Chapter 1

GENERAL INTRODUCTION

INTRODUCTION

People who have experienced depression often say that they would not wish it on their worst enemy. The all-encompassing and oppressive emptiness, sadness, and constant despair with no hope of improvement make depression the severe and debilitating condition it is, with major implications for the quality of life and the ability to participate in society (1,2). One excellent illustration is the video clip that the WHO posted on its website, in which it characterizes depression as a great, omnipresent black dog that affects its master's life in disastrous ways (3).

Figure 1: Still from "I had a black dog. His name was depression" (WHO, 2012)

In my work as a nurse and, later, as a clinical nurse specialist, I often encountered older people whose treatment for depression – performed according to the relevant guidelines – was inadequate, causing the depression to become chronic in nature. When the course of a depression becomes this adverse, with no improvement in sight, with the patient, his loved ones, and the treatment providers feeling helpless, and with the burden on the patient and his or her family being unrelenting, the clinical problem is enormous for all concerned (4,5). The helplessness that I experienced as a practitioner led me to think that when depression becomes chronic in nature, there may be a "missing link" in the known chain of cause and effect. That link might consist of a particular aspect of treatment that largely escapes the notice of practitioners, causing the patient's feelings of depression to persist – in other words, dealing with the patient's unmet needs. My assumption was that the consequences of depression can be expressed in "unmet needs" but that there is a reciprocal relationship in this regard whereby the depression creates needs on the one hand, while unmet needs have an unfavourable effect on the course of the depression on the other.

There has been very little research on the unmet needs of older people with depression and the reciprocal relationship referred to above (6), an observation that inspired me to undertake this study. To place the research in a more specific context, I formulated the general research problem as follows:

> *There has been insufficient research exploring the consequences of a depressive disorder for the daily lives of older people. It is thus unclear to what extent the course of depression in later life is associated with unmet needs, particularly with regard to the individual's ability to play a role in society.*

The usual start for a diagnostic and treatment trajectory for depression is illustrated in Vignette 1. In many cases, depressed patients recover following treatment. However, as the outcome of the described case shows, a late-life depression can often have a less favourable course with major consequences for the patient.

Vignette 1: the case of Mrs Baker

Mrs Baker[1]*, age 78, is one of the respondents I interviewed for the first two studies in this thesis. At the time of the interview, she was living alone in an upstairs apartment in a large city in the centre of the Netherlands. Her husband had passed away several years prior and her only daughter lived abroad. She had no contact with her neighbours. Seven months earlier, Mrs Baker had gone to her GP for memory problems, loss of appetite and anhedonia. The GP referred her to the Geronto-Psychiatric Team at the local mental health centre, where she was diagnosed with major depressive disorder (MDD) and received out patient treatment according to national guidelines. Unfortunately, Mrs Baker's depression did not improve.*

The five studies presented in this thesis all concern the consequences of depression for human functioning later in life. Three clinical studies are presented in Chapters 2, 3 and 4. These studies address the functioning of individuals suffering from late-life depression in various domains of life and their associated care needs: environmental needs, physical needs, psychological needs and social needs. Two population-based studies are then presented in Chapters 5 and 6. These studies focus on the social domain of life. In the first of these studies, the longitudinal course of late-life depression is examined in relation to network size and perceived loneliness. In the second of these studies, the longitudinal course of depression is examined in relation to the long-term exchange of support (i.e., receiving but also giving emotional and instrumental support).

[1] To ensure anonymity, all names and personal characteristics of the patients mentioned in this thesis have been changed. Patients also gave written consent for the use of relevant data.

