The patient’s perspective on recovery from depression
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Chapter 1

General introduction
Chapter 1

The present thesis offers the knowledge and experience of patients with regard to self-management and professional treatment of major depressive disorder (MDD). It contains a collection of studies that were conducted in an effort to thoroughly understand how patients are able to self-manage their depression on a day-to-day basis, and what factors of professional treatment they experience as helpful, not helpful or even harmful. In this first chapter, the background, context, aims and research questions are described.

Depression

Major depressive disorder, from this point called ‘depression’, causes a significant burden for patients and their carers, as it is associated with severe symptoms and role impairment. The life-time prevalence of depression has been estimated at 16.2% and depression affects twice as many females compared to males. In addition, depression constitutes a major financial health problem in today’s society. Although tentative, the World Health Organisation (WHO) estimates that depression will be the leading cause of burden of disease in high-income countries by the year 2030.

Although a wide range of evidence-based treatments are available, such as pharmacotherapy, psychotherapy and additional help from psychiatric nurses, creative- and psychomotor therapists, not all patients seek, accept or continue these treatments. If they do, unfortunately more than 50% of all patients experience insufficient improvement. Interestingly, scientific research, mental health care organisations and professional guidelines mainly reflect their own perspective about what is helpful for depressed patients, and currently, they mainly focus on short-term symptom reduction and (cost) effectiveness.

Therefore, there is a critical need to understand more about what is helpful for depression from the patient’s perspective. Specifically, there is a need to know how patients cope with their depression on a day-to-day basis, given the fact that depression is increasingly recognised as a chronic disease, characterised by multiple recurrences. The recurrence rate after a first depressive episode is more than 50%, and after the second and third episodes, the risk of relapse rises to 70% and 90%, respectively, and as many as 20% of the depressive episodes become chronic. Moreover, patients have unique experiences regarding how they cope with depression, leading to different needs for treatment and different uses of ‘self-management’ strategies. Patients may differ from one another in
their preferences for self-management strategies, based on e.g. gender, age, history with depression, depression severity and other clinical characteristics.

Conceptualization of self-management

The conceptualization of self-management is confusing because several terms exist to describe the same phenomenon, such as self-help, self-care, collaborative care and self-management-support (SMS).\textsuperscript{13} Therefore, the conceptualization of self-management is confusing. Although these terms are generally meant to describe a similar phenomenon, there are distinctions between these concepts: \textit{Self-help} is generally characterised as being predominantly independent of professional contact and is intended as “a (psychological) treatment, where the patient takes home a standardized (psychological) treatment and works through it more or less independently”\textsuperscript{(p. 1934)}.\textsuperscript{14,15} \textit{Self-care} is a broad concept that describes what people do for themselves to establish and maintain health, encompassing prevention of illness.\textsuperscript{16} \textit{Self-management} is a key-component of collaborative care, which can be described as a “multicomponent, healthcare system-level intervention that uses case managers to link primary care providers, patients, and mental health specialists”\textsuperscript{(p. 526)}.\textsuperscript{17} \textit{Self-management-support (SMS)} is the systematic provision of educational and supportive interventions by (non-physician) professionals. It is an adjunct to conventional treatments and is aimed at preventing a relapse given the chronic nature of disease.\textsuperscript{18} Although the terms are used interchangeably, the approaches are different. Self-management is the most comprehensive approach to preventing and managing depression, and therefore will be the focus of the work in this thesis.

The definition of \textit{self-management} used in this thesis is the one described by Barlow (2002):\textsuperscript{19} ‘the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition’. This particular definition is used because, for depression, self-management is not mainly aimed at (relapse) prevention, but also aimed at coping with (recurrent or chronic) depression on a day-to-day basis. It entails the patient’s active involvement in the management of his or her own health (care) process.
Evolution of self-management

The development of self-management arose in the mid-1960s from chronic somatic diseases, such as diabetes and arthritis, to increase patients’ involvement in their treatment and control its effect on their lives. Self-management is currently a well-established and evidence-based approach to a number of somatic diseases and many self-management programmes have been developed worldwide. For example, for asthma, many effectiveness studies have been conducted and have identified self-management for the improvement of quality of life and disease severity. In the United States, the ‘Arthritis Self-Management Program’, developed by The Stanford Patient Education Research Centre (http://med.stanford.edu/patienteducation) has significantly improved behaviours, role functioning and even communication with physicians. In the United Kingdom, the Expert Patient Program has been developed for people who are living with a chronic disease, and in The Netherlands, self-management for several somatic diseases such as diabetes, has become part of integrated care (‘ketenzorg’) in general practices.

In mental health care self-management is much less widely used compared to chronic somatic diseases because it is a relatively new approach. For example, for schizophrenia, self-management initiatives are still in development. For bipolar disorders, psychoeducation has been developed to help patients understand and manage their disease more effectively. For mood and anxiety disorders, Villagi et al (2015) identified self-management strategies to be used and promote recovery and symptom reduction. But for most mental diseases, such as eating- or personality disorders, the various professional guidelines (APA, NICE and Dutch guidelines) yet hardly mention self-management for the use as a new approach. However, research and evidence for self-management in mental health care is growing: For depression self-management, only 46 scientific publications were found in the archives of PubMed in 2000, whilst 544 articles were found in 2014.
Current emphasis on self-management for depression

Self-management for depression has become an important priority in today’s mental healthcare, which could be attributed to the following social developments:

1. Autonomy and responsibility have become key concepts in our current individualized society. Thereby, the evolution of self-management in the last decade has accompanied the trend of collaborative care, in which the professional and the patient share their expertise to achieve the best possible disease management. The professional is not only seen as an expert anymore, neither is the patient a passive recipient of care. 12

2. The profound burden and prevalence of depression causes the public health need for the development of new models of care.

