

## Chapter 7

### SUMMARY AND GENERAL DISCUSSION

## INTRODUCTION

In this chapter – a general discussion – I start by looking at the aims I had hoped to achieve. I then summarize the results and the clinical relevance of the various subsidiary studies. After some methodological considerations I will discuss the main findings by viewing them in the context of the far-reaching transition that is currently taking place in the Dutch health care system. I close with a general conclusion and recommendations for practical innovations and future research.

My aims for the research project as a whole were:

1. To identify the unmet needs of older people living in the community who have been diagnosed with a depressive disorder and are being treated as outpatients at an institution for geriatric psychiatry.
2. To explore to what extent older people with a depressive disorder, their caregivers, and treatment staff agree about the most common unmet needs and to what extent this measure of (dis)agreement is influenced by the severity of the depression.
3. To describe the impact of three courses of depression (in remission, fluctuating and chronic) on aspects of social participation operationalized using the following variables: network size, loneliness, emotional support (received and given), and instrumental support (received and given). These aspects play an important role in determining the level of social participation possible for older people with depressive symptoms living in the community.

## SUMMARY AND DISCUSSION OF THE MAIN FINDINGS

The results of the various subsidiary studies and the clinical relevance of the results must be considered in light of major changes in Dutch society. The traditional Dutch welfare state is being transformed into a participatory society, the aim being to control public spending on social welfare and health care and – in view of the growing number of older persons requiring care in the coming decades – to organize care so that it is “future-proof” (1).

### *Case study: Needs assessment as a basis for treatment (Chapter 2)*

The first study in this thesis was an N=1 case study. It describes the situation of Mrs Brown, an 84-year-old widow with chronic depressive disorder who had been admitted to the psychiatric ward of a general hospital for an extended stay. Upon her dismissal after eight months, the risk of suicide had been reduced but the actual severity of the depression had remained virtually the same. She also had a variety of depression-related symptoms, such as sleeping problems, fear and unbearable stress levels that greatly affected the quality of her life. It was unclear why the depression persisted. At the start of outpatient treatment, a clinical nurse specialist assessed the severity of the depression using the Montgomery Åsberg Depression Rating Scale (MADRS) and the Camberwell Assessment of Need for the Elderly (CANE). It turned out that Mrs Brown had a clear need for meaningful daytime activities, for company, and for social contact, but also for support in coping with psychological distress. Moreover, she had a need for a safe home environment and for support in the use of the medication.

In addition to a pharmaco-therapeutic adjustment, specific interventions were deployed to address the needs that had been identified using CANE. These included practical solutions to improve Mrs Brown’s personal safety at home and to ensure regulated and evenly spaced contact with her family. Arrangements were also made to allow Mrs Brown to take part in meaningful daytime activities at the local nursing home, where she would meet people of her own age. This systematic approach was effective. Mrs Brown felt understood and heard. She had fewer negative cognitions about the futility and emptiness of life and fewer feelings of psychological distress.

The results of this case study suggest that the use of interventions aimed at fulfilling needs improved the depressive condition and led to a better quality of life. Many of those needs involved a desire for human contact and to avoid being alone. They were largely needs that could be met by offering Mrs Brown the opportunity to meet contemporaries and to engage in meaningful daytime activities. The case study shows that relatively simple activities focusing on such unmet needs can already produce an improvement in the patient’s condition and life situation. The depressive symptoms decline and social

participation increases. The social context is decisive for the patient's participation in such activities.

### *The association between depression severity and needs (Chapter 3)*

This study involved a sample of 99 older patients recruited from six mental health care institutions in the Netherlands. All 99 had been diagnosed with Major Depressive Disorder (MDD). We began by establishing the patients' depression severity using the Montgomery Åsberg Depression Rating Scale (MADRS) and their needs using the Camberwell Assessment of Need for the Elderly (CANE). Our aim was to explore the relationship between severity of depression and (unmet) need. Previous research by Blazer has shown that unmet basic needs can be an effective predictor of depressive symptoms (2). In this subsidiary study, we explored a reverse relationship, namely with depression severity as a predictor and unmet needs as dependent variable. Analysis of CANE results made clear that the severity of a depression had a strong association with unmet psychological needs and unmet social needs.