LATE-LIFE DEPRESSION

It has long been recognized that the process of aging is associated with many losses. Among these are loss of physical functions, loss of mental functions, loss of social roles/functions and loss of significant others. The biological and psycho-social factors associated with these losses form important risk factors for the development of late-life depression (7–9). It is well known that depression is one of the most prevalent and threatening mental health disorders observed in later life (10,11). In a review of studies of the prevalence of depression in later life, for example, Blazer (12) found a prevalence of 1.4% to 12.4% for major depressive disorder (MDD) and 9% to as much as 35% for clinically relevant depressive symptoms. Given the rapid expansion of the population of older people in society today, it can be expected that the number of older people suffering from depression will only increase. And this poses a huge challenge for both our health care system and mental health professionals as late-life depression is particularly associated with an increased utilization of health care services, social services and deficits in economic resources (10). More than 50% of people suffering from depression later in life develop an unfavourable depression course (13,14). A recurrent or chronic course of depression is associated with both adverse health and quality-of-life effects because it disturbs not only the social and psychological functioning of the individual but also the physical functioning of the individual.

Vignette 2: depression and its consequences for everyday life

---

Depression had far reaching consequences for Mrs Baker, including her ability to perform everyday life activities. She could not do her laundry and had trouble doing housekeeping. Depression also affected her physical health. Her physical condition continued to deteriorate with persistent fatigue occurring due to a lack of physical exercise and malnutrition. Her mental condition declined with very low self-esteem emerging along with feelings of worthlessness and guilt, which tormented her constantly. In her opinion, bed was the only place where she could endure her agony. And in the end, she only went out to shop when her fridge was empty.

While depression is considered a treatable disorder for all age categories, treatment outcome is often poor due to under-detection and/or inadequate treatment (15). Treatment non-compliance can also lead to disappointing treatment response (16).

In this thesis, two different operationalisations of depression were adopted. In the clinical studies, the DSM IV-TR criteria for a major depressive disorder were called upon (see Table 1). In the two population-based studies, the Center for Epidemiological Studies Depression Scale (CES-D) was used to identify a clinically relevant level of depressive symptoms. The CES-D is a self-report instrument designed to measure depressive

symptoms within a community (17). See Table 2 for an overview of the features of the CES-D. The life impact for individuals suffering from late-life depression may be particularly marked and far-reaching, given the already vulnerable position of so many in this age category.

Five (or more) of the following symptoms, each present within the same time period of two weeks for most of the time almost every day, pointing at a change compared to a prior level of functioning. One of the symptoms must be either (a) depressed mood, or (b) loss of interest.

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). (In children and adolescents, this may be characterized as an irritable mood).
2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day.
3. Significant weight loss without dieting or weight gain (e.g., a change of more than 5 of body weight in a month), or a decrease or increase in appetite nearly every day.
4. Insomnia or hypersomnia nearly every day.
5. Psychomotor agitation or retardation (observable to others, and not only a subjective feeling of restlessness or inhibition), nearly every day.
6. Fatigue or loss of energy, nearly every day
7. Feelings of worthlessness or excessive or inappropriate guilt nearly every day.
8. Diminished ability to think or concentrate, or indecisiveness, nearly every day.
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

Table 1. Diagnostic criteria for Major Depressive Disorder (APA,2000)

Center for Epidemiologic Studies Depression Scale (CES-D), National Institute of Mental Health (NIMH) (18) Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.				
	During the past week			
	Rarely or none of the time (less than 1 day)	Some or little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	o	o	o	o
2. I did not feel like eating; my appetite was poor.	o	o	o	o
3. I felt that I could not shake off the blues even with help of my family or friends.	o	o	o	o
4. I felt I was just as good as other people.	o	o	o	o
5. I had trouble keeping my mind on what I was doing.	o	o	o	o
6. I felt depressed.	o	o	o	o
7. I felt that everything I did was an effort.	o	o	o	o
8. I felt hopeful about the future.	o	o	o	o
9. I thought my life had been a failure.	o	o	o	o
10. I felt fearful.	o	o	o	o
11. My sleep was restless.	o	o	o	o
12. I was happy.	o	o	o	o
13. I talked less than usual.	o	o	o	o
14. I felt lonely.	o	o	o	o
15. People were friendly.	o	o	o	o
16. I enjoyed life.	o	o	o	o
17. I had crying spells.	o	o	o	o
18. I felt sad.	o	o	o	o
19. I felt that people dislike me.	o	o	o	o
20. I could not get "going".	o	o	o	o
SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.				

