Chapter 1. Introduction

In recent decades there has been a growing interest in the wellbeing of, and the need to support, caregivers of persons with severe mental illness such as bipolar disorders, schizophrenia, anxiety disorders and depression. Gradually, the evidence base for the importance of caregiver (family) support has broadened, and the previously held view of caregivers being a potential obstacle to the patient’s treatment and hence to achieving the patient’s goals, has been abandoned. This changed view has fuelled research on caregiver needs, caregiver support and the recognition of the need for collaboration between mental health professionals and caregivers.

This thesis concerns the support of a subgroup of caregivers, namely those who care for older adults with severe mental illness, and a subgroup of core professionals in mental health care, the mental health nurses. The study started in 2008, from the realisation that a nursing support intervention for caregivers of older adult patients with a severe mental illness might lead to greater wellbeing for both caregiver and patient.

In recent decades, the policy of deinstitutionalization in Western countries has resulted in an increasing number of people, including elderly, with severe mental illness living in the community where they rely on their families and others for support in daily living (Ministry of Health, Welfare and Sport 2001, Rose et al., 2002; Muhlbauer, 2002). As a consequence of the emphasis on patient treatment and recovery in the community, patients’ families and others have been increasingly pushed into the role of caregiver. These caregivers shoulder the psychosocial burden of care which was previously assumed by health care professionals.

Mental illness is associated with increased psychological distress, leading to an elevated risk of mental illness, especially depression and anxiety disorders (Cochrane et al., 1997; Dorsslaer, 2007; De Boer et al., 2009, 2012; Hammond et al., 2013). Caregivers also have more stress-related physical health problems like high blood pressure, cardio vascular diseases or diabetes (Pinquart, 2003; Collins et al., 2012). Many, often aged, caregivers are involved in long-term caregiving which interferes with numerous aspects of their daily life and often exceeds the boundaries of usual informal care. In fact, all levels of interaction between caregivers, care-
receivers, their social environment, and the interpersonal relationship are affected by caregiving. Relationships become unequal and often frail. Due to substantial psychosocial problems as a result of the long-lasting impact of a stigmatized disease on their daily lives together with the absence of perspective on recovery of the patient and a lack of social acceptance, the prevention of emotional distress and enhancement of quality of life for these caregivers is important. To prevent severe impairment of their quality of life, leading to a possible withdrawal from caregiving, these caregivers need support. Mental health nurses play an essential role in the care of these patients and their caregivers. They are in a position in which they have easy access to the caregiver. They are approachable, and from an inside position they often witness the complex nature of the interpersonal relationship between the patient and the caregiver.

The development of the nursing caregiver support intervention was based on the model of Van Meijel (2004). Building blocks needed for the design of the intervention comprised a literature study (chapter 2) in which scattered and partial explanations of the origins of perceived burden were described. A problem analysis and needs analysis (Chapter 3) explored the variability in the suffering of caregivers and increased insight into the needs of caregivers. A current practice analysis (Chapter 4) led to an improved understanding of the perception and content of mental health nurses support. Chapter 5 describes the developmental process of the nursing intervention. A qualitative explorative field study was conducted to investigate caregivers’ appreciation of the intervention and its acceptability, the benefits caregivers experience from this intervention for their own needs, and underlying processes that may affect the results of the intervention (Chapter 6).

Chapter 2. Review. Perceived burden of informal caregivers of elderly persons with a severe functional psychiatric syndrome and concomitant problematic behaviour.

The developmental process of the nursing intervention started with a review of the scattered and partial explanations of the origins of perceived burden. The findings of the literature search concerning the determinants related to perceived burden were organised in a conceptual model adapted from the work of Lazarus and Folkman (1984) (chapter 2), and consist of three major
interrelated components: 1) the stressors in the actual situation, 2) the process of how these stressors evolve and change in relation to the use of internal and external resources and 3) the research results related to outcomes such as perceived burden itself and various health consequences. Thus, an overview of the various determinants of perceived burden and a clear picture of the possible interrelatedness appears. In developing the intervention, attention must be devoted to the appraisal of the situation by the caregiver. This study stresses the importance of taking account of the dynamics, the circularity of the process and the interrelatedness of these relationships in the design of intervention strategies to reduce caregiver burden. This strategy is likely to be more effective than interventions that focus on one, or just a limited number of potential causes of perceived burden. For this reason, a multivariate intervention is deemed which is comprehensive, long-term, individually tailored and has the flexibility to meet the dynamics of burden over time.