The study also revealed that an individual's needs most likely to be met are his or her physical needs, indicating that people may feel more comfortable talking about their physical needs or it may simply be easier to meet those needs. Within the psychosocial domain we frequently measured unmet needs scores on the CANE items "daytime activities," "intimate relationships," and "company." Within the physical domain high scores on "eyesight/hearing" could be observed. It is not hard to imagine that unmet needs in these areas contribute to feelings of loneliness and isolation, and thus cause depression to persist. Conversely, meeting these needs may help a person recover from a depression.

### *Unmet needs: Patient, staff, and caregiver perceptions (Chapter 4)*

This chapter discusses patient, caregiver, and staff perceptions of unmet needs. In this study, the same sample was used as in the study described in Chapter 3, but this time we included CANE data obtained from caregivers and staff. The aim of this study was threefold. First, we wished to establish which unmet needs patients, caregivers, and staff mentioned most often. Second, we explored how much patients and caregivers agreed on the needs that they perceived as being unmet, doing the same for patients and staff. Finally, we tried to establish whether depression severity in older people could predict the level of agreement between patient and caregiver or between patient and staff. This is relevant because when staff and patient, or patient and caregiver, agree on the nature and the extent of the patient's unmet needs, it becomes easier to draw up a tailored treatment and care plan that both parties support.

Our analysis of the results revealed that, on average, patients scored highest on unmet needs, followed by caregivers and then staff. The difference between patients and staff was statistically significant. We assume that patients and staff may perceive unmet needs differently. Practitioners should therefore not be too quick to conclude that they and their patients agree about unmet needs or an avenue of treatment. Our findings also revealed a relationship between depression severity and level of agreement about needs. Practitioners have to realize that the perception of a patient with severe depression may be negatively influenced by his or her low mood, which makes it more difficult to reach agreement on certain CANE items. In this study, the CANE items on which there was least agreement were “psychological distress,” “behaviour,” “memory,” “food,” “daytime activities,” “caring for other,” and “benefits.”

### *Impact of course of depression on network size and perceived loneliness in older people (Chapter 5)*

The study described in Chapter 5 made use of the Longitudinal Aging Study Amsterdam (LASA). The aim of our study was to explore the long-term impact of depression course on the social network and feelings of loneliness of older people living in the community who had scored 16 points or more on the 20 items of the Center for Epidemiological Studies Depression Scale (CES-D). The study involved 277 respondents. The course of depression was measured using 11 successive CES-D tests spaced five to six months apart and three clinical interviews. Three courses of depression were identified: in remission, fluctuating, and chronic. Network size and perceived loneliness were measured five times over a 13-year period. Generalized Estimating Equations (GEE) were used in the statistical analyses. The covariates in the analyses consisted of age, gender, partner status, educational level, degree of urbanization, and presence of chronic illness. We found that the course of depression does in fact have an impact on the network size and perceived loneliness of older people. In line with expectations, older people whose depression was in remission had the largest networks and the lowest scores on loneliness. Those who had a chronic course of depression reported a significantly smaller network and had higher scores on loneliness. When we introduced the variable “time” into our model, the loneliness scores – but not the network size – of older people with a fluctuating course of depression varied significantly over the 13 years of the study, with feelings of loneliness lessening in older people in remission and increasing in those with a chronic course of depression. Finally, our analysis took the influence of covariates into account, e.g. gender, age, partner status, degree of urbanization, educational level, life situation, and presence of chronic illness. The covariate “gender” had a significant influence on the relationship between course of depression and network size, with men showing greater variations in network size than women at the chosen reference point (wave 3). Gender did not, however, influence the interaction between covariates, course of depression, and “time” (three-way interaction).

This may indicate that the differences in network size between men and women with a certain course of depression remained static during the research period. We did find such three-way interactions, however, for personal characteristics such as age, partner status, degree of urbanization, and presence of chronic illness. This means that when the course of depression is unfavourable and the patient is older, or has no partner, or lives in an urban area, this combination of circumstances will eventually have an unfavourable effect on his or her ability to maintain a social network. The longitudinal relationship between depression course and loneliness scores was not found to be modified by sample characteristics.