Table 2. Example of the CES-D Questionnaire

NEEDS

Differences in the characteristics of individual patients and differences in their responses to treatment emphasize the importance of attending to patient-specific characteristics and providing personalised interventions tailored to the patient's needs (19).

Vignette 3: depression and needs

When I visited Mrs Baker for the research interview, her house was quite messy and showed clear signs of neglect and lack of maintenance. Although it was summer, the central heating was turned up to 25 degrees centigrade and Mrs Baker stated that she was always cold. She also told me that she had not seen or spoken to friends and neighbours for weeks and felt extremely lonely. Mrs Baker sighed that she believed that her situation would never improve again. When I expressed my concerns about her situation and asked if she had spoken to her GP about her condition, she stated that she was afraid of burdening him. She also confessed to feeling that she was not able to look after her home, do her washing or perform other household activities. During the administration of the Montgomery Åsberg Depression rating Scale (MADRS), Mrs Baker confided that she thought that only death could provide relief.

It is well known that mental health problems, including depression, may be associated with multiple and therefore complex needs. This is due to frequent psychiatric and/or physical co-morbidity but also additional social and sometimes environmental problems (20,21). In several studies, the necessity of carefully assessing care needs in cases of mental illness and severe mental illness has been emphasized (6,22–24). However, in evaluating the research literature on this topic, the term "need" was found to be interpreted in multiple, often very different manners.

Among the definitions of *need*, when provided, I found several synonyms to be frequently used: *demand*, *want*, *requirement*, *lack of* and *necessity*. These conceptual discrepancies can be attributed at least in part to different health-care disciplines with distinctive backgrounds and theoretical frameworks (25). Known as standard for the assessment of need is nevertheless the work of Bradshaw (26) who distinguishes four types of service needs in his 'Taxonomy of social need'.

1. Normative need: a need determined or defined by an 'expert' and compared to a standard.
2. Felt need: synonym for 'want', a need for aid, care or service perceived by an individual in a population and limited by the subjective perception of the individual.

3. Expressed need: synonym for ‘demand’, also defined as ‘a felt need turned into action’.
4. Comparative need: need determined by comparing a group with certain characteristics ‘in receipt of a service’ to another group, with the same characteristics but ‘not in receipt of a service’. The group not in receipt of a service may be considered ‘to be in need’.

One of the most widely used definitions of the term ‘need’ within the context of assessing care needs refers to the individual abilities of the person compared to ‘a standard population of peers’. This means that a person can be identified as having a need when that person does not have what other persons coming from the same age group and similar circumstances have (27). Viewed from a health-economic perspective, however, the term ‘need’ can be defined as ‘the ability to benefit from health-care’ (24).

In the present thesis I use a definition of the need concept which refers to Bradshaw’s felt need concept (26). I consider a need as ‘*a physical, psychological, social or environmental demand for aid, care, or service aimed to resolve a problem perceived and expressed by an older person and related to an underlying psychiatric condition’*. From this perspective, a need is generally seen to arise from a mental problem or the psycho-social consequences arising from this mental problem (25).

A further distinction can then be made between *met* and *unmet needs* (28). If a problem can be judged to have adequately been addressed, the underlying need can be said to be *met*. If a problem remains unsolved and/or inadequate care for the problem is being received, the underlying need can be said to be *unmet*. Meeting unmet needs has been shown to be critical as such needs can: induce depression or prolong existing depression, lead to higher health care costs and generally have negative impact on the person’s quality of life (6,29).