Chapter 3. Differences in impact of long-term caregiving for mentally ill older adults on the daily life of informal caregivers.

The aim of this study was to explore and understand the suffering of caregivers by investigating underlying factors that may shed new light on the caregivers’ appraisal of the situation, which may cause these differences in the impact of long-term caregiving on the quality of life of caregivers. In this study the concept of freedom of choice came to the fore as the key in explaining the impact of long-term caregiving. This concept adds a new perspective to the research on caregiver burden. Based on the concept of perceived freedom of choice, two main types of caregiver are defined. These two types of caregiver differ in how they experience two domains of daily life that are typically affected by caregiving: the quality of the relationship with the patient and the caregiver’s own psychosocial wellbeing. Aspects of relationship quality that are affected include expectations, equality, togetherness, and respect. The psychosocial wellbeing of the caregiver is affected by the presence or absence of grief and mourning, autonomy and meaning, and participation in social life.

For those who have a perceived freedom of choice to engage in caregiving – type 1 caregivers - caregiving is mainly a process of gain, despite the
invested time and energy. Caregiving gives extra meaning to their relationship with the patient and their psychosocial wellbeing. For those who do not perceive they have the freedom to quit caregiving - type 2 caregiving is a continuous confrontation with loss.

Within this group of type 2 caregivers we can identify two subtypes. The first subtype is the caregiver who accepts the loss and caregiving as part of their life and are prepared to bear the consequences. They manage to adapt their expectations. They are able to notice reciprocity and they experience togetherness by interpreting reciprocity. To some extent they retain autonomy while they reflect on a poorer but nonetheless meaningful life. The second subtype is the caregiver who feels captured. On the one hand they cannot imagine a life without the patient, while on the other hand they suffer because their sick partner or parent never shows any sign of gratitude. They do not consent to the consequences but can also not evade them. These caregivers feel absorbed by the demands and cannot handle caregiving.

This study has shown that the loss is mainly felt within the quality of the relationship and in psychosocial wellbeing. In fact, all levels of interaction between caregivers, care-recipients, their social environment, and the interpersonal relationship are affected by caregiving. Based on the findings of this study an empowering approach to encourage caregivers to redefine their personal life and focus on their caregiving strengths, and on 'living', rather than on the reduction of caregiving tasks and their subjective burden, is indicated.

With this concept of freedom of choice, a highly relevant new dimension is added to the understanding of the impact of caring on caregivers’ wellbeing. The concept of freedom of choice adds to our understanding that differences in impact cannot be explained solely on the basis of stressors, buffers and contextual factors found in the research to date, and explains the variation in impact on a caregiver’s life. Freedom of choice appears to give coherence to the factors that aggravate caregiving.

The studies in chapters 2 and 3 endorse the main focus of the intervention, namely unmet personal needs due to the impact of the caregiving role. Based on these two studies the outline and the main focus of the intervention could be determined.
Chapter 4. Mental health nurses’ support to caregivers of older adults with severe mental illness.

A current practice analysis gave insight into mental health nurses perspective and the content of current mental health care nurses’ practice of support.

In a qualitative study the mental health nurses’ vision and their understanding of their role and responsibilities as well as the content of their behaviour, were explored. This knowledge is required to make choices about the content of the intervention and its application. Accordingly, the aim of the study was to explore and interpret current practices in mental health care nurses’ support to caregivers.