3. Albeit a plethora of professional treatments are available, still more than 50% of all depressive patients experience insufficient improvement. 6 Therefore, the development of new and more effective treatment approaches is needed.

4. As healthcare costs for depression continue to rise, policy makers and health care providers are identifying ways to manage this progression. 36 Self-management holds promising prospect to be a cost-cutting strategy to reduce the financial burden of chronic depression care. 36

5. Finally, the rapid developments in the field of information and communication technologies (ICT) further increase self-management as a promising approach, because ICT offers great opportunities to support self-management. 37
Chapter 1

**Depression self-management in Dutch mental health care**

The Dutch government emphasizes self-management approaches for depression since 2009. In 2009 the Dutch Ministry of Health, Welfare and Sport (VWS) launched and financed the four-year ‘National Action Program Self-management’ (NAPS), to implement self-management (support) in Dutch Health Care. Several recommendations were drawn regarding depression, including development of strategies for chronically depressed patients and education programmes in order to support patients to gain more control and strive after ‘shared decision-making’.

Moreover, several initiatives regarding self-management have emerged in the last decade, such as the online programmes ‘Kleur je leven’ (www.kleurjeleven.nl) and ‘Grip op je dip’ (www.gripopjedip.nl). However, most of these programmes focus on sub-threshold depression and prevention rather than chronic depression. They do not use professional support and most of them make use of cognitive behavioural treatment-based approaches.

Programmes that focus on strategies for the rehabilitation of recurrent or chronic depression are scarce. An exception is the programme ‘Het roer in handen’ for chronic depression and anxiety which has currently been investigated for efficacy in The Netherlands. This programme is based on a rehabilitation programme which was developed for severe depression in 2005.

**Rapid self-management initiatives pre-date scientific developments**

In addition to the programmes developed within the Dutch government, there are various international self-management programmes that are worthy of notation. Examples include the international web-based programmes ‘Here to Help’ (www.heretohelp.bc.ca/managing-depression) and MoodGYM (moodgym.anu.edu.au/welcome). The popularity of self-management approaches is causing rapid self-management initiatives to emerge that seem to pre-date scientific developments. In reviewing the scientific field of self-management strategies for depression, Morgan has identified 48 strategies for sub-threshold depression, which include mainly lifestyle (e.g. engage in physical activity) or psychosocial (e.g. reward themselves for reaching a small goal) strategies. Moreover, Coulombe et al (2015) constructed a Mental Health Self-Management Questionnaire which includes strategies with themes such as ‘Empowerment’ and ‘Vitality’ for mood and anxiety disorders, and is based on the work by Villagi et al (2015), who identified self-
management strategies used by people with depressive, anxiety and bipolar disorders. However, strategies that focus specifically on the more severe, chronic depressed population have not yet been identified.

**Self-management for depression**

Self-management for depression aims to have patients recognize changes in depressive symptoms, take actions in solving problems and know where to find reliable and relevant information to gain control over their lives. Corbin and Strauss (1988), two qualitative researchers focussing on medical sociology in London, were among the first to identify the process of self-management and defined three tasks for the chronically ill patient:

1. (Learn) to *manage all the emotions* associated with having depression; anger, frustration, feelings of impotency, anxiety and sadness. The patient must adapt his/her expectations about the (near) future.

2. Maintain, change or create *new behaviour* or a new role in society. For example, a teacher who is depressed and who is known for his creative ideas must change the way he used to teach by accepting that ideas do not come effortless anymore.

3. Learn the *medical management* of depression, such as the need to cope with symptoms such as fatigue or loss of appetite, find information about depression or search for a suitable treatment.

On the basis of these tasks, a patient first needs to accept the depression in order to be able to self-manage the disease.

**Self-management paradox**

In terms of depression, the term self-management may seem rather paradoxical than supportive. For example, it can be misunderstood for the reason that it falsely implies that patients are responsible for the management of the disease on their own, while depressive patients in general lack confidence, have a passive and avoidant coping style rather than actively deal with feelings of guilt and hopelessness. Nevertheless, most patients agree about their longing to gain back the control they lose over their lives. To learn to cope with depression, learning to ‘self-manage’, can reinforce mastery. Self-management addresses
the strength of the patient and highlights the ‘healthy part’ of the patient who is longing for autonomy.

**Effectiveness of self-management for depression**

The interest in self-management for mental health diseases has developed only recently, and little is known about the effectiveness. Ryan *et al* (2010) designed an adjunctive depression programme for difficult-to-treat depressed patients and their families in the USA, in an effort to help these patients and families cope more effectively with depression. Although they only included 19 patients, they found improved patient’s perceived quality of life and functioning, reduced depressive symptoms, and improved perception of their family’s functioning. In Italy, Franchini *et al* (2006) created a psychoeducational intervention for strategies to improve antidepressant treatment and they found significantly less relapse in the group of patients who participated in this psychoeducational intervention. However, this study was aimed at medication adherence, not strategies to cope with depression itself.

Furthermore, in The Netherlands, a research group created a psycho-educational prevention (PEP) programme for self-management in primary care depressed patients, but results from this randomized controlled trial (RCT) that compared the