### *Course of depression and its relationship to long-term support exchange in older people* **(Chapter 6)**

The study described in this chapter explored the relationship between the natural course of depression in older people and social support exchange over a 13-year period. We also investigated whether demographic factors influence the relationship between course of depression and social support exchange. The study once again made use of data collected in the Longitudinal Aging Study Amsterdam (LASA). The research method was the same as the method described in Chapter 5.

Once more, the independent variable was “course of depression.” The ability to exchange emotional and instrumental support can be regarded as a vital aspect of growing older. We operationalized the concept “support exchange” using four dependent variables: emotional support received, emotional support given, instrumental support received, and instrumental support given. We then included the demographic factors gender, partner status, and age as covariates in the analyses. Based on our study of the influence of depression course on network size, we expected that older people with an unfavourable course of depression would receive and give lower levels of emotional and instrumental support. This expectation, however, was only confirmed for instrumental support received by older persons with a chronic course of depression. There was no significant relationship between depression course and changes in emotional support received and given and instrumental support given. Using GEE analysis, we also investigated three-way interactions between the chosen demographic characteristics, course of depression, and time, as well as their influence on the dependent variables. We discovered that partner status had an interaction effect with course of depression and time on emotional support (received and given) and on instrumental support (received), indicating that having a partner is a favourable condition to receive and give emotional support, and to receive instrumental support on the longer term.

Gender interacted with course of depression and time in the relationship with emotional support received and instrumental support given. More specifically, older persons who

had a chronic course of depression, who had no partner, or who were male were most likely to lose emotional support over time. Older people without partner also lost instrumental support. The results of this study can be used to legitimize the development of tailored interventions intended to preserve older people's social networks and maintain the desired level of social support exchange.

## METHODOLOGICAL CONSIDERATIONS

The research results presented in this thesis are based on three clinical studies conducted by the author, including an N=1 study and two cross-sectional quantitative studies (Chapters 2 to 4), and two population based cohort studies (Chapters 5 and 6) using data taken from the Longitudinal Aging Study Amsterdam (LASA). The cross-sectional studies are descriptive in nature. Descriptive studies are important because they document the frequency with which or the scale at which a specific situation arises or appears to be related to variables within the given research context (3). A needs screening tool such as CANE makes it possible to establish the patient's needs from multiple angles and to identify any discrepancies between patients, staff, and informal caregivers. Such an instrument is, therefore, of immense value when attempting to objectivize unmet needs and then organize community care and offer indicated health care (4–6). To our knowledge, the needs of older people with a depressive disorder living in the community have never before been investigated on this scale. One serious limitation of a cross-sectional design, however, is that it is impossible to establish causal relationships. We were therefore unable to determine whether need is caused by a depressive disorder, only that there is a relationship between the two. More research is needed to understand the assumed reciprocal relationship between unmet needs and depression.

The two cohort studies in this thesis made use of data taken from LASA. Both studies had a longitudinal design, with course of depression being included in the analyses as the independent (predictor) variable and aspects of social participation being included as dependent variables. One key advantage of LASA was that it allowed us to explore the relationship between the chosen predictor variable "depression course" and the various dependent variables described in Chapters 5 and 6 at five points over a period of 13 years. This is much longer than most other longitudinal studies concerning late-life depression. The predictor variable "depression course" was derived from the results of 14 measurements between T1 (1992-1993) and T3 (1998-1999) in a LASA side study involving the same LASA subsample on which the two cohort studies in this thesis were based.

One point of concern in long-term longitudinal studies is respondent dropout. In LASA, the most common reason for dropout was death (24.4%/13 years); the second and third most

common reasons were the patient's refusal (5.15%/13 years) or inability to participate due to frailty (2.6%/13 years) (7,8). Refusal was unrelated to demographic factors or personal characteristics such as a physical or mental disorder. There are various ways of handling dropout (7). We decided to utilize the GEE technique of data analysis and not to impute specific values for missing data, because the GEE technique enabled us to deal with unknown dependence between variables (9).