ASSESSMENT OF NEEDS AS A BUILDING BLOCK FOR DEVELOPMENT OF EVIDENCE-BASED INTERVENTIONS

In addition to the clinical importance of providing needs-driven care, there is also a scientific reason for gaining greater insight into the needs of people with depression in general and a late-life depression in particular. Little is known about the best practices or implementation of evidence-based nursing interventions for the care of older patients suffering from depression. This is therefore one of the core objectives of nursing science and the nursing profession today, namely contribute to a relevant knowledge base with the development, validation and empirical testing of nursing interventions aimed at the treatment and support of older people with psychiatric disorders, including depression. The systematic assessment and analysis of existing problems and felt needs for the

population of depressed older patients constitutes a critical first step in this regard (30). In keeping with the model of van Meijel (30) for the development evidence-based nursing interventions (see Figure 1), a thorough review of the literature and analysis of the relevant problems and needs provides the building blocks needed to develop effective, evidence-based nursing interventions. Following the design, validation and further testing of these interventions, they should be made available for groups of care recipients but require tailoring of the care plans to the individual needs of the care recipients as part of their application.

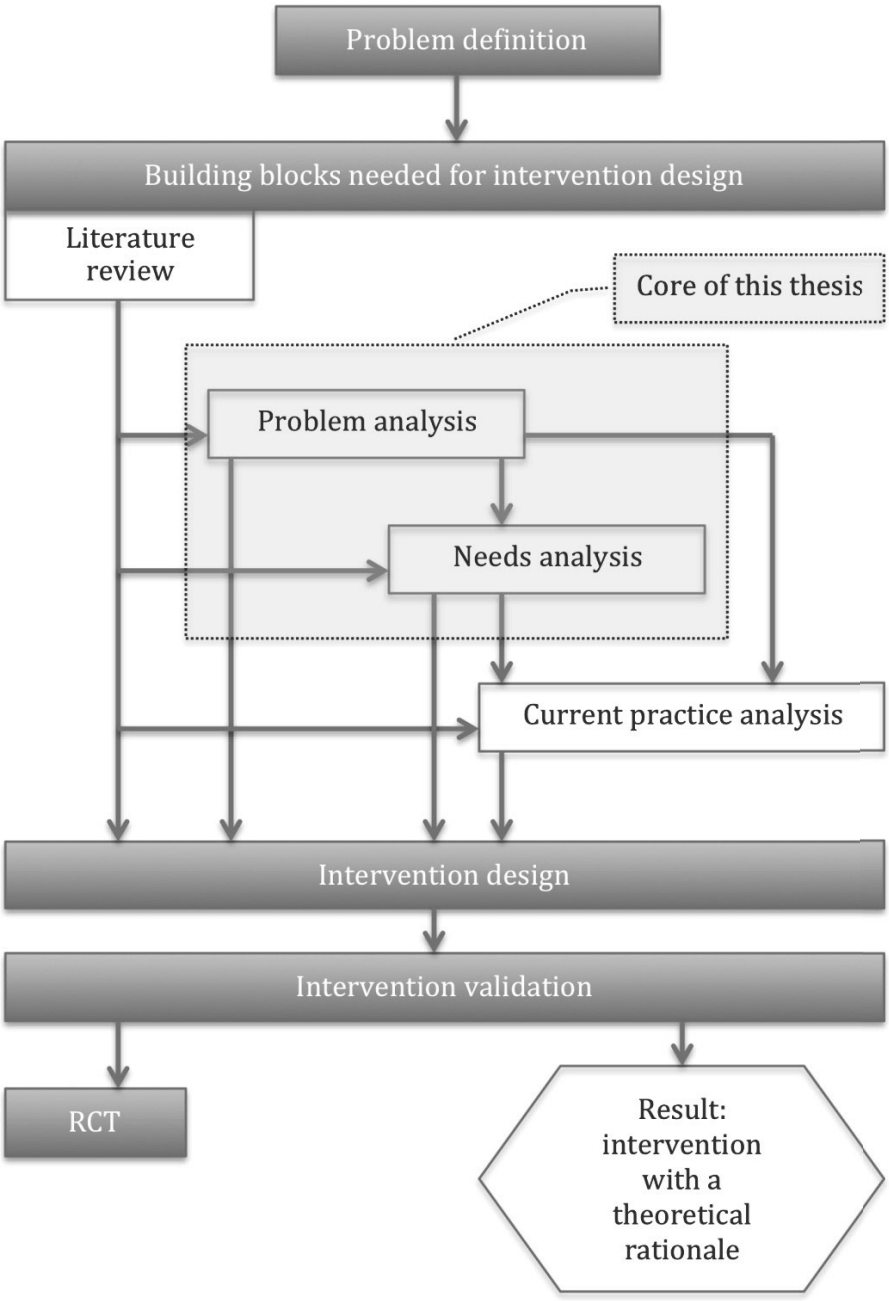

Figure 1: diagram of the development of evidence based interventions (30)

Interrelations between late-life depression and unmet needs

It has been demonstrated repeatedly in research that negative perceptions of an individual's quality of life) and health in addition to the existence of unmet needs can predict negative health outcomes, depressive symptoms and even mortality (6,31). Other research has repeatedly shown that unmet needs can arise from severe mental illness, including depression (24,32,33). For these reasons, depression and unmet needs are presumed to be interrelated or — in other words — unmet needs are assumed to be both a predictor and a consequence of late-life depression. This cycle of unmet needs and late-life depression is depicted in Figure 2, which also outlines the central concepts in this thesis. These central concepts are often not just related sequentially to each other, as depicted in the figure, but also interrelated and related bi-directionally to each other, which has not been depicted in the figure for the sake of simplicity. Physical deterioration and thus an unmet need for mobility or exercise can give rise to accompanying social or psychological problems and therefore also give rise to potential unmet needs within these domains (34). Conversely, a lack of social support may lead to loneliness and thereby to depression (35).