The mental health nurses acknowledge the importance of family relationships, “nobody can do without a family”, but nonetheless, their caregiver support varies considerably. Based on the extent to which they believe that the informal caregiver plays a necessary role in the client’s support system, and that the caregiver’s wellbeing is important, three prototypes of mental health nurses can be distinguished. At one end of the spectrum, we have the mental health nurse who sees the caregiver and the patient as inextricably connected with each other. In these cases the mental health nurse directs her/his intervention towards both the informal caregiver and the patient. They realize how much the caregiving affects the life of the caregiver, and consider their wellbeing as a legitimate concern of them. We call these the concerners. At the other end of the spectrum we see a mental health nurse who is basically only concerned with the wellbeing of the patient and considers the caregiver to be a potential obstacle in reaching the client’s goals. We call these the tolerators. In the middle position are mental health nurses who realize that caregivers are important agents in attaining the client’s goals, and consider preventing them from becoming overburdened as the main goal of their support. We call these the preventers. For each type we described the mental health nurse’s vision, their interpretation of their role and responsibilities, their acknowledgement of the relationship with the caregiver, how the caregiver’s needs are defined and the interventions used in relation to the caregiver.
With the three prototypes this study enriches the dichotomous approach prevalent in studies concerning nurses’ attitudes to supporting family members. These studies report that nurses either give attention to caregivers or not. The preventer is supportive to the caregiver but does not consider the wellbeing of the caregiver as their legitimate concern. To be within his/her domain they focus on burden and their aim is to contribute to the continuation of caregiving.

Chapter 5. Development process of a caregiver-centered nursing intervention to support caregivers of older adults with severe mental illness

The aim of this article is to describe the development process of a caregiver-centered nursing invention designed to meet the needs of caregivers of older adults with severe mental illness such as schizophrenia, bipolar disorder, major depression and anxiety disorders. In the development of this nursing intervention the “Utrecht model” for the development of complex nursing interventions of Van Meijel and colleagues (2004) is used as a guiding framework. The Utrecht model comprises three phases: 1) collecting building blocks for the design of the intervention; 2) the intervention design; and 3) intervention validation. In this article, we describe the first two of the three phases from the model. Phase three of the Utrecht model, the validation of the intervention, is outside the scope of this study.

Application of phase 1 and 2 of the Utrecht model.
Insight and understanding in both the origin of perceived burden and the impact of caregiving on the wellbeing of caregivers is a prerequisite for an evidence based practice caregiver centered intervention to become meaningful. First, the burden of caregivers and the impact of caregiving on their daily lives were explored by literature review and qualitative research. In the second phase, results from these studies relevant to the development of the intervention were used for the design of the newly developed intervention. The results of two studies, supplemented with additional literature review and consultation of experts is used for the design of the intervention. The literature review and the consultation of experts took place at different times over a one-year period and the latter in varying formations.
Consultations have been prepared by the researcher and two experts: a psychiatrist who is an expert in long-term and severe mental illness and one of the PhD supervisors. Then, nine experts - two caregivers, one member of a family council (also a caregiver), three systemic therapists, two nurses with a scientific background and a specialist nurse all working in specialist psychiatry of the elderly, were consulted. The steps taken are described consecutively. In reality, it was mostly an iterative process.

In sum the consultation of experts and literature led to the following recommendations:

The consultations were supportive in further formulating the outline and content of the intervention. A proactive approach by type 2 caregivers is recommended as they can be considered a risk group and thus the target group. To identify the needs of the caregiver, an individual assessment based on the research results is recommended as well as freedom of speech. Caregivers need to feel free to tell their story to the mental health nurse. Therefore, the conversations ought to take place in the absence of the patient. These conversations have the nature of an open discussion about frequently occurring problem areas. During the period of support regular alignment with the patient- and treatment goals is needed.

None of already existing caregiver interventions found literature fit the needs of the type 2 caregivers. Because the issues in the narratives of type 2 caregivers have similarities with the symptoms of a mild depression, interpersonal counselling (IPC) is advised as a basis for the development of the intervention. This type of counselling is for "healthy individuals" (read caregivers without psychiatric problems) with depressive symptoms has been developed by Weissman and Klerman (1993). The purpose and the content of IPC appeared to fit the nature of the problems of these caregivers. The overall aim of the intervention is to optimize interpersonal functioning and to improve psycho-social wellbeing.