## IMPLICATIONS

The major transition in Dutch health care system (fuelled in part by the economic crisis and the increasing numbers of older citizens in the coming decades), puts a strong emphasis on self-sufficiency of people in need for care and stimulates care participation from partners, families and friends, demonstrating a genuine paradigm shift in the way the Dutch government thinks about health care and the individual's responsibility in that context.

The current Cabinet's aim of having older people live independently in the community for a longer period of time corroborates the wishes of many older people to remain independent and autonomous (10). However, also converse opinions could be heard demonstrating a growing public unrest about the apparent erosion of the welfare state after 2015. For example, 2014 was the last year in which older people in need for personal and house hold care received care funded under the Exceptional Medical Expenses Act [*Algemene Wet Bijzondere Ziektekosten*, AWBZ]. The year 2014 was also the last year in which socially deprived older people could enjoy daytime social activities funded under the act and organized by local care institutions.

Long before the start of the transition, the first news items appeared in the Dutch media about the announcement that under the new act, home care agencies would stop providing domestic help to older people. Moreover, people were presented who felt short-changed by the way their local government intended to apply the new Act, for instance by considering that meeting basic personal care needs or house hold needs would become the responsibility of loved-ones or neighbours (11). The media also reported that people went to court claiming maintenance of the level of assistance they received under the old act (12).

Although the Dutch Prime Minister Mark Rutte, speaking on behalf of the Cabinet, informed the House of Representatives on April 7, 2014 that the welfare state would remain for people "who cannot participate because they are sick, do not have a network, or are otherwise insufficiently equipped to do so," (13), as of 2015 the Social Support Act [*Wet Maatschappelijke Ondersteuning*, WMO] in fact will have municipal WMO teams



deciding, after a “conversation at the kitchen table”, whether an older person with unmet needs qualifies for assistance under the Act (read: from the local government). It is unclear whether local governments will succeed in assembling WMO teams with sufficient expertise to objectively determine an older person’s “level of self-sufficiency.” A survey conducted by national newspaper *de Volkskrant* indicates that “almost all local governments are worried about whether their budgets will allow them to pay for social support and participation” (12).

If the studies described in this thesis are interpreted in the light of the transition to a new health care system, the results appear to be very meaningful. A depressive disorder can pose a threat to the social participation of older people, especially if the disorder becomes chronic in nature. That is why it is important to utilize care-specific depression prevention methods as indicated, consisting of information and education, a tailored range of course offerings and support groups (14), and not only for patients who are experiencing their first depressive episode, but also for those who recovered from one or more depressive episodes and who are at risk of relapse.

It is important that family physicians and their support staff (POH-GGZ) who suspect the onset of depression (or a relapse) use a diagnostic questionnaire to actively screen the patient for depression. If the patient has a high score, the physician or support staff should follow up with a comprehensive diagnostic interview combined with a systematic investigation of the patient’s needs. If the diagnosis of depression or dysthymia is confirmed, early treatment in line with multidisciplinary guidelines and protocols is advised, preferably as part of the basic mental health care system (referral criteria for basic mental health care [*basis GGZ*]).

Depending on the outcome of the investigation, the complexity of care that will be needed can then be determined. The presence of a complex major depressive disorder combined with the need for highly complex care, expressed in multiple unmet needs in various life domains, would indicate a need for multidisciplinary treatment in the specialist mental health care system [*specialistische GGZ*].

Research has shown that risk-indicated prevention, focusing specifically on older people with depressive symptoms, can be effective at averting more severe symptoms and a chronic course of depression (15). The effect of interventions that are available within the context of indicated prevention can be enhanced if unmet needs are given close attention. Because early detection and prevention of depression are important, family physicians and the professionals who assist them with mental health issues (POH-GGZ), as well as the professionals who work within WMO teams, should have a system in place for detecting unmet needs, for example using a needs screening tool such as the Camberwell

Assessment of Need for the Elderly (CANE). The use of CANE allows care providers to determine not only the needs perceived by the patient but also the needs perceived by his or her caregivers and treatment staff. This is an important advantage of CANE. It gives practitioners the opportunity to discuss discrepancies in perceived needs, the aim being to identify a course of treatment that has the backing of all the parties (mutual goal setting). The social context is decisive for the patient's participation in such activities. Detection of unmet needs related to housing and social welfare will require close cooperation with the municipal WMO teams; unmet physical needs will require close cooperation with the district nursing team.