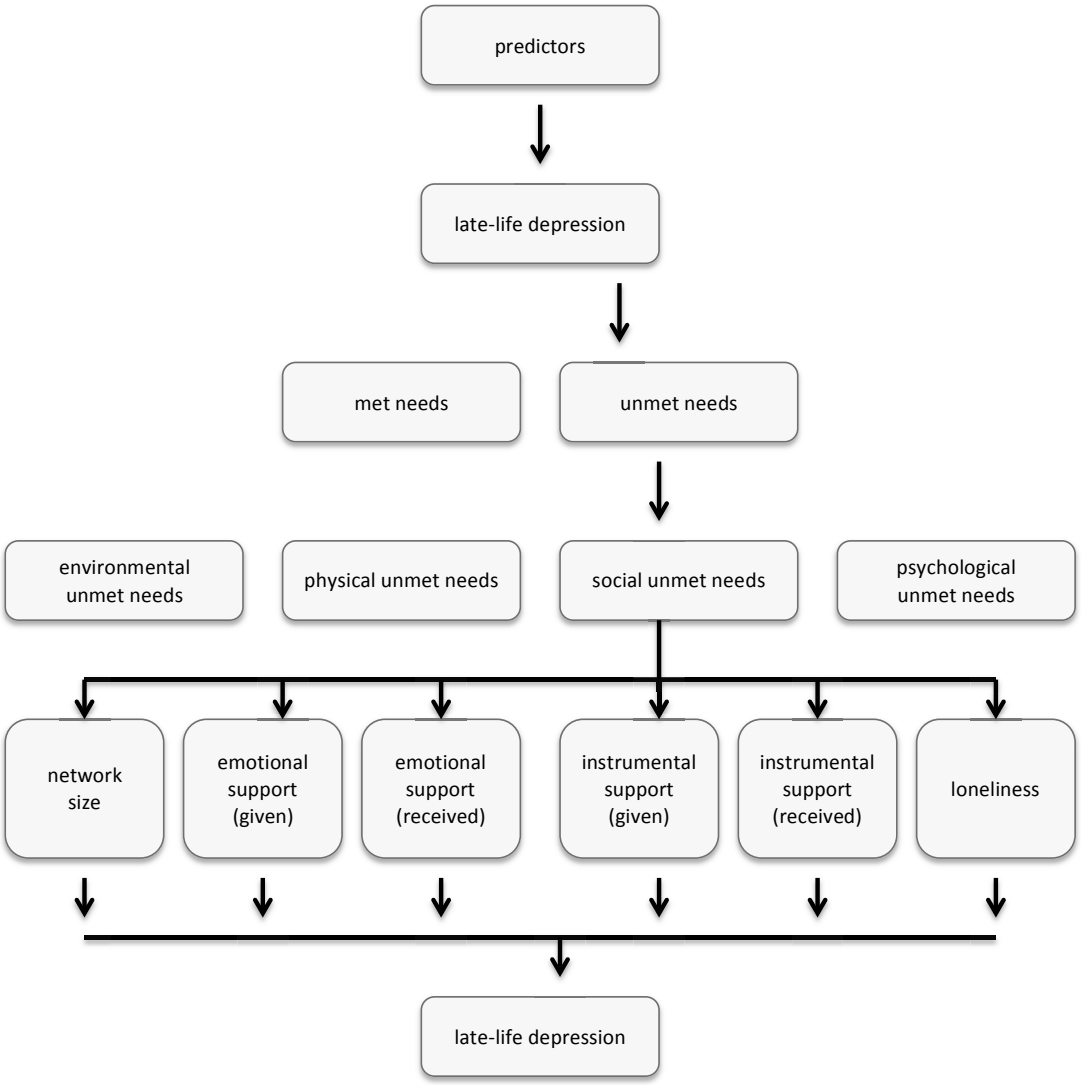

Figure 2: focus and central concepts of this thesis

OUTLINE AND AIMS OF THE THESIS

Traditionally, the main goal of mental health nursing is to guide and support people with the management of problems and care needs arising from a psychiatric disorder. Nurses play a leading role in the planning, coordination and conduct of such interventions (i.e., interventions aimed at recovery and/or a better quality of life for the patient). However, little is known about the specific problems and needs perceived by older people and occurring as a consequence of late-life depression. Within the context of the present research, it was assumed that gaining greater insight into the perceived problems and needs of older patients with late-life depression will enable nursing professionals to develop, test and implement much needed evidence-based interventions for their care in the future. More evidence-based knowledge is also needed to tailor the available care to the needs of individual patients and help health care professionals support older people living independently.

In **Chapter 2**, the case of Mrs Brown is introduced. In this N=1 case study, the clinical status of the 84-year-old woman is shown to improve significantly after systematically charting her unmet needs using the Camberwell Assessment of Needs for the Elderly (CANE) and applying tailored nursing interventions to meet her most urgent needs.

In **Chapter 3**, the needs of 99 community-dwelling outpatients who have been diagnosed with a major depressive disorder are assessed. The associations between their expressed (i.e., unmet) needs and the severity of their depression are then documented.

In **Chapter 4**, the perceptions of the unmet needs of patients by the patients themselves, their care professionals and their informal caregivers are compared and contrasted. This was done with three objectives in mind. First, to identify the most frequently mentioned unmet needs among outpatients with a major depressive disorder, according to the patients, their care professionals and their informal caregivers. Second, to determine the level of agreement among the patients, care professionals and informal caregivers with regard to the presence of different needs. Third, to gain insight into the influence of depression severity on the extent of agreement between patients and informal caregivers with respect to assessed patient needs but also patients and care professionals with respect to the same.

In Chapters 2, 3 and 4, the emphasis is on reliable identification of the needs of patients with late-life depression. In Chapters 5 and 6, the long-term consequences of late-life depression for the social participation of a population of elderly individuals are considered to expand upon an important part of the results of the clinical studies.

The objective of the population-based study described in **Chapter 5** was to gain insight into the impact of the natural course of depression on the size of the individual's personal network and perceived loneliness over time, among older people initially still living independently within the community. Data from the Longitudinal Aging Study Amsterdam were used to trace older individuals with clinically relevant levels of depression across a period of 13 years.