Based on the building blocks the following three phases of the intervention protocol are proposed:

1. The preparatory phase, in which caregiver and patient are given information about the patient's illness and treatment and about the
possible impact on the caregiver’s life. An appointment is made to assess caregiver needs.

2. The second phase, in which the mental health nurse coaches the caregiver on topics that appear to be frequently occurring problem areas for the caregiver’s quality of life: tension in the relationship; role transitions; grief; loneliness and isolation, and the feeling of entrapment.

3. The third phase has an emphasis on further energizing the caregiver’s own competence and validating what the caregiver has achieved. Also, the need for follow-up conversations is addressed.

This newly developed caregiver centered intervention distinguished itself from existing interventions by a strong emphasis on exploring the caregiver’s perspective in considerable depth. Insight into the caregiver’s perspective and profound knowledge of their needs is necessary for the choices to be made in the support of caregivers. The intervention helps the mental health nurse to find a cognitive explanation for the impact of caregiving on the caregivers’ wellbeing and on their relationship with the patient and others. The intended result is a reduction in symptoms of stress, alleviation of caregivers’ lack of wellbeing, and changes in interpersonal relationships - leading to prevention of (further) mental health problems in caregivers.

The intervention protocol offers the mental health care nurses a clear structure in the execution of the intervention but also provides sufficient space for adapting the method to the individual characteristics and needs of the caregiver and the specific context in which the support is provided.

Chapter 6. Trust: an essential condition in the application of a caregiver support intervention in nursing practice

Finally, a qualitative explorative field study was conducted to investigate caregiver’s appreciation of the intervention and its acceptability, the benefits caregivers experience from this intervention for their own needs, and underlying processes that may affect the results of the intervention.
By the end of the pilot period, 13 of the 17 participating caregivers had participated in a semi-structured interview conducted by the first author. One caregiver died, two caregivers did not participate due to relapse of the patient and one caregiver was too much burdened to participate.

From the perspective of the caregivers a trusting relationship between caregivers and the mental health nurse showed to be an essential condition for the depth and hence the effectiveness of the caregiver-centered counseling intervention. This trust is initiated when the MHN, as a first step in the intervention, explicitly invites the caregiver for a conversation (without the patient) about the impact of caregiving on his/her personal life. Through our analysis we found that the development of this trusting relationship is facilitated by a pro-active non-judgmental attitude in the mental health nurse. The development of a trusting relationship is an interactive collaborative process. This relationship is supportive and helpful for caregivers who consider themselves to be supporters of the patient and not a person in need of care. The trusting relationship intensifies in strength and depth through three overlapping mutually reinforcing phases (1) Phase of engagement, (2) Phase of Recognition of personal needs and (3) Phase of hope and optimism (table 1). The mental health nurses’ recognition of caregiver (needs) and acting as an ally in the support of the patient allowed the caregiver to gain insight into their own needs and to learn new ways of dealing with the impact of caregiving on the interpersonal relationship with the patient.

The added value of building trusting relationships between caregivers and (mental health) nurses has received little attention in caregiver research. From our study we argue that caregivers need the same aspects of recognition and intersubjectivity (connectedness) for strengthening their sense of self (identity), empowerment and overall life (hope and optimism) as patients (Tidefors et al., 2011, Eriksen et al., 2014). Therefore, we figure a relational perspective as already described by Peplau (1997) should not only be applied in patient-mental health nurse relationships. Research in patients and (mental health) nurses underpin our finding that collaborative relationships provide a healthy framework in which the mental health nurse can assess and help not only patients but also caregivers in taking on new roles and responsibilities, thus increasing the likelihood that new activities and opportunities will be planned and carried out in ways that promote...
wellbeing rather than endanger empowerment (Repper et al., 1994, Coatsworth-Puspoky et al., 2004, Young et al., 2008, Eriksen et al., 2014).