and registered nurses, enrolled nurses in nursing homes tend to be the most optimistic regarding the possibility of influencing the resident's quality of life (Kane et al., 2006). Previous studies suggest that caregivers should focus on building good relationships with care recipients as well as relatives (Häggström et al.,

2007; Büscher et al., 2011). It has been suggested that in order to increase the perceived level of care, caregivers must both interact appropriately with relatives and attain increased competence (Hasson et al., 2011). In order to maintain a good quality of life among residents in nursing homes and to facilitate fruitful relationships, it is important to focus on the resident's needs, desires and resources (Hansebo et al., 2004), and good relationships may also benefit the caregivers as they have been described as a recourse for countering difficult challenges (Fläckman et al., 2007).

2.4 HEALTH CARE SYSTEMS

A health care system includes all organizations, institutions and other resources aiming to improving health in the population (World Health Organization, 2007). With the changing health care needs that follow an increase in the older population, many health care systems will face challenges regarding the care of older persons with mental disorders (Clinton, 2007). The particular health care systems and related organizations providing care and service to the old vary among countries, depending on its structure and finances. In Sweden, the government carries the responsibility for legislation, whereas the county councils are responsible for health care and the municipalities for all other care efforts (Ekwall, 2010). In 1992 the Swedish government concluded that persons with mental disorders were not cared for in an adequate manner and thereby laid the foundation for implementing the psychiatric care reform (NBHW, 1999). The reform aimed to transfer the responsibility for the psychiatric care to social services, and the process of deinstitutionalization began. In the reform, co-operation between the social services and psychiatric care organizations was emphasized. Although the psychiatric care reform is shown to have improved the situation for the target group (persons with psychotic disorders) it may simultaneously have impaired the situation for persons with diagnoses other than psychotic disorders, due to altered prioritizations and decreases in the budgets (Arvidsson et al., 2005).

In Sweden, a person with a mental disorder or another disability can receive daily assistance, as outlined within the law on support and service to persons with disabilities (LSS) (SFS, 1993:387). However, if a person's condition first was diagnosed after their 65th birthday, they usually receive their support within the Social Services Act (SFS, 2001:453). Whereas the LSS is focused on the individual aspect, provides persons with all-encompassing support and gives them an opportunity to manage life and remain in the own homes, the Social Services Act does not emphasize the individual needs but simply states that the older persons should have a reasonable standard of living, which gives space for structural interpretations and personal preferences. The international systems for mental health care delivery are shown to fail when it comes to detection and alleviation of needs of persons with mental disorders (Middelboe et al., 2001), and mental disorders among the old are rarely recognized and caregivers require both education and strategies in order to identify and manage the disorders (Hassall et al., 2008).

2.4.1 Municipal care of the old

Swedish citizens have a legal right to receive care and support when they are old and in need. With the implementation of old age reform in 1992, each of the 290

municipalities in Sweden was given the responsibility for providing older persons with adequate care, as well as financial and organizational preconditions to promote autonomy, integrity and security in health care and social services (NBHW, 1996). This care includes home help services in a person's ordinary housing, daily activity center, or nursing home, as well as ordinary housing adaptations. Recently, a national set of moral values was included in the Swedish Social Services Act stating that the care provided by the social services should aim to make older persons feel safe, live a dignified meaningful life, and be treated with respect (SFS, 2001:453). The guiding principle for municipal care of the old assist all older persons in remaining in their own homes, to the extent possible (NBHW, 2007), and older persons with extensive needs have been shown to increasingly remain in their own homes (NBHW, 1996).

2.4.1.1 Home help services and nursing aides

The type of support provided by the home help services to older persons in Sweden are tailored to a person's particular needs and generally includes personal care, cleaning and purchasing groceries. Not only is there a tendency for older persons to remain in their own homes dependent on informal care (Olivius et al., 1996), but older persons with depressive symptoms are also shown to receive home help service to a low extent (Larsson et al., 2004). The National Board of Health and Welfare (2011a; 2012a) concluded that older persons with severe conditions are the most dissatisfied with the care and service they receive. With the governmental reforms (NBHW, 1996; 1999) leading to more service and care efforts in ordinary housing, nursing aides or enrolled nurses may consequently face persons with severe disorders to a higher extent.

The majority (80%) of the personnel in municipal home help service in Sweden are nursing aides and enrolled nurses and, at present, 81% of those with a permanent employment hold an education corresponding to a high school level (NBHW, 2012a). Whereas enrolled nurses should have completed the high school level training, nursing aides require no relevant education to begin working in municipal home help services. Although the older population is increasing, likely resulting in an increase in the number of older persons with mental disorders, there is no concurrent increase in number of personnel in municipal home help service (NBHW, 2011a), and current prognoses conclude that there is an acute need for more nursing aides in the municipal care of the old (SALAR, 2011). Hence, the employed nursing aides and enrolled nurses each face an increased workload. An increased workload and pressure result in nursing aides resigning from their jobs, and to retain the work force their skills should be used and developed in the most efficient and best way (Fläckman et al., 2008).

2.4.2 Health care organizations and specialist health care

Health care organizations in Sweden must comply with the health care act (SFS, 1982:763), which defines health care as measures to medically prevent, investigate and treat disorders and injuries. In Sweden, health care organizations are divided into two categories: outpatient (going home after treatment) and inpatient (admission to hospital) care. Health care centers generally represent the first intervention an older person encounters when experiencing ill-health; however, services are limited at such centers.

In order to facilitate continuity, the physicians at the health care centers are mainly specialized in general medicine (National County Councils, 2011), and are thus responsible for evaluating the older person's condition and, if deemed necessary, referring them to more specialized treatment. Unfortunately, discontinuity is common and older persons may encounter several different physicians when visiting the health care centers.

Previous international research has shown that although older persons are subjected to severe disorders and ailments the time allotted to mental health concerns during consultations is generally low (Tai-Seale et al., 2007). Whether influenced by the organizational structures or by diagnostic processes, physicians tend to pay insufficient attention to the effect of age on the patients (Adams et al., 2006), and the tendency of physicians without specialist education to make referrals to adequate specialist care is shown to decrease with increasing age of the patients (Noble, 2001). Being treated by geriatric teams has been shown to help retain function and promote quality of life in older persons (Stuck et al., 1993; Saltvedt et al., 2002) as well as increase the possibility for the older person to remain at home (Baztan et al., 2009; Ellis et al., 2011). Aside from the positive benefits of geriatric teams in the treatment of older persons, health care personnel also prefer interdisciplinary teams comprising different specialists when treating or caring for older persons with mental disorders (Stuijt et al., 2008; Fried et al., 2011).

During the undergraduate training to become a licensed physician in Sweden, a maximum of two weeks are allocated to the field of geriatrics (NBHW, 2011b). In order to attain a specialist degree as a physician in Sweden, five years full-time specialization with supervised sessions and complementary education is required in addition to the general undergraduate studies.

2.4.2.1 Treatment of mental disorders

It is important to consider a broad spectrum of strategies for the management of mental disorders in order to improve the quality of mental health care (Lauber et al., 2005). Several factors are important for preventing depressive symptoms, including an active lifestyle and recurrent physical activity (Aihara et al., 2011) as well as the composition of the surrounding neighborhood (Beard et al., 2009). The National Board of Health and Welfare in Sweden (2011a) has concluded that a holistic perspective is needed in the care of older persons. This conclusion came in response to findings that physicians are often encumbered by a lack of time and personnel, demands from relatives, and ignorance, and tend to prescribe drugs as a primary therapy as opposed to other available and sometimes more suitable therapies. The value of drug therapy is under debate and questions have been raised concerning who the therapy benefits most; for instance drug therapies may be more useful for caregivers in controlling a patient's behavior than in improving the patient's experience of health (Barker et al., 2012). Alternative therapies such as cognitive behavioral therapy are almost never used in comparison to the treatment of younger persons with mental disorders (NBHW, 2012b). When symptomatically stable, older persons tend to focus less on drug management and alternative therapies and instead emphasize physical health, education on their disorders and social functioning as their main needs (Auslander et al., 2002).

Although the older population in Sweden represents a minority of the population they consume one quarter of the drugs prescribed (Berg, 2007), and psychotropic drug prescriptions tend to increase with increasing age in Europe (Alonso et al., 2004). The complexity in treating older persons with mental disorders is further challenged by the pharmacodynamic and pharmacokinetic changes related to age, influences of concurrent disorders, and adverse drug reactions. Polypharmacy and inappropriate drug use are common among the old nationally (Johnell et al., 2007; Johnell et al., 2008), as well as internationally (Hosia-Randell et al., 2008), and older persons are often treated for several synchronous conditions, somatic as well as mental, and thus the risk for adverse drug reactions is increased. Pharmaceutical companies usually test their products on young or middle-aged persons, which implies that possible adverse effects related to age is still unknown, making correct dosing very challenging and calling for increased attention from the prescribing physician. In addition, older persons are shown to encounter several different prescribers, which further decreases the quality of the drug therapy (Bergman et al., 2007).

2.5 THEORETICAL FRAMEWORK

In order to facilitate understanding of the situation of persons with mental disorders, Barker (2009) claim that all kinds of life experiences must be considered. These experiences are related to three various dimensions involved when people construct their identity. All dimensions, world, self and others, need to be acknowledged (Barker, 2001b). Ontologically, human beings are unique and defined by their experiences and relationships, and the meaning of their experiences may develop their sense of self and the world (Barker, 2001b). Previous research has concluded that the polarization splitting the world in two parts, must be reduced as the persons exist and experience a reality in which these parts are always intertwined and dependent upon each other (Källerwald, 2007). Interactions with the surrounding environment (people, groups or organizations) lay the ground for human problems (Barker, 1998) and ill health may involve loss of self (Barker, 1996). Health is a dynamic state, characterized as part of the being and living; it is individually defined and understood, and linked to all aspects of one's life, including social, economic, cultural and spiritual aspects (Barker, 1999). Acknowledging the older person's complexity and uniqueness, promoting dignity and equity of access, and positive staff attitudes is emphasized in gerontology and gerontological caring (Kelly et al., 2005; Eliopoulos, 2010). Psychiatric caring is defined as a long-lasting, interpersonal, mutual activity with the purpose of providing mentally ill people with the prerequisites necessary to experience growth, development and change (Barker, 2009).