The same sample was used in the study reported on in **Chapter 6** where the interrelations between the natural course of depression, providing emotional and instrumental support and the receipt of emotional and instrumental support over time are described and analysed. Three-way interactions with the gender, partner status and age of the participants are also examined and described.

In the General Discussion, presented in **Chapter 7**, the main findings of this research are summarised and discussed. Moreover, also implications of the results for nursing practice in an aging society will be examined. Finally, directions for care improvement will be presented.

REFERENCES

1. Beekman AT, Deeg DJ, Braam AW, Smit JH, Van Tilburg W. Consequences of major and minor depression in later life: a study of disability, well-being and service utilization. Psychol Med. 1997;27(6):1397–409.
2. Blazer DG. Depression and social support in late life: A clear but not obvious relationship. Aging & Mental Health. 2005;9(6):497–9.
3. WHO | Depression [Internet]. WHO. [cited 2014 Aug 26]. Available from: http://www.who.int/mediacentre/factsheets/fs369/en/
4. Gensichen J, Jaeger C, Peitz M, Torge M, Güthlin C, Mergenthal K, et al. Health care assistants in primary care depression management: role perception, burdening factors, and disease conception. The Annals of Family Medicine. 2009;7(6):513–9.
5. Martire LM, Schulz R, Reynolds CF, Karp JF, Gildengers AG, Whyte EM. Treatment of Late-Life Depression Alleviates Caregiver Burden. Journal of the American Geriatrics Society. 2010 Jan;58(1):23–9.
6. Blazer DG, Sachs-Ericsson N, Hybels CF. Perception of Unmet Basic Needs as a Predictor of Depressive Symptoms Among Community-Dwelling Older Adults. J Gerontol A Biol Sci Med Sci. 2007 Jan 2;62(2):191–5.
7. Blazer DG, Hybels CF. Origins of depression in later life. Psychological Medicine. 2005 Feb 18;35(09):1241.
8. Cacioppo JT, Hughes ME, Waite LJ, Hawkley LC, Thisted RA. Loneliness as a specific risk factor for depressive symptoms: Cross-sectional and longitudinal analyses. Psychology and Aging. 2006;21(1):140–51.
9. Glaesmer H, Riedel-Heller S, Braehler E, Spangenberg L, Luppa M. Age-and gender-specific prevalence and risk factors for depressive symptoms in the elderly: a population-based study. International psychogeriatrics. 2011;23(08):1294–300.
10. Beekman AT, Copeland JR, Prince MJ. Review of community prevalence of depression in later life. Br J Psychiatry. 1999;174:307–11.
11. Licht-Strunk E, van der Kooij KG, van Schaik DJ, van Marwijk HW, van Hout HP, de Haan M, et al. Prevalence of depression in older patients consulting their general practitioner in The Netherlands. International journal of geriatric psychiatry. 2005;20(11):1013–9.
12. Blazer DG. Depression in late life: review and commentary. J Gerontol A Biol Sci Med Sci. 2003;58(3):249–65.

13. Comijs HC, Nieuwesteeg J, Kok R, van Marwijk HW, van der Mast RC, Naarding P, et al. The two-year course of late-life depression; results from the Netherlands study of depression in older persons. BMC Psychiatry [Internet]. 2015 Dec [cited 2015 Apr 11];15(1). Available from: http://www.biomedcentral.com/1471-244X/15/20

14. Cuijpers P, Beekman ATF, Reynolds CFI. Preventing depression: A global priority. JAMA. 2012 Mar 14;307(10):1033–4.

15. Licht-Strunk E, Beekman ATF, de Haan M, van Marwijk HWJ. The prognosis of undetected depression in older general practice patients. A one year follow-up study. Journal of Affective Disorders. 2009;114(1-3):310–5.