The huge challenge facing social welfare and health care professionals is to find effective solutions at short notice for the unmet needs of older people with a depressive disorder in this changing social welfare and health care landscape. The intention of the Dutch government to enable older people in need for help due to mental and physical conditions, to stay independent and keep living on their own as long as possible requires the provision of both cost effective and high quality care.

However, I have to question whether the district WMO teams will be sufficiently equipped to indicate personalized care in older persons at risk after 2015, so that timely interventions can be introduced to prevent the erosion of their social networks and to avoid for instance the threat of loneliness. In my view, the higher risk of loneliness among older people with a chronic course of depression points up the necessity of choosing interventions that encourage social participation. I believe that the practitioners at various echelons must take on the task of continuing to form care chains after January 1, 2015, specifically to assist older people who are limited in their ability to benefit from initiatives in the participatory society. By continuing facilities that allow older people to get together with their contemporaries, but now WMO-funded, we can promote their participation in society, help them develop social networks, and support them in battling loneliness.

The Cabinet's recognition of, and support for the position of the district nurse in the process of indicating and providing care is important in this regard. It also clears the way to reconsider the profession of community psychiatric nurses (CPNs). When CPNs are regarded as district nurses with specific expertise in needs-driven care for older persons with mental health problems e.g. depression, they may prove to be the missing link in the care chain following the above-mentioned major change in the Dutch health care system.

## CONCLUSIONS

The main aim of this thesis was to gain knowledge of the consequences of depression for older people as expressed in unmet needs in several domains of functioning, with particular attention to the social domain of functioning. The findings provide insights on 1) how to improve the quality of individual patient care and 2) develop evidence-based nursing interventions. I briefly address both of these aims below.

### *Improve the quality of individual patient care*

In my view, the results of this study can help raise awareness among the professionals who work in general medical practice and in basic and specialist mental health care of the importance of systematically investigating needs and aspects of social participation in relation to depression, in addition to establishing a diagnosis of depression.

The knowledge that we have acquired in this study can support the use of interventions meant to reduce the negative consequences of depression, but also support the prevention of depression or a chronic course of depression. The systematic investigation of needs can also be seen as a diagnostic intervention within the domain of mental health nursing. It can help nursing staff to identify where self-management falls short among older care recipients.

The results of one of the subsidiary studies indicate that patients with depressive symptoms and treatment staff or caregivers do not automatically agree with one another about the patient's needs. We therefore recommend the use of tools that can provide an objective view of those needs. CANE, which was developed especially to examine the needs of older patients, is excellently suited for that purpose. In cases where treatment of depression proves ineffective, it is important to recognize the reciprocal relationship between need and depression so as to identify the factors that may cause a depression to persist, i.e. the patient's unmet needs. Future research will have to determine whether and to what extent fulfilment of unmet needs contributes to recovery from depression or prevents a chronic course of depression.

### *Developing nursing interventions*

It is important to systematically investigate the needs of depressive older people in order to understand those needs in the broader sense, i.e. across a population. Identifying the needs and problems associated with depression on the population level, will make it possible to develop appropriate nursing interventions that then can be tested on their feasibility and effectiveness. Mental health nursing interventions can focus on all the domains covered by CANE, ranging from very practical interventions that support the patient in his or her daily life to interventions that improve the patient's ability to function

mentally and socially. Because CANE covers all these areas, it is excellently suited to surveying needs in the target group of older patients with depression.

Clinical nurse specialists can help investigate interventions based on a problem- and needs-based survey, for example by undertaking a case study to evaluate the form, content and feasibility of a new intervention. After careful development and an initial small-scale test, the effectiveness of the intervention can be tested in experimental or quasi-experimental form. A systematic investigation of needs should be included in multidisciplinary mental health guidelines and in existing and new procedures in primary care in order to guarantee optimal care for patients covered under the WMO. This will provide a sound basis for optimizing care within the municipal health care system, family medical practices, and the basic and specialist mental health care system.

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