In line with these theoretical underpinnings knowledge development must account for the view of personhood as linked to different dimensions. Epistemologically the use of mixed methods expands the scope of research studies and facilitates elaboration of the phenomenon (Sandelowski, 2000). In order to improve the situation for older persons with mental disorders it is important to explore their lived experiences. As the experiences depend on the way reality manifests itself to the older persons it is equally important to describe the health care situation, as it would bring additional knowledge that will help illuminate the complexity of their life situation. An

interdisciplinary approach is preferable when developing new knowledge, and the various disciplines should be regarded as complementary, cooperative and supplementing one another (Scheel et al., 2008), and the importance of multidisciplinary research in gerontology has been enhanced all through the 20th century (Park, 2008). Hence, the epistemological underpinnings in this thesis are based on the combination of different perspectives to develop a deeper understanding and enhanced knowledge of the life situation of older persons with mental disorders.

3 RATIONALE

Although there is an increasing interest in old age psychiatry and research, plenty of indicators suggest that older persons with mental disorders do not receive adequate health care and support, nor are they acknowledged or prioritized in the health care system. The literature to date has focused primarily on older women's experiences of depression and early-onset mental disorders, and thus far has overlooked the complexity found within the heterogeneous group of older persons with different, and late-onset, mental disorders.

With the future rapid changes in the demographics of Swedish society, persons with mental disorders will remain in their own homes and consequently there is a need to deepen the understanding of how they experience their life situation in ordinary housing. It is suggested that the prevalence of mental disorders among the old will rise with the increase in the older population. However, figures on the extent of mental disorders among the old vary widely and overall figures are lacking. Developing knowledge on the current prevalence of mental disorders on large national samples may help guide efforts implemented within the health care system and ultimately benefit the older persons and alter their situation, if necessary.

With the increased use of municipal home help services nursing aides will care for persons with severe mental disorders to an increasing extent. When relating the knowledge on how older persons experience their life situation to the experiences of the nursing aides, areas where the older persons' experienced needs are in discrepancy with the nursing aides' experiences of their work can be identified. The older persons are involved in a chain of care and their life situation may be impacted by the therapies provided. With drugs constituting the major medical treatment for older persons it seems relevant to evaluate the prescriptions on drugs for mental disorders. In addition, the prescriptions are dependent on the competence of the prescribers and evaluating their formal competence will contribute with knowledge that may help improve the quality of older persons' treatment, if needed. Adequate therapy is a prerequisite for symptomatic stability, which in turn could benefit the municipal care providers. Hence, all aspects are intertwined in an endless loop ultimately affecting the life situation of older persons with mental disorders. All in all, a deepened understanding of their life situation may serve to reduce the stigma associated with mental disorders and provide a foundation for the municipalities and county councils in the planning, quality and direction of care and health care efforts for older persons with mental disorders.

4 AIMS

The overall aim of this project was to develop a deeper understanding and enhanced knowledge about the life situation of older persons with mental disorders, including their contacts with municipal care, health care and their representatives. In order to fulfill the overall aim, four separate studies (I-IV) were conducted. The specific aims of these studies are listed below:

I: Illuminate the meaning of the life situation as experienced by dependent older persons (aged 70 years or older) with mental disorders except dementia disorders, living at home and receiving assistance from home help service and/or psychiatry.

II: Approximate the prevalence of mental disorders, except dementia disorders, among the old (aged 65 years and older) in Sweden from 2006 to 2008, by estimating the use of drugs for mental disorders.

III: Illuminate the meaning of caring for older persons with mental disorders, except dementia disorders, as experienced by nursing aides in Swedish municipal home help services.

IV: Evaluate the prescription of drugs for mental disorders to older persons (aged 65 years and older) in Sweden during the three-year period from 2006 to 2008, focusing on the medical specialties among the prescribing physicians and the amount of drugs prescribed to older men and women.

The roman numerals I-IV will be continuously used in reference to the separate studies.

5 METHODS

5.1 DESIGN

The thesis is descriptive and combines qualitative and cross-sectional research (Table I). Sandelowski (2000) suggested that in order to explore intricate human phenomena, complex research designs mixing quantitative and qualitative methods or different paradigms may be used to broaden the scope and deepen the insights. Consequently, guided by the research questions outlined in Table I, two different approaches were used in the thesis: the lifeworld approach and a descriptive epidemiological approach. To increase the understanding of older persons' life situation, their experiences are explored in relation to how the reality for the group of older persons is manifested. The lifeworld approach (Dahlberg et al., 2008) provides an opportunity to develop new knowledge through understanding and was considered relevant when aiming at understanding older persons (I) and nursing aides' (III) lived experiences. A descriptive epidemiological approach (Andersson, 2006) was used for studies II and IV as it facilitates exploration of the extent of disorders and factors of health in the entire population. In the first study (I), the older persons own experiences of their life situation while living at home with support from the municipal home help services and psychiatry were illuminated. The second study (II) aimed to improve the understanding of the magnitude of mental disorders among older persons by examining the prevalence of mental disorders as approximated by registered drug use. The third study (III) explored the experiences of nursing aides in order to develop knowledge on the challenges faced by caregivers in municipal home help service. Finally, to develop knowledge about older persons' contacts with health care, the prescription of drugs for mental disorders and the competence among the prescribers were investigated (IV).

5.2 SETTING, PARTICIPANTS, SOURCE AND POPULATION

5.2.1 Older persons with mental disorders (I)

The geographical boundaries used in study I encompassed five districts in Sweden: one urban district (more than 100 000 inhabitants) and four rural (less than 100 000 inhabitants). Each participant was in contact with one of four outpatient psychiatric wards specialized in psychotic disorders and were forwarded the invitation for participation by the caregivers with whom they had the most regular contact. The inclusion criteria for participants were as follows: aged 70 years and older; currently receiving treatment or under examination for mental disorders by primary health care or psychiatric care; current or previous contact with home help services, caregivers in primary health care or psychiatric care; not subjected to compulsory institutional care; not diagnosed with a dementia disorder; and, able to communicate in Swedish. The caregivers returned the willingness to participate to the interviewer of those who met the inclusion criteria, including either a phone number in order to contact the older persons directly or a set date and time for the interview. The interviewer contacted all persons that encouraged a first contact over the phone and explained the study more thoroughly. All potential participants were given opportunities to ask further questions or decline participation.

Table I. Overview of studies I-IV

Study	Research question	Participants	Context	Data collection	Analysis
I	How do older persons with mental disorders [‡] experience their life situation?	7 older persons (age ≥ 70)	Ordinary homes	Interviews	Phenomenological hermeneutics
II	How common are mental disorders [‡] among the old?	188 024 older persons (age ≥ 65)	Health care	Register-based data	Descriptive statistics
III	How do nursing aides experience caring for older persons with mental disorders [‡] ?	9 nursing aides	Municipal home help service	Interviews	Phenomenological hermeneutics
IV	Who prescribes drugs for mental disorders [‡] to older persons and to what extent?	188 024 older persons (age ≥ 65)	Health care	Register-based data	Descriptive statistics

[‡]Mental Disorders defined as psychotic, anxiety and affective disorders, excluding dementia disorders.

Seven older persons were invited to participate through convenience sampling, and they all agreed to participate. Two of the older persons participating were men and five women. All older persons were living in their own homes and receiving support from the municipal home help services and/or psychiatry. They were all included in the fourth dependent age and their ages ranged from 71 to 75 years at the time of the study. The older persons who agreed to participate were in old age diagnosed with (or under investigation for) schizophrenia, schizotypal and delusional disorders, corresponding to F20-29 in the International Classification of Diseases, version 10 (ICD-10) (World Health Organization, 2009). Three of the older persons included were simultaneously diagnosed with affective disorders (F30-39 ICD-10).

5.2.2 Nursing aides in municipal home help service (III)

The nursing aides worked within the municipal home help service in one urban and two rural districts. Some of the nursing aides included in the study were part of the general staff and visited both older persons with or without mental disorders, while others visited only older persons with mental disorders. Mental disorders were defined in this study as diagnosed affective, psychotic and anxiety disorders, and importantly excluded dementia disorders. Depending on the organizational schedule of the nursing aides, the encounters with the older persons with mental disorders varied from short single or recurrent daily visits to visiting one older person for the entire day.

The departmental heads at the six participating organizations assisted in the selection of nursing aides. All nursing aides eligible and meeting the following inclusion criteria were included through convenience sampling: employed as a nursing aide, experience in caring for older persons (aged 70 years and older) with non-dementia mental disorders, and varying length of experience in the home help service. Nine nursing aides agreed to participate and their work experience in municipal settings ranged from 8 to 41 years with an average age of 25 years.

5.2.3 Older persons in the Swedish Prescribed Drug Register (II, IV)

The Swedish Prescribed Drug Register (SPDR), administered by the NBHW, was used as the data source for gathering information on mental health in studies II and IV. At the time of data collection no national registers existed covering all types of care for all diagnoses. Due to the lack of complete registers in primary health care and the high number of unrecorded cases in inpatient registers and public health surveys, the SPDR was the preferred source for data gathering. The SPDR contains complete information on all drugs dispensed at national pharmacies to the entire Swedish population. The register does not contain over the counter drugs or those used in hospitals.

The study population in studies II and IV consisted of every person in Sweden, aged 65 years and older (3rd and 4th ages), who received one or more of the specified drugs for the treatment of mental disorders from national pharmacies during the years 2006, 2007 or 2008. The mental disorders included were schizotypal, affective and anxiety disorders defined by ICD-10 codes F20-42 (World Health Organization, 2009) and consequently excluded dementia disorders. To avoid analyzing persons with

diffuse symptoms that could be classified as either mental disorders or dementia disorders, all persons with any prescription for drugs targeting dementia disorders (ATC: N06DA02-04, N06DX01) or recommended as firsthand choices in dementia disorders (ATC: N05AA-AX, N05CF-CM, N06AB, N06DA-DX) were excluded. Prior to the application of this exclusion criteria, the data included a total of 737 049 older persons who together received 22 429 097 dispensed drugs over the three years; the application of the exclusion criteria reduced the study population to 188 024 older persons who together received 2 013 079 dispensed drugs for mental disorders during 2006, 2007 and 2008.

5.3 DATA COLLECTION

5.3.1 Interviews (I, III)

5.3.1.1 Older persons with mental disorders

Interviews were the source for data collection used to illuminate the life situation as experienced by older persons with mental disorders. Each interview began with a thorough oral information session about the purpose of the study and voluntariness, and the older persons were again given the opportunity to decline participation; all agreed to participate. Four of the older persons preferred the interview to take place in their own homes, while three preferred to meet with the interviewer at the psychiatric outpatient wards with which they were familiar. In the interviews the older persons were asked to narrate situations from their daily lives and various situations in which they encountered their caregivers. To facilitate active listening and allow the phenomenon to reveal itself, the interviewer must attain a position of openness for the narration (Kvale et al., 2009), and attaining an open attitude means to want to see, listen and understand the phenomenon (Dahlberg et al., 2008). Within the open attitude clarifying questions, such as “Can you tell me more about that?” or “What do you mean by that?” et cetera, were asked to encourage further narration. The interviews lasted from one to two hours, were audio recorded and transcribed verbatim by the interviewer.

5.3.1.2 Nursing aides in municipal home help service

Interviews were the source for data collection used to illuminate the meaning of caring for older persons with mental disorders as experienced by nursing aides. The nine participating nursing aides determined the time and place for the interviews; all interviews were conducted at the nursing aides’ work places. At the time of the interview, each of the nursing aides was presented with the opportunity to decline participation; all agreed to participate. The nursing aides were asked to narrate situations in which they had encountered and cared for older persons with mental disorders. Clarifying questions, as previously mentioned, were asked during the interview to encourage the nursing aide to narrate further. The interviews lasted 40-75 minutes, were audio recorded and transcribed verbatim by the interviewer.

5.3.2 Register-based data (II, IV)

Studies II and IV were based on data from the years 2006 to 2008; social security numbers which allowed the determination of patient age and sex, were first included in

the SPDR from July 2005. The missing data on social security numbers were less than 0.01% in the study population. Each of the disorders included in the studies (schizotypal, affective and anxiety disorders) was evaluated to determine the associated recommended drugs using the Swedish Medicines Information Portal (LIF, 2009). The evaluation was discussed in the research group and with practicing psychiatrists. In order for the cross-sectional studies to distinguish mental disorders from dementia disorders to the extent possible, all drugs suspected of use in treating dementia were excluded, including those regarded as firsthand choices (ATC: N05AA-AX, N05CF-CM, N06AB, N06DA-DX) or intended for use with dementia disorders (ATC: N06DA02-04, N06DX01). Following the evaluation, Anatomical Therapeutic Chemical Classification (ATC) codes, level 5 (chemical substance) were applied.

5.3.2.1 Data measurement studies II and IV

The variables included in the cross-sectional studies were age (65 years and older), sex, ATC codes up to level 5 (chemical substance), and prescribing and dispensing dates. All personal information was replaced with serial numbers. Specialist codes for the prescribing physicians were included in study IV in order to analyze their competence.

5.4 DATA ANALYSIS

5.4.1 Phenomenological hermeneutics (I, III)

5.4.1.1 Theoretical framework

To increase the understanding of the meaning of the life situation of older persons with mental disorders (I), as well as the meaning of caring for older persons with mental disorders (III), a lifeworld phenomenological hermeneutical method was used (Lindseth et al., 2004). This method is inspired by the philosophy of Paul Ricoeur and is used to interpret and understand the lived experiences of the participants. Phenomenological hermeneutics is based on the idea that interpretation of a text facilitates exploration and understanding of the meaning of the lived experience. Ontologically, phenomenological hermeneutics attempts to part from the dualistic view of Descartes and claims that with our participation in the world we cannot hold an objective position against the world. The lifeworld approach thus reduces the distance between science and daily life. According to Husserl (1970), our consciousness is always aiming at the world and our existence is being in the world and in order to part from the reductionist view of the world Husserl introduced the concept of lifeworld. The lifeworld is a prescientific world, our basic reality and the world we face when all theories and preconceived ideas are stripped away. It is a world that exists as a foundation no matter what we do or take for granted during the course of life. Unconsciously we face our lifeworld every day, are inseparable from it, and share it with others. The lifeworld can never be escaped.

Life consists of experiences, and phenomena are consequently a part of life. The phenomenon shows itself to us and, in our dialogue with the world, we participate in the meaning of the phenomenon. Although, the meaning of the phenomenon is there, we may not concretize it or be aware of it in our natural attitude. Phenomenological hermeneutics is a way to explore the world that we participate in and build new

understandings of life; epistemologically, phenomenological hermeneutics is about parting from the natural attitude. In phenomenological hermeneutics the focus lies on the meaning of the experience rather than the factual experience (Lindseth et al., 2004), and the subject needs to be receptive and open in order to allow the phenomenon to emerge (Lindseth, 2010). Openness, an important aspect in phenomenological hermeneutics involves “bracketing” what we think we know about the phenomenon (Husserl, 2004). With awareness of our preconceived ideas and founding values, we may better explore the phenomenon in a new way and develop new understandings. It should be noted that these ideas and values constitute our previous knowledge and may differ from pre-understanding (Lindseth, 2010). Our pre-understanding cannot be described objectively as it constitutes the basis in life; nothing is understandable except in the light of pre-understanding.

As the phenomena in studies I and III concern life itself and the lived experience, one way to access them was to ask the participants to narrate them. The narratives are then recorded in writing, thus creating a text open for interpretation that can then facilitate understanding of the essential meaning of the phenomenon. Phenomenological hermeneutics is about assimilating the text, not in the form of ownership but by being open for the being of the text (Thornquist, 2003). Ricoeur (1976; 1991) suggests that the understanding of the text is about a movement, from what the text says to what it speaks about, and that we may understand the being in the world by what shows itself in front of the text. Ricoeur (1981) considered the text as entailing a life beyond the intention of the author and suggested that the interpretation of the text is about understanding the meaning of the text itself rather than the author’s intention. Our consciousness is aiming at something that involves a meaning according to phenomenology, and this something is not given in advance but has to be interpreted according to hermeneutics.

5.4.1.2 Analysis

The analysis was carried out after the interviews had been transcribed to text. This analysis involved the movement from the whole (naïve reading), to the parts (structural analysis), and back to whole (comprehensive understanding). The dialectic in the analysis moves from understanding to explanation, and from explanation to understanding or comprehension (Ricoeur, 1976). During the understanding we participate in the text and in the subsequent explanation we exit from the text in order to put it down into words (Lindseth, 2010). In the first step, the naïve reading, the text was read in its totality several times in order to grasp a first naïve understanding. Once the naïve understanding had been formulated in words, the structural analysis was initiated. The structural analysis was guided by the naïve reading, the aim and research question in the study. The text was first divided into meaning units which varied in size from a single sentence to lengthy paragraph, depending on what expressed one meaning. After all the meaning units in the text had been established they were condensed in order to let the meaning of the meaning unit appear explicitly, and consequently reduce the size of text. The condensed meaning units were still closely linked to the original text when it came to choice of words and expressions.

The condensed meaning units were then analyzed and compared with respect to differences and similarities in the meaning. Condensed meaning units that expressed one overall meaning were subsequently gathered and abstracted into sub-themes, which were short sentences or words that expressed the overall meaning of the included units. Similar to the abstraction of condensed grouped meaning units into sub-themes, the sub-themes were in turn analyzed with respect to differences and similarities and gathered into themes. Finally, once the text had been thoroughly analyzed and the different steps of the structural analysis fulfilled the themes were further analyzed, gathered and abstracted to form one main-theme. When finalizing the structural analysis, the entire analysis was reflected upon and considered to validate the naïve reading.

Once the naïve reading and structural analysis had been finalized the entire analysis as well as relevant literature and the authors' previous knowledge were brought together to create a new understanding of the phenomenon. The final comprehensive understanding contributed with a philosophical anchorage, a scientific discussion and a deeper understanding of the phenomenon.

5.4.2 Epidemiological analyses (II, IV)

Epidemiological studies aim to describe sickness, health or ill-health through circumstances, prevalence or events among a group of people (Andersson, 2006). Epidemiology can describe and highlight the factors, structures and methods that may facilitate the promotion of health in a population. Descriptive epidemiological studies can provide a basis for further research with analytical methods (Djurfeldt et al., 2003) or bring knowledge that may help plan efforts inaugurated in health care and care service organizations. The health care situation of older persons with mental disorders was described by focusing on the prevalence of drug prescriptions for, and the corresponding approximated prevalence of, mental disorders among the old (II), as well as the amount of drugs prescribed and the competence of the prescribers (IV).

5.4.2.1 Analyses

Both studies II and IV were analyzed using descriptive epidemiological methods. Univariate descriptive analyses with frequency distribution and 95% confidence intervals (CI) were carried out to analyze the register data. The CI gives the range of values that includes the true value with 95% probability (Matthews et al., 2007). SPSS 16.0 for Windows (SPSS Inc., Chicago, IL, 1989–2007) and IBM SPSS Statistics 19.0 for Windows (SPSS Inc. an IBM company, 1989-2010) were used for the analysis in study II and IV respectively.

In study II, the prevalence of mental disorders among the old was approximated by evaluating the prevalence of drug prescriptions, which was calculated as the percentage of persons in the older population (aged 65 years and older) in Sweden receiving drugs for mental disorders, besides those for dementia disorders. To calculate the prevalence of drug prescriptions for mental disorders the following denominators (total population of the old (aged 65 years and older) in Sweden) were

used; year 2006: 1 581 437; year 2007: 1 608 413; and year 2008: 1 645 081 (Statistics Sweden, 2009).

Study IV analyzed the amount of drugs prescribed and dispensed, as well as the specialist codes of the physicians. There were 62 different specialties possible to attain during 2006 to 2008 and each physician may hold several specialties. The following four categories of specialization were used in the analysis: general practitioners (GPs), geriatricians, psychiatrists (including specialist education in forensic psychiatry as well as children and young peoples' psychiatry) and "other specialists" including all other specialists. Licensed physicians with no specialist education were analyzed separately.

5.5 ETHICAL CONSIDERATIONS

The project was ethically revised and approved by the regional ethics board (Dnr 2008/345, 1-2) and ethical considerations were continuously discussed throughout this project in order to raise our consciousness to the potential impacts of the work. Study I involved interviews conducted with vulnerable older persons, a process that may pose a threat to the older persons' integrity as narrating situations from their daily lives and their encounters with their caregivers could sensitize them to their physical and mental state. The asking of questions requiring the older persons to more deeply consider their situation and verbalize both positive and negative aspects may evoke detrimental and destructive thoughts and feelings. In order to minimize the unfolding of such destructive thoughts and to alleviate the older person's mind, off the record conversations followed each interview. It should also be noted that the narration of their positive and negative experiences and situations might also benefit the older persons. Studies have shown that presenting vulnerable persons with an opportunity to share their experiences can lead to a sense of relief (Holloway et al., 2007; Wiklund-Gustin, 2010). The interviews provided the older persons with the time necessary to verbalize their thoughts and the opportunity to be heard and listened to by someone outside their daily lives.

The older persons were encouraged to share their thoughts about what the interview involved during the conversations that followed the interview, providing the opportunity to see their situation in its entirety and facilitating clarity and raising the awareness about the good in their life situation. A previous study concluded that vulnerable older persons appreciate the opportunity to talk (Sofaer et al., 2005) and the interviews may have contributed to a sense of participation and contribution to society. In order to ensure close follow-up with the older persons, with respect to what reactions the interview may have initiated, they were all scheduled appointments with their caregivers in the psychiatry or municipal home help service shortly after the interviews.

In order to reduce the risk that the older persons would perceive the research interview as compulsory, the invitation of participation was forwarded by their caregivers in the psychiatry (psychologists, welfare officers and nurses) with whom they had less frequent contact compared to their caregivers in the municipal home help services. This strategy was selected, as it was the least likely to provoke suspicion that regular help would be influenced or altered, and thus could help minimize added anxiety. In addition, the caregivers in the psychiatry ought to have adequate and up-to-date knowledge on the mental health of the potential participants and were therefore

left to decide whether or not the older persons would cope with participating. The caregivers were thoroughly informed about the study before reading the invitation of participation together with the old person, after which they remained available for questions and/or referral to the persons conducting the study. Voluntariness was emphasized during this process and in subsequent contact, both in writing and orally, along with the assurance that declining participation at any time would in no way impact the care they receive. The caregivers were also informed about the risks associated with the interviews and were encouraged to be observant for any changes in the individual needs of the older persons. The older persons' participation in the interview was considered informed consent. In the transcripts of the interviews, all personal information was replaced with codes and the codes and their corresponding transcripts were stored in different locked cabinets at the university.

Although the nursing aides participating in study III professionally possess more power than their care recipients, they may nonetheless find themselves in a position of vulnerability during a research interview. The interview in itself, with reflection on their work performance and their own personal shortcomings may induce feelings of insufficiency or feelings of being judged. However, the interviews also may have contributed to their personal development, both as caregivers and as persons, by providing the opportunity to reflect upon their values and thoughts about the older persons with mental disorders, thus facilitating clarity, positive feelings and acknowledgment of their positive experiences. The nursing aides were informed about the study and presented the opportunity to withdraw participation at any time; all agreed and signed a consent form. All personal information was replaced with codes in the transcripts and the codes and transcripts were kept in different locations in locked cabinets at the university. Interestingly, requesting interviews with nursing aides in municipal home help service caused astonishment both among the heads of the included organizations and the nursing aides themselves. Consequently, the interview process may have benefited the nursing aides individually and led to an increased appreciation of their competence within their organizations, as well as highlighting areas requiring improvement.

Ethical considerations are equally important for register-based studies. The main concerns include the usefulness of data, the relevance of the research study, and how it can benefit the people included or provide knowledge that may help improve health care organizations. The SPDR was considered to be a relevant tool for examining the health care situation of older persons. All measures available to prohibit the use of, or connection to, the personal identification numbers of each of the persons included were undertaken by the NBHW, Stockholm, Sweden. Consequently, all personal information was securely kept at NBHW and replaced with serial numbers that were presented to the researchers in this project.

6 FINDINGS

The findings of the four studies (I to IV) are summarized and presented under the following headings: “Life situation experiences of older persons with mental disorders (I)”, “Extent of mental disorders among older persons (II)”, “Caring for older persons with mental disorders in municipal home help service (III)”, “Specialist prescribing of drugs for mental disorders to older persons (IV)”.

In study I and III, the main themes constitute the final step of the structural analysis within phenomenological hermeneutics, and the understanding of the main themes thus evolves from all themes and sub-themes. For this reason, the summarized findings will focus on the understanding of the main themes emerging in each of the studies.

6.1 LIFE SITUATION EXPERIENCES OF OLDER PERSONS WITH MENTAL DISORDERS (I)

One main theme, “Struggling for existence” emerged from the analysis of the older persons’ narrated experiences of their life situation. This main theme consisted of the three themes “Being vulnerable”, “Being powerless”, and “Wanting to be respected as a person”, which in turn consisted of 13 sub-themes. The struggle for existence was interpreted and understood as a continuous existential brooding involving a desire to be acknowledged, recognized as equals and considered to possess their own abilities and knowledge. The older persons were self-conscious, powerless and vulnerable, existential issues encompassed their life situation and they experienced themselves as outcasts and neglected. The existential quandaries involved questioning the meaningfulness of life and pondering why the disorders had developed and what exits were available. The older persons were aware of their own mental and physical changes and had an immense need for accessing others’ knowledge in the efforts to understand the causes leading up to their present situation. Being denied access to the knowledge of others was frustrating and struggling for existence involved living under the jurisdiction of others.

The older persons sought sanity, security and safety in their attempts to conquer the own existence and avoid surrendering to the fatalistic prospect of life. In order to shield the own sanity, they maintained hope that life will mend with time, and strategies were implemented to cope with daily life. Although they were reluctant to trouble others, they longed for the help necessary to facilitate taking an active role in managing the own lives. Their life situation was overshadowed with fear; fear of being an obstacle, unequal, misunderstood and labeled. Being labeled diminished the sense of self and restricted the opportunity for them to be themselves. The older persons struggled to maintain their dignity by opposing the categorization by others, while at the same time needing to submit themselves to others and retain their mercy. The own home brought a sense of security and freedom and they fought to regain the respect from their surroundings. The struggle for existence involved a desire to not be singled out but be a part of something bigger.

6.2 EXTENT OF MENTAL DISORDERS AMONG OLDER PERSONS (II)

Based on drug prescriptions, the approximated prevalence of mental disorders, such as psychotic, anxiety and affective disorders, among older persons in Sweden during 2006 to 2008 was 6.6%. Eight percent of the population of older women received drugs for mental disorders, as did 5% of the population of older men. The prevalence was lowest among 65 to 69 year olds and increased with age.

6.3 CARING FOR OLDER PERSONS WITH MENTAL DISORDERS IN MUNICIPAL HOME HELP SERVICE (III)

“Being altruistically egoistic” emerged as the main theme in the analysis of the nursing aides’ experiences of caring for older persons with mental disorders in municipal home help service. This main theme consisted of the four themes “Putting oneself first”, “Acknowledging the older person”, “Enduring the unknown” and “Striving to make the best of the situation” which in turn consisted of 17 sub-themes.

The nursing aides’ experiences of caring for older persons with mental disorders was interpreted and understood as a movement between being altruistic and egoistic. When altruistic, the nursing aides were present in the situation, considered each older person as an equal human being and adjusted their daily routines according to their needs and desires. They acknowledged the older person and encouraged participation to the extent possible. Although time was restricted, the nursing aides showed the older persons that they took the time to be there; they worked for and together with the old, and fought to make the older persons’ desires known. The older persons were respected as human beings and as the owners of their homes. The nursing aides experienced contradictory feelings of joy when meeting the older person and fear at the prospect of the older person acting based on their own reality. In order to maintain calmness, routines were kept and the nursing aides were clear and straightforward in their conversations with the older persons.

When egoistic, the nursing aides put themselves first, acknowledging their own needs and priorities. Caring for older persons with mental disorders involved feelings of helplessness; in such situations the nursing aides utilized previous experiences to cope with the workload. To avoid becoming overly attached or engaged, the nursing aides found ways to escape situations that could threaten their integrity or safety. They attained the older persons’ frame of mind and struggled with and endured complex feelings. They distinguished between their professional and personal lives and chose to act professionally. However, a close relationship to the older person involved difficulties in drawing clear boundaries. Own goals were set for the particular situation that required actions for bringing about the best outcome, which could come into conflict with the older person’s will. To carry out the tasks as scheduled, the nursing aides often needed to endure situations involving a feeling of resignation. They faced realities not corresponding to their own, which involved fear, powerlessness and caused unexpected reactions in need of enduring. They used their work load as an excuse to facilitate escape from threatening situations and they distanced themselves from the older persons, which was understood as a recourse to prioritize themselves and diminish the value of caring.

6.4 SPECIALIST PRESCRIBING OF DRUGS FOR MENTAL DISORDERS TO OLDER PERSONS (IV)

GPs constituted the majority (65%) of physicians prescribing drugs for mental disorders to older persons, while geriatricians and psychiatrists accounted for 4% and 3%, respectively. Of the remaining 28% of prescribing physicians, 14% were physicians with specialist education other than those previously mentioned (mainly specialists in internal medicine, cardiology and neurology) and 14% were physicians with no specialist education. GPs and geriatricians prescribed a higher number of drugs with increasing age of the patient while psychiatrists, other specialists and physicians with no specialist education handed out fewer prescriptions with age.

During 2006, 2007 and 2008, one-half million prescriptions for drugs for mental disorders were prescribed and dispensed yearly at national pharmacies in Sweden. The anxiolytics oxazepam and diazepam and the antidepressant amitriptyline were the most commonly prescribed drugs for mental disorders and were prescribed and dispensed to 39%, 18% and 11%, respectively, of the older population receiving drugs for mental disorders. During the three-year period studied, the prescribing tended to decrease for the majority of the chemical substances included. With respect to the top three prescribed drugs, men received their prescriptions to a higher extent from other specialists and physicians with no specialist education than women.

The majority (85%) of the older population received one chemical substance, while the remaining 15% received two or more substances. Of the physicians prescribing several substances to women in 2006, geriatricians were increasingly represented as the number of substances increased; this trend was not seen for men. A similar tendency was seen in the prescribing made by psychiatrists in the year 2006 to both men and women, as psychiatrists represented a higher proportion of prescribing physicians as the number of substances increased. During 2007, geriatricians and physicians with no specialist education prescribed drugs to a low extent to both men and women. Psychiatrists prescribed drugs increasingly with increasing number of substances for women while their prescribing to men decreased with more than five substances. In 2008, both men and women received their prescriptions from geriatricians to a low extent, and psychiatrists handed out prescriptions increasingly with increasing number of substances.

7 DISCUSSION

7.1 THE LIFE SITUATION OF OLDER PERSONS WITH MENTAL DISORDERS

Taken together, the findings of the older persons' experienced situation (I) in relation to how the reality is manifested to them (II-IV) suggest that the life situation of older persons with mental disorders is challenging, complex and in need of improvement to facilitate health and well-being. Neither life nor health is in a static state; both consist of varied experiences. The concept of health implies "wholeness" and the experience of health or ill-health is dependent on how the persons live their lives (Barker, 1999), and persons with mental disorders have been found to define health as a process aiming towards satisfaction, harmony and meaning in the present (Svedberg et al., 2004). The older persons' experiences interpreted as struggling for existence implied vulnerability and being neglected as a result of their disorders (I). Being an older person stricken by mental disorders also includes the challenges old age brings. Old age has been suggested to involve a changed perception of the world based on person's previous experiences that help mold the reality and create new definitions and values (Tornstam, 2005). The older persons included in this thesis experience deterioration and powerlessness, as well as a lack of meaningfulness in their life situation (I), all of which suggest that their process towards health is obstructed and emphasize the need to provide them with appropriate, all-embracing, care and health care.

Older persons struggling with mental health issues do not represent a few isolated cases. During 2006 to 2008, the approximated prevalence of mental disorders among the old, with drug use used as a proxy for diagnoses, suggest that almost every 15th older person are presenting their physicians mental health concerns in need of drug treatment (II). Future demographical changes in society will possibly lead to greater numbers of older persons with severe disorders in need of home support and care. It is possible that the prevalence of mental disorders among the old is higher, since older persons with mental health issues are under diagnosed worldwide and do not receive adequate treatment and care to the extent necessary (Olivera et al., 2008; Seelig et al., 2008; Garrido et al., 2011). However, although the treatment of older persons with mental disorders is complex, physicians in Sweden tend to prescribe drugs as a primary therapy when treating older persons with mental disorders (NBHW, 2011a). Thus the approximation should include many of the older population receiving treatment for their disorders. Considering that the older persons experience themselves as alienated and neglected (I), this high prevalence (II) highlights the importance of acknowledging this group and calls for increased attention in the health care systems.

The findings of study I suggest that older persons experience a struggle for existence and recognition while fearing being stigmatized and labeled. The label entailed deprivation of the older person's true self and increased the experienced powerlessness. Whether these experiences are the direct result of their disorders or rather intensified by their symptoms is to some extent a side issue, as persons with mental disorders receiving support from home help service and/or psychiatry are struggling for their existence. This suggests that the dimension of self, included in

personhood (Barker, 2001a), is lacking the emotional security necessary for development; thereby possibly diminishing the older persons' sense of well-being. The experience of health among older persons is quite dependent on the behavior of their caregivers (From et al., 2007). Thus the experience of health and well-being can easily be disrupted, and powerlessness is suggested to be the essence of ill-health (Strandmark, 2004).

When entering the older person's home the nursing aides perceived the older person first and foremost as a fellow human being, and took the time needed to properly perform their tasks even when time was not permitting (III). Showing mutual respect and establishing a personal relationship with the older person is one of the vital components for promoting health in mental health care (Svedberg, 2011), indicating that the nursing aides' humanitarian approach may help the older persons retain their well-being. However, the lack of recognition and respect experienced by the older persons (I) suggest that the nursing aides efforts to acknowledge and respect the older person (III) during care were insufficient. Difficult issues and human problems derive from the intricate person-environment interactions we all exist in (Barker, 1996), thus suggesting that the older persons' experiences are dependent on the nursing aides' approach. Caring for older persons with mental disorders in municipal home help service was understood as being altruistically egoistic (III); nursing aides caring efforts were at times altruistic or egoistic, depending on the situation, and they struggled to find a good balance. In their attempts to cope with difficult situations and meet organizational standards, the nursing aides adopted what they felt was "a professional role" (III), despite the fact that such a role is neither described nor outlined by the organizations, leaving the nursing aides to assume what it entails. This led to the down prioritizing of caring in order to cope with or endure discomfort and situations in which the own personal knowledge was exceeded. Close relationships to the older persons interfere with boundaries, and in order to maintain professionalism the nursing aides distanced themselves from the older person (III). Distancing is suggested to serve as a defense mechanism to avoid engagement in the interpersonal relationship (Määttä, 2006), and results from the caregivers' necessity to protect themselves and avoid showing personal vulnerability (Lindseth et al., 1994).

The older persons struggle for existence was understood as trying to access the knowledge of others to understand the causes leading up to their situation (I). In their attempts to reach others' knowledge they were in contact with several organizations such as municipal care and health care. Drugs constitute the major treatment intervention in Sweden (NBHW, 2011a; 2012b). Therefore older persons in contact with health care presenting their physicians mental health concerns are likely to receive drugs for mental disorders. Hence the analysis of the SPDR (IV) elucidates which physicians the older persons met with during 2006 to 2008. As for the rest of the population the older persons are likely to meet GPs in their contacts with health care, and the findings of study IV show that GPs represent the main prescribers of drugs for mental disorders to older persons. With the complexity in the treatment of older persons in general and older persons with mental disorders in particular an increased contact with geriatricians and psychiatrists could be expected. However, the findings of this thesis show low number of referrals to specialists in geriatrics or psychiatry in health

care (IV). Interestingly, with the increasing age of the older person, their drugs are prescribed by geriatricians to an increasing extent (IV), which could imply a tendency of older persons to be treated by geriatricians as they approach 100 years of age. The proportion of prescriptions written by psychiatrists was even lower than that of geriatricians, and this proportion decreases even further with increasing age of the patient (IV). The increase in prescriptions made by geriatricians and decrease by psychiatrists with age (IV) implies that, within the health care organizations, the older persons are primarily seen as old and secondarily as mentally ill.

7.1.1 Contending with existential issues

The life situation of older persons with mental disorders involves existential quandaries in which the meaningfulness of life was questioned (I). In this struggle to be recognized (I), various existential issues encompassed their life situation, including issues concerning the elements of human life such as freedom, death, meaning, and isolation (Yalom, 1980). Fear encompassed the older persons' life situation, fear of being an obstacle, misunderstood and labeled (I). A previous study suggested that we all struggle with existential issues from time to time; for persons with mental disorders, this struggle is taken to the extreme (Perseus et al., 2005). A lack of meaningfulness in everyday life can leave an existential void among young and middle-aged persons with long-term mental disorders (Erdner et al., 2002); however, they tend to experience an increased acceptance and ability to cope with their disorders with increasing age (Cohen, 2000; Tryssenaar et al., 2003). The importance of the relationship to oneself is emphasized to understand the experience of what constitutes a good life for the person with mental disorders (Barker, 1999). The older persons' self-images were shattered (I) and diminished as they experienced themselves as unworthy and subordinate. The self-images reflect all the dimensions of personhood, world, self and others (Barker, 2003); suggesting that their experienced unworthiness may be increased by aggravating relations to the world and others. A review on lived experiences of persons with mental disorders has shown that they seek normalcy and integration in the community, calling for therapeutic relationships based on respect (Zolnierrek, 2011). Although the older persons tried to avoid surrender to the fatalistic prospect of life by creating strategies for maintaining sanity (I), they were diagnosed in old age, implying a shorter amount of time to adapt to their new situation. This could in part explain the increased existential brooding in the absence of adequate help and support.

Existential isolation goes beyond the interpersonal and intrapersonal isolation and implies being separated from existence; this isolation persists even if the person is committed to oneself and engaged in the world (Yalom, 1980). The struggle to be acknowledged and receive recognition for the own existence involved seeking togetherness (I), which was understood as a will to be part of a greater whole that exceeds the individuals and organizations. Paradoxically, receiving support, care and health care from the home help service and/or psychiatry meant living under the jurisdiction of others (I). With the lack of autonomy in daily life, vulnerability and invisibility was commonly experienced (I). A person's sense of isolation is affected by the person's anticipations, diminished self-respect and attitude towards others (Erdner et al., 2005). The older persons' struggle to belong and exist (I) could be understood as

having lost the dignity of identity, which is connected to the body, mind and self-image of the older persons and is affected both by changes within oneself as well as by the actions of persons nearby (Nordenfelt, 2004; 2005). The findings in study I suggested that the dignity of identity was not necessarily diminished by their disorders but rather by the anticipated prejudice of people nearby. This corresponds to a previous study showing that women with depression resign as a result of their conviction that their caregivers depreciate them (Allan et al., 2009). Loss of dignity or being stigmatized is closely connected to humiliation, which impairs the self-esteem and reduces the ability to appreciate oneself and the own life (Statman, 2000; Edgar, 2004). Persons with mental disorders are shown to experience shame and fear being alienated when trying to become integrated in the community (Granerud et al., 2006). Barker and colleagues (2008) suggest that failing to acknowledge the individual person and the differences between persons impairs their processes of recovery and development. Consequently, the self-image of older persons with mental disorders may be further impaired as they struggle to be acknowledged (I) and the acts of surrounding people may hinder their achievement of a higher self-esteem and self-respect.

Mental disorders are debilitating and often give rise to suicidal ideation. The older persons experienced a fatalistic view of life in which the meaningfulness of life was questioned and exits were sought after (I). Older men and women with mental disorders commit one out of four suicides in the total population in Sweden each year (NBHW, 2012b), highlighting the severity of older persons' ideation. Several factors such as medical comorbidity and hospitalization (Erlangsen et al., 2005) and depressive symptoms (Sun et al., 2012) are strongly associated with suicide among older persons. Additionally, a low rated subjective quality of life is shown to be associated with high suicidal behavior among persons with schizophrenia (Kao et al., 2012). Those who commit suicide are functionally declined, distrust health care services and fear being dependent (Kjolseth et al., 2010). Indeed, the older persons lack of autonomy to rule the own life (I) entailed loss of dignity of identity, and brought about feelings of dejection, meaninglessness and powerlessness, which together decreased the will to live.

Although nursing aides' humanitarian approach (III) is a valuable component of municipal care of the old, they may lack relevant knowledge to cope with challenging situations that arise when caring for older persons with mental disorders. Caring for older persons with mental disorders often involved feeling helpless and powerless (III); indeed feeling powerless is a common reaction, as is fear and insufficiency, among caregivers caring for older persons acting in a violent manner (Åström et al., 2004). To manage these situations and cope with the workload, the nursing aides utilized their previous experiences (III). This is in line with a previous study showing that caregivers take spontaneous decisions to act in the most suitable way possible and use their tacit knowledge to set boundaries when caring for persons acting in an aggressive and violent manner (Carlsson et al., 2000). There is a fine balance between helping and causing harm; well-performed caring activities can help compensate for the older persons' obstacles and facilitate a sense of well-being, whereas the same activities performed either poorly or in rudeness can increase dependency or ill-health (From et al., 2007). A previous study suggested that caregivers in municipal care of the old need support and supervision in order to maintain a good self-esteem and relationship with

the older person (Häggström et al., 2010). Hence, nursing aides should be provided with sufficient support to be able to cope with the state of mind of the older persons. Providing good care for persons with mental disorders is suggested to imply an approach in which the persons are accepted for who they are, and such acceptance may result in a positive change (Nyström et al., 2002).

The older persons struggled to maintain their dignity by rejecting the categorization by others, while at the same time needing to submit themselves to others in order to retain their mercy (I). Without the help provided by the caregivers, their capacities would likely diminish even further. Following loss of capacity, regardless of the origin, comes a loss of basic dignity (Moody, 1998), suggesting that the older persons are subjected to loss of dignity in several aspects. Experiencing lack of dignity and worth in the eyes of others could intensify the existential vulnerability, as it is associated with feelings of shame and degradation and a decreased will to live (Chochinov et al., 2002). In addition, the older persons experienced objectification and felt that they had been equated with their disorder (I). This experience of being equated with their disorder could possibly be reinforced by the distancing undertaken by the nursing aides (III). Objectification, whether it is a result of caregiver's attitude or the older person's shattered self-image, implies a risk of violation of the older person's dignity (Moody, 1998). Although diagnoses may increase objectification, they may also provide the older persons with recourse and a better understanding of their situation. The older persons were aware of their mental and physical changes and searched for and desired access to the knowledge of others in order to grasp their situation (I). A previous study on young and middle-aged persons suggested that being diagnosed released the burden of guilt and helped with acceptance of the situation (Nyström et al., 2007). However, the outcomes of a diagnosis involve both the aspects of recourse and understanding as well as objectification and reductionism. Mental disorders pervade the person's entire lifeworld (Nyström et al., 2007) and the diagnosis account as labels reflecting the apparent dimensions of the disorders rather than including all aspects of the persons' life (Rusner et al., 2009). In addition, diagnosis with a mental disorder increases the likelihood of being targeted of stigma and discrimination and older persons with mental disorders in Europe experience discrimination and stigmatization among the public and health care sectors (de Mendonca Lima et al., 2003), possibly increasing the older persons' existential queries.

7.1.2 Older persons and health care

Considering the dimensions composing personhood, world, self and others (Barker, 2001a) developing knowledge on the health care situation of older persons with mental disorders promotes understanding of factors influencing the world dimension. The world dimension of personhood is focused on the need to be understood and receive validation of the experienced disorders (Barker, 2001a). The diagnosis is necessary in providing the older persons with adequate therapies, which subsequently could increase their well-being and improve their situation. Although diagnoses may increase the experienced objectification (I), they may, paradoxically, facilitate understanding of the situation both from the aspect of the older persons as well as their caregivers. The findings show that prescriptions on drugs for mental disorders to older persons are

common (II) and most often prescribed by GPs (IV). It should be noted that the majority of licensed physicians in Sweden are GPs. Hence, there is no surprise that they constitute the majority of the prescribing physicians for the old (IV). However, the high prescribing rate by GPs and the remarkably low prescribing rate by geriatricians and psychiatrists could be indicative of the health care system's differentiation according to the severity of symptoms; patients with complex symptoms and disorders are more often referred to psychiatry, while those perceived as having mild forms of mental disorders are treated in primary care where the majority of physicians are GPs. This evokes questions concerning whether or not older persons with less severe symptoms need less specialized care. Perhaps the referral of patients with mild forms to psychiatry would facilitate the prevention of deterioration and thus reduce the financial costs for society. However, such issues remain unclear in the present study and call for further studies.

After excluding drugs used in plausible dementia disorders or drugs recommended as first-hand choices in dementia disorders, the most commonly prescribed drugs for mental disorders were anxiolytics and tricyclic antidepressants (IV), despite their association with a high risk of adverse effects in the old (Laroche et al., 2007). This indicates that there is a need to regularly examine the prescriptions given to older persons with mental disorders. This is in line with previous studies suggesting that in order to reduce inappropriate prescribing and adverse effects, the competence in the chain of care surrounding the older persons should be utilized (Griffiths et al., 2004) and the prescriber should scrutinize the list of drugs prescribed and dispensed on a regular basis (Garcia, 2006).

During 2006, 2007 and 2008 men tended to receive their prescriptions from physicians without specialist education and specialists other than GPs, geriatricians and psychiatrists to a higher extent than women (IV). It has been shown that men's symptoms of depression are more likely to remain unrecognized by GPs (Crawford et al., 1998) and men are less willing than women to admit to depressive symptoms (Rutz et al., 1995). Thus, these trends suggest that the awareness of mental health issues among older women possibly is higher, which may have led to more frequent referrals to specialists such as geriatricians and psychiatrists. The findings of study II also suggest that the prevalence of drug use increases with increasing age. Whether or not this increase is related to an increased prevalence of mental disorders or to the increased likelihood of receiving drug prescriptions remains unclear. A previous study has shown that the incidence and prevalence of depression increases with increasing age (Skoog, 2004), suggesting that the approximated prevalence based on drug use could indicate an increase in mental disorder diagnoses with age. However, several other studies have shown that the prevalence of anxiety or psychotic symptoms or disorders is higher among 70 year olds (Olafsdottir et al., 2001; Sigström et al., 2009) than 78 year olds (Forsell et al., 1997), and affective disorders is highest among 65 year olds (Gottfries et al., 1997) and decreases with increasing age (Forsell et al., 1997; Olafsdottir et al., 2001). Thus it seems likely that the increase of drug prescriptions with increasing age (II) is correlated to the increased likelihood of receiving drug treatment with increasing age rather than new diagnoses. This further strengthens the importance of scrutinizing the drug list of older persons to reduce

inappropriate prescriptions, decrease possible adverse effects and increase the older persons' well-being.

7.2 OLDER PERSONS WITH MENTAL DISORDERS AND THE ORGANIZATIONS

The older persons were fighting to conquer the own existence and to be seen as equals with their own abilities and knowledge, and the struggle for existence involved being bothered, powerless and urging to be respected for who you are (I). Older persons in municipal care lack alternatives or possibilities to influence the care given (Persson et al., 2009), and the additional stigmatization frequently experienced by older persons with mental disorders (I) makes it very likely that they encounter the same limitations, though possibly to an even greater extent. In addition, reports from the NBHW conclude that older persons with mental disorders do not receive care and support to the extent needed (NBHW, 2008b) and are neglected in health care systems (NBHW, 2008a).

The third dimension included in the personhood is the dimension of others. In this dimension, the focus is on the combined need of interventions that facilitate an ordinary life (Barker, 2001a). The older persons' struggle for equality and respect (I) suggest that the municipal care organizations and psychiatry care may act according to their own agenda without regard for the older persons' own will or needs, or at best the care efforts implemented are not adequately communicated to the older person. This is supported by a previous study showing that care in a psychiatric ward is primarily given in line with the caregivers' beliefs and values rather than the person's own self-image (Enarsson et al., 2011). The older persons' struggle for existence (I) could also be reinforced by the lack of prescribers with specialist competence in geriatrics or old age psychiatry (IV). This implies that they experience neglect not only on the personal level but also on an organizational level. The organizations and the included staff thus hold a responsibility to acknowledge the older persons and provide them sufficient support and health care. Hence, this implies that the health care system is in need of practice development. Development of the practice may contribute to a focus on the older persons' needs rather than the setting and separate organizations; such development is considered as important to promote well-being among persons with mental disorders (Barker, 2001a). Practice development focuses on the interconnectedness of the different levels in the health care system, aiming to improve the care for the patient by implementing developmental changes in organizational culture and context where the care is given (McCormack et al., 1999). Collaboration both in terms of caregivers' collaboration with patients as well as social services collaboration with health care constitute necessities in order to provide older persons with mental disorders adequate help and support (Barker, 2009). As a process, practice development supports healthcare teams in developing their knowledge and skills as well as transforming the environments to meet the needs of the patients, to ultimately improve the person-centered care (Garbett et al., 2002), and is used to integrate research, development and practice (Kitson et al., 1996). In order to facilitate practice

development it is important to understand which improvements older persons value as well as the challenges caregivers face.

The older persons struggle for existence involved a desire for recognition, respect and participation (I), suggesting that relational aspects of care were very important to the older persons. Previous studies have indicated that in order for older persons to retain well-being and experience their care as positive, they must feel appreciated and acknowledged for who they are, and contribute to decision-making (Bridges et al., 2010). Caregivers therefore need to secure a good quality caring relationships (Custers et al., 2010) as interpersonal relations contribute to the progression of persons with mental disorders as human beings (Barker, 2000). Hence, the distancing undertaken by the nursing aides (III) may lead to an impaired relationship and disturb the older persons' progress. Relevant knowledge is a prerequisite for properly maintaining the balance between being distant and present as a caregiver (Carlsson et al., 2004). Acknowledging the older person's lifeworld and sharing the experiences is important for all caregivers. A previous study has shown that a holistic approach, in which the person in their entirety is acknowledged, is favorable when caring for persons with mental disorders (Rusner et al., 2010).

With their altruistic actions (III), the nursing aides provide an important function in the lives of the older persons. However, to level the balance between the altruistic and egoistic actions and to decrease work rotation among the personnel in municipal home help service, there is a need for better support and supervision. The nursing aides were subjected to organizational prohibitions of changes in time and structure, resulting in a commitment to avoid complicated situations or alterations in routine that could consequently disturb the work schedule (III). Without the necessary time to reflect and process their experiences, the nursing aides relied on their previous experiences for insight into handling difficult situations (III). The importance of experience is thus clear, as it facilitates the prediction of which reactions a given action may induce and provides a basis for moral thinking and wisdom (Mill, 2001). Gustavsson (1996) suggested that although the use of previous experiences involves a deep personal involvement and devotion to the old, it is based on a lack of theoretical education and professional knowledge. The nursing aides' experiences may be sufficient to a certain extent; however, for nursing aides to feel secure and confident during challenging encounters with older persons with mental disorders they require more theoretical education to complement their previous knowledge.

Although the prescribing of drugs for mental disorders made by psychiatrists and geriatricians is low (IV), the findings are inconclusive as to whether these specialists are at all present in the organizations. Several studies have highlighted the importance of good collaboration and communication between GPs and other specialists to improve the care of older persons with and without mental disorders (Jones et al., 2009; Anthony et al., 2010; Moen et al., 2010). GPs that lack good communication with other specialists often feel insecure when needed to surpass their own level of competence when treating the patient (Rahmner et al., 2010), and facing the complexity of the older persons' feelings is often problematic for physicians in primary care (Vannoy et al., 2011). GPs are shown to play an important part in mental health care and their gate-keeping function to mental health specialists necessitates good collaboration with other

health care (Fredheim et al., 2011). However, good collaboration may be hindered by fragmented systems. Fragmentation is common in the Swedish health care system and includes various challenges, such as managing and organizing the different organizational units, unifying different specialists and benefiting from each other's competence (clinical fragmentation), as well as sharing common values among health care personnel in different units (cultural fragmentation) (Åhgren, 2007). Fragmented systems are unable to achieve unity of efforts (Axelsson et al., 2006). Furthermore, Åhgren (2007) concluded that it is important to integrate and reduce fragmentation in the Swedish health care system in order to facilitate patient satisfaction and decrease the risk of "loosing" patients in the chain of care. A previous study has shown that, although changes can be made on the local level, the national systems must be scrutinized to facilitate long-lasting changes and to improve the situation for frail older people (Clarfield et al., 2001). The involvement of several organizations in the care of older persons with mental disorders (municipal care (III), health care (II, IV)) increases the risk of such fragmentation and can ultimately impair the older persons' situation.

Improving the organizations' ability to provide adequate incentives to encourage nursing aides and physicians with specialist education remain in the care of the old is of the utmost importance. Barker and Buchanan-Barker (2008) have suggested that although organizational obstacles may hinder a changed approach, the individual caregiver each carries a responsibility to alter the way they work and increase acknowledgment of the care recipients. A study on career intentions of students becoming caregivers demonstrated that mental health nursing and geriatric care is often down prioritized and considered to hold a low status (Hayes et al., 2006). Furthermore, assistant nurses often regard their work with older persons as meaningful but not always challenging enough to retain work interest (Sandmark et al., 2009). Registered nurses employed in the care of the old have also been shown to lack relevant specialist competence in geriatric care, and those who do hold such specialist competence mainly work in dementia care (Josefsson et al., 2007). For older persons with mental disorders, fragmentation within the health care system is common as caregivers and physicians are unlikely to accept full responsibility for their health care or social services efforts (Bartels, 2004; NBHW, 2008b). The older persons experienced struggle for existence (I), the magnitude of mental health issues among the old (II), the challenging caring experienced by the nursing aides (III), as well as the lack of geriatricians and psychiatrists in mental health care (IV) suggest that there is a need to increase collaboration and competence among different health care providers in order to improve the older persons experienced well-being.

Consequently, with the high prevalence of drugs prescribed for mental disorders to older persons (II), indicating that mental health concerns are common among the old, and increasing numbers of older persons with severe disorders requiring municipal care, it is important to help nursing aides balance their altruistic and egoistic actions (III), feel encouraged and supported such that they continue working with the old and consider the encounters with the older persons with mental disorders as challenging but manageable. To provide the nursing aides with encouragement sufficient support and training is a necessity. In fact, several studies have shown that clinical supervision and education increase job satisfaction among home care and nursing home caregivers

(Magnusson et al., 2002; Häggström et al., 2005; Fläckman et al., 2007), and to improve the quality of the care given, positive collaboration between registered nurses and enrolled nurses is shown to be a necessity (Karlsson et al., 2008). The question of increasing the status of gerontological and geriatric care is not solved easily, but efforts to decrease stigma and increase the value of older persons in general and older persons with mental disorders in particular should be implemented in all levels: political, organizational and personal.

7.3 METHODOLOGICAL CONSIDERATIONS

A number of issues arose during the research process that may have influenced the findings of this thesis, and these issues merit discussion.

7.3.1 Design and participants

A lifeworld phenomenological hermeneutical method (Lindseth et al., 2004) was used in studies I and III to reach a better understanding of older persons' experiences of their life situation and nursing aides' experiences of caring for older persons with mental disorders. The selection of participants, variation and realization were carefully made in order to ensure validity. Transparency is emphasized as important for ensuring validity in qualitative research (Walsh et al., 2006), and consequently the research process has been described as carefully and transparently as possible.

During the recruitment of participants in study I, several different organizations in both municipal home help services and psychiatry were contacted in order to reach as many older persons as possible. Although many older persons fulfilled the inclusion criteria, the personnel in several organizations refused to forward the invitation of participation. This refusal is known as gate-keeping, defined as caregivers' prevention of access to eligible patients in research (Addington-Hall, 2002), and was a major setback during recruitment. Previous research has shown that gate-keeping during data collection generally arises from the intention to protect the eligible persons from disturbances; however, denying a person the right to decide for themselves is ethically indefensible (Barnes et al., 2005; Hudson et al., 2005; Sharkey et al., 2010). In addition, persons with depression are considered to be vulnerable to such an extent that their own capabilities to respond to invitations are neglected (Mason et al., 2007). Gate-keeping during the recruitment process occurred at different levels within the organizations, most often by their closest caregivers; investigating their exact intentions was beyond the scope of this study and calls for further studies. Although purposeful sampling in qualitative studies is believed to strengthen variability and facilitate inclusion of those traditionally discounted (Barbour, 2001), the gate-keeping necessitated convenience sampling and limited the sample size and diversity.

The lifeworld perspective, which guided the research process in studies I and III, emphasizes the importance of variation to increase the quality of the sample rather than striving for a precise number of participants (Dahlberg et al., 2008). To reach a varied sample in study III, the nursing aides sought-after for interviews included both men and women with different experiences of caring for older persons with mental

disorders. However, several of the organizations contacted for participation excluded persons with mental disorders aged 65 years and older from their services, and only six of the organizations contacted provided care for older persons with mental disorders. The selection of nursing aides thus was made through convenience sampling rather than purposeful, especially since the heads of the organizations selected one or two of the staff with relatively long work experience that were assigned care recipients with mental disorders. Consequently only nine nursing aides were eligible, and due to a high overrepresentation of females in the organizations they were all women with no less than eight years of work experience. Their narratives did, however, offer enough variation and depth to be included in the analysis.

In studies II and IV, data on mental health among older persons was difficult to access, partly due to the lack of reliable registers on mental health in old age in primary health care at the time of the study. The register of in-patients at hospitals was reliable but includes a very limited sample of those with these disorders, and public health surveys include only a small sample of the inhabitants with very few over 65 years of age. The cross-sectional design used in studies II and IV does not facilitate conclusions on causality but rather facilitates analysis of large nationwide populations with high statistical precision. The use of register-based data allows researchers to study populations without the disclosure of personal data or invasiveness (Olsen, 2011), and more studies including the vast majority of the population will make comparisons between future studies more feasible and contribute to a more extensive knowledge about mental disorders. The SPDR, administered by the NBHW, holds reliable information on drugs dispensed and prescribed to the entire population, and the study population therefore consisted of approximately 200 000 older persons in studies II and IV, which must be considered as a strength of these studies. The use of SPDR entails the exclusion of persons receiving non-pharmacological treatment such as electroconvulsive treatment (ECT) or cognitive behavioral therapy (CBT) for depression or anxiety. However, during the years 2006 to 2008 the non-pharmacological treatment to older persons was almost non-existent and not included in the clinical guidelines (NBHW, 2009). Hence, the exclusion of older persons receiving non-pharmacological treatment should not substantially influence the study findings.

7.3.2 Data collection and analyses

7.3.2.1 Interviews (I, III)

Interviews are an invaluable source for developing understandings of the meaning of the participants' experiences (Kvale et al., 2009). The participants, both the older persons (I) and the nursing aides (III), were interviewed once each. Even so, they appeared relaxed and gave rich and deep narratives of their experiences. The possible benefits of repeated interviews include a more robust data collection, the opportunity for participants to deepen their narratives, and more practice and skill development for the novice interviewer. The researcher is seen as a tool (Polkinghorne, 2006), and it is important that the researcher is aware of the own lifeworld and reflects upon the own influence and understandings in order to produce valid data (Dahlberg et al., 2008;

Kvale et al., 2009). The importance of listening, caring and taking time after the interview for debriefing has been emphasized when interviewing persons with schizophrenia (McCann et al., 2005). Building trust is a necessity when interviewing vulnerable older persons, and it requires respect, acceptance and understanding on the part of the interviewer (Truglio-Londrigan et al., 2006).

As an inexperienced interviewer, albeit with capacities to listen and encourage the participants to share their experiences, I took a course in interview techniques, as well as other relevant research courses such as methodology, prior to conducting the interviews in order to counteract the factual inexperience. In addition, the interviews were frequently discussed with the research group, who were experts in both the method and interviewing techniques, to increase awareness about the role of the interviewer. Education and availability to experts have been suggested to compensate for inexperience (Dahlberg et al., 2008), and the courses and discussions mentioned above, along with time and experience led to an improvement in interviewing skills. It should be noted that the richness of the narratives provided by each of the interview participants was unaffected by my inexperience, suggesting that my own level of comfort was more easily influenced than that of the participants. In retrospect, my initial lack of experience with conducting research interviews and qualitative studies may have contributed a valuable naivety, promoting genuine curiosity to increase the understanding of the participants' experiences as well as prompting genuine follow-up questions such as "What do you mean by that?".

It is important to differentiate between therapeutic and research interviews (Kvale et al., 2009) and to maintain the researcher identity during the interview (Dahlberg et al., 2008). The researchers had no established relationships with any of the included participants, nor had the participants any relation to each other. While an established relationship could help participants to feel secure and comfortable, it may at the same time increase the likelihood of the interviews becoming therapeutic or preventing the maintenance of the researcher identity. Importantly, the quality of the analysis is dependent upon the quality of the interviews (Kvale et al., 2009). To ensure accuracy and increase the reliability of the data collected (I, III), the interviews were audio-recorded and later transcribed by the interviewer. The transcripts were double checked to make sure the written text reflected the situation, and the non-verbal expressions were also noted in the transcripts.

When acknowledging older persons and their situations, it is counterproductive to categorize or label them, as such prejudgments may increase ageist views and stigma. However, one of the linchpins of this thesis is to develop knowledge on the situation of older persons with mental disorders; therefore, the categorization by mental disorder diagnosis is one of the main features defining the subpopulation of older persons. The phrase "older persons with mental disorders" is used simply to define the participants of the study and is not intended to neglect the individuals preceding the diagnosis nor is it used with the assumption that older persons with mental disorders constitute a homogenous group of people. In this thesis, the overall definition of the concept of "mental disorders" includes psychotic, anxiety and affective disorders. In study I in particular, the definition of mental disorders pertains to the diagnoses the older persons held at the time of the interview (psychotic and affective disorders). The

nursing aides (study III) were encouraged in the interviews to narrate freely regarding situations in which they encountered older persons with non-dementia mental disorders. Consequently, the concept of “mental disorders” was not defined further than excluding dementia disorders; this was done in order to access their experiences of situations that had affected them to some extent. As there were similarities in their narratives irrespective of the specific disorder of each older person, the comprehensive concept “mental disorders” was continuously used.