16. Mitchell AJ, Subramaniam H. Prognosis of Depression in Old Age Compared to Middle Age: A Systematic Review of Comparative Studies. Am J Psychiatry. 2005;162(9):1588–601.

17. Berkman L, Berkman C, Kasl S, Freeman D, Leo L, Ostfeld A, et al. Depressive symptoms in relation to physical health and functioning in the elderly. American Journal of Epidemiology. 1986;(124):372–88.

18. Radloff LS. The CES-D Scale A Self-Report Depression Scale for Research in the General Population. Applied Psychological Measurement. 1977;1(3):385–401.

19. Fredman SJ, Korn ML. Improving the Treatment of Depression by Tailoring Interventions to Patients' Needs [Internet]. Medscape nurses. 2014 [cited 2014 May 14]. Available from: http://www.medscape.org/viewarticle/436394

20. Badger TA. Depression, Physical Health Impairment and Service Use Among Older Adults. Public Health Nursing. 1998;15(2):136–45.

21. Reynolds T, Thornicroft G, Abas M, Woods B, Hoe J, Leese M, et al. Camberwell Assessment of Need for the Elderly (CANE). British Journal of Psychiatry. 2000;176:444–52.

22. Arvidsson H. The development of needs in a group of severely mentally ill. Social psychiatry and psychiatric epidemiology. 2008;43(9):705–13.

23. Meesters PD, Comijs HC, Dröes R-M, de Haan L, Smit JH, Eikelenboom P, et al. The Care Needs of Elderly Patients With Schizophrenia Spectrum Disorders. The American Journal of Geriatric Psychiatry. 2013;21(2):129–37.

24. Wiersma D. Needs of people with severe mental illness. Acta Psychiatrica Scandinavica. 2006;113:115–9.

25. Hancock GA, Orrell MG. Introduction: Defining need. In: Hancock GA, Orrell M, editors. CANE: Camberwell Assessment of Need for the Elderly. London: Gaskell; 2004. p. 1–2.

26. Bradshaw J. A taxonomy of social need. IN MCLACHLAN (Ed.) Problems and progress in medical care. London, Oxford University Press; 1972.

27. Brewin CR, Wing JK, Mangen SP, et al. Priciples and practice of measuring needs in the long-term mentally ill; The MRC needs for care assessment. Psychological Medicine. 1987;17:971–81.

28. Slade M, Leese M, Taylor R, Thornicroft G. The association between needs and quality of life in an epidemiologically representative sample of people with psychosis. Acta Psychiatrica Scandinavica. 1999;100(2):149–57.

29. Slade M, Leese M, Cahill S, Thornicroft G, Kuipers E. Patient-rated mental health needs and quality of life improvement. The British Journal of Psychiatry. 2005;187(3):256–61.

30. Van Meijel B, Gamel C, van Swieten-Duijfjes B, Grypdonck M h. f. The development of evidence-based nursing interventions: methodological considerations. Journal of Advanced Nursing. 2004;48(1):84–92.

31. Alonso, Orfila F, Ruigomez A, Ferrer M, Antó JM. Unmet Health Care Needss and Mortallity among Spanish Elderly. American Journal of Public Health. 1997;87(3):365–70.

32. Hays JC, Krishnan KRR, George LK, Pieper CF, Flint EP, Blazer DG. Psychosocial and physical correlates of chronic depression. Psychiatry research. 1997;72(3):149–59.

33. Heikkinen R-L, Kauppinen M. Depressive symptoms in late life: a 10-year follow-up. Archives of Gerontology and Geriatrics. 2004;38(3):239–50.

34. Hoogendijk EO, Muntinga ME, van Leeuwen KM, van der Horst HE, Deeg DJH, Frijters DHM, et al. Self-perceived met and unmet care needs of frail older adults in primary care. Archives of Gerontology and Geriatrics. 2014;58(1):37–42.

35. Luanaigh CÓ, Lawlor BA. Loneliness and the health of older people. International journal of geriatric psychiatry. 2008;23(12):1213–21.