7.3.2.2 *Phenomenological hermeneutics*

To ensure reliability in qualitative research, examinations of trustworthiness are crucial (Golafshani, 2003). The process of phenomenological hermeneutical analyses (I, III), entails a thorough discussion of the method used and the findings in order to ensure reliability or trustworthiness. In developing the comprehensive understanding, the findings were reflected upon and discussed in conjunction with different theories and philosophies with the aim of deepening the understanding of the phenomena. The chosen literature and the text should illuminate each other to deepen the understanding (Lindseth et al., 2004). The philosophies and theories included in the analyses were found to be congruent with the aim and theory of science behind the method and design. It should be noted that although different understandings may emerge in light of alternative theories or philosophies, the possible interpretations of the text vary in terms of credibility (Ricoeur, 1976). During the analysis process in studies I and III, the findings and interpretations made were thoroughly scrutinized, and critically reflected upon in conjunction with existing literature as well as the knowledge held amongst the researchers. In addition, the research findings were discussed with other researchers at seminars. All of these aspects add to the credibility of the interpretations. The process of data collection and analysis was characterized by openness, in the sense of attaining an approach to the phenomenon in which it is seen through the assumptions and thoughts held in relation to it (Dahlberg et al., 2008). Direct quotations were used in the studies (I, III), as they are suggested to aid the reader to judge the credibility of the interpretations (Fleming et al., 2003) and reflect the context and the style of the narratives (Roberts et al., 2006).

Pre-understanding is commonly discussed in qualitative studies and such discussions are believed to increase the validity of the study. However, the pre-understanding, as understood in phenomenological hermeneutics, cannot be described as it constitutes our basis in life and nothing is understandable except in the light of the pre-understanding (Lindseth, 2010). Nonetheless, in order to make sure the analyses are valid it is important to describe the own previous experiences and knowledge that may influence the understanding and the process of data collection. In this project, four researchers (including myself) were involved in the analyses and we each contributed with different views, professions and previous knowledge. Prejudice and assumptions, as well as matters otherwise taken for granted were emphasized in the light of our different experiences and knowledge, and such matters were discussed amongst the authors and their impact minimized.

7.3.2.3 *Descriptive univariate analyses*

The SPDR is a high quality register administered by the NBHW. Nonetheless, all registers have errors and although the level of missing data in terms of personal identification numbers is low, this could affect the outcome when discriminating the data with respect to sex or age. As a measure of the precision of the findings in studies II and IV, 95% confidence intervals were used throughout. The inclusion criteria for studies II and IV were aged 65 years or older and receiving one or multiple prescriptions for drugs for mental disorders, excluding those used primarily for dementia disorders. Drug use was used as proxy for diagnoses, as the register does not include diagnosis information. Although we feel that this method for identifying participants is fairly robust, it does introduce a few potential challenges and possibilities for bias that should be disclosed. Firstly, some of the drugs that were included may have been issued to persons in conjunction with issues or life crises other than mental disorders. However, questioning, evaluating and specifying the duration of a mental disorder was beyond the scope of the study, and thus the inclusion of single prescriptions was not considered to limit the findings. Secondly, another potential source of selection bias in these studies was the exclusion of drugs used for dementia disorders as there are obvious difficulties in separating mental disorders from dementia disorders among the old solely based on drug prescriptions. In order to minimize inaccuracy of drug exclusions and to counteract this bias as far as possible, clinical guidelines and treatment recommendations set for each year of the study were thoroughly scrutinized with the help of practicing psychiatrists. Some of the drugs excluded due to possible use for dementia disorders may actually have been prescribed for a mental disorder diagnosis (diagnosis bias). Furthermore, not all persons with dementia disorders receive anti-dementia drugs but rather drugs recommended as firsthand options for treating dementia disorders or symptoms (e.g. SSRIs and antipsychotics); these drugs were also excluded in order to facilitate exclusion of persons with plausible dementia. These inclusion and exclusion criteria based on the types of drugs prescribed may have affected the approximated prevalence figures in study II. The inclusion of SSRIs and antipsychotics would likely lead to a higher estimated prevalence of drugs used for mental disorders and thus a higher approximated prevalence of mental disorders, suggesting that the approximated prevalence presented might be underestimated. However, the lack of diagnoses in the SPDR might have resulted in the inclusion of drugs prescribed for other indications than mental disorders, thus suggesting an overestimation of the prevalence. To counteract these biases, future studies should examine sub-samples of the population as well as evaluate the daily doses and adjust the estimated figures if necessary. Although the register does not include diagnoses, it does deliver reliable information about the competence of the prescribing physicians.

7.3.3 **External validity**

The generalization of findings from lifeworld studies is possible but dependent upon the phenomenon, study and context (Dahlberg et al., 2008). In study I the older persons were both men and women, narrated different situations and lived in different

municipalities, suggesting that the sample provided as much variation as possible, which may increase the generalizability within the group of older persons with mental disorders. Study III focused on a more universal phenomenon, the meaning of caring, which strengthens the possible generalizability of the findings to others who care for vulnerable persons. It is important to note that the accessibility to eligible nursing aides limited the study to the narratives of experienced female nursing aides in Swedish municipal home help services (no males or new staff). Before generalizing the findings, the contextual underpinnings influencing the experiences must be taken into consideration, and the reader must incorporate the understanding in to their own situation for it to improve the care for others (Lindseth et al., 2004; Dahlberg et al., 2008).

Generalizability in epidemiological studies is dependent on the representativeness of the sample (Rothman et al., 2008). Studies II and IV analyzed the prescription of drugs for mental disorders in a large nationwide population of older persons. The study population included only those with yearly prescriptions on drugs for mental disorders and thus all older persons with mental health issues not recognized by their physicians or receiving non-pharmacological treatment were not represented in these studies. Additionally, clinical guidelines concerning drug treatment are subjected to continuous review, thus the analyses of the drugs used among older persons reflects the situation during the years of data collection.

8 CONCLUSIONS AND IMPLICATIONS

In 1934, it was concluded that the problem of mental disorders was urgent, and there was a need to lessen the focus on the medical conception of the disorders and increase the understanding of the persons affected in a broader sense, ensure proper and sufficient education for caregivers such that persons with mental disorders could be acknowledged as equal human beings not equated to their disorders (Bentley et al., 1934). The findings of this thesis, almost a century later, not only highlights the same issues but also seconded that conclusion.

The findings suggest that the three various dimensions of personhood are not acknowledged to the extent necessary to facilitate health, development and well-being. The older persons struggle for their existence and in this struggle they experience themselves as alienated, ignored and disrespected, suggesting that the dimension of self and the included need for emotional and physical security are neglected. They experience an existential isolation that goes beyond the common loneliness and possible geographical isolation, and desire respect for the own being. Hence their experiences of their disorders are not validated by others, suggesting a neglected world dimension. The large proportion of older persons seeking health care and receiving drugs intended for use in mental disorders suggest that mental health issues are common among the old. This emphasizes the need to acknowledge these older persons and provide them with adequate care and treatment; such efforts would benefit all those involved, from the older persons themselves to the health care system.

The third dimension of personhood, others, emphasizes the need to recognize the support and services necessary for the older persons to live ordinary lives. In the recognition of this dimension, it is important to acknowledge the work performed by nursing aides, particularly as they provide the bulk of municipal home help services. With their person to person approach, they provide the older persons with an important anchorage to the outside world. During home help visits, nursing aides encounter different realities and persons with severe anxiety or psychosis; they are therefore in need of guidance and support to help balance their altruistic and egoistic actions and best cope with such challenging situations. In addition, the findings show that referrals of older persons with mental health issues to physicians specialized in geriatrics and psychiatry are rare. Furthermore, the prescription of drugs for mental disorders clashes to some extent with the clinical guidelines concerning treatment of older persons. These findings raise questions about the adequacy and quality of the health care situation of older persons.

When considering the historical perspective, these findings are indicative of a lack of translation from research to practice in the area. The prominent question is then how to improve the situation for the older persons. An easy and obvious suggestion is to increase the number of nursing aides in the municipal home help services in order to decrease the work-load and facilitate time for presence, reflection as well as guidance. This thesis concludes that the support network for nursing aides is severely lacking with respect to formal education with specialized skills. Hence the network surrounding the nursing aides should be improved in both the municipal care as well as the health care sector, as theoretical knowledge in combination with previous experiences may

increase understanding and facilitate openness towards the older persons. However, such measures are restricted by finances, which are controlled by politicians. Although the above suggestions seem obvious for all, there is one important remaining question that could make such changes in the system possible in the long run: how do we improve the recognized status of working with the old in general and older persons with mental disorders in particular? Increasing the status of working in geriatric psychiatry in the municipal care of the old as well as in the health care sector would ultimately benefit the older persons and improve their situation.

9 FUTURE RESEARCH

This thesis aimed to describe the present situation for older persons with mental disorders living in their own homes with support from home help service and psychiatry. Hence the thesis does not attempt to provide instructions for how to care, and further research is needed for creating, evaluating and implementing interventions to find alternatives, facilitate transfer of research evidence to practice and improve the care given. Furthermore, it would be interesting to explore the gate-keeping that occurs frequently at all levels in the organizations. Understanding gate-keeping among caregivers in mental health care would bring important new knowledge that may contribute to reducing stigma and discrimination as well as improve the overall care.

Another aspect that calls for further research is the process preceding decision-making by departmental heads in municipal home help services concerning who should care for whom. Research on the factors involved in such decisions may reveal whether or not there is an awareness of the difficulties encountered by nursing aides and if this awareness impacts decision-making. It would also bring a deeper understanding of the contextual factors influencing care, which in turn may help decrease work rotation and increase stability and continuity of care. It would also be interesting to explore physicians' experiences of caring for older persons with mental disorders, to illuminate the challenges they encounter and in what way their specialist education influences their provision of health care.

The evaluation of drug treatment was limited in this thesis. Questions regarding alternative therapies, non-pharmacological treatment, adherence to drug treatment, drug interactions and studies on sub-samples of the population were beyond the scope of the thesis and would, if scrutinized, contribute to important knowledge that could facilitate the improvement of the older persons' situation. Possible matching of the SPDR with population-based studies could be an interesting approach. Evaluating the prescribing and use of alternative therapies may also help to evaluate their correlation to treatment by psychiatrists and geriatricians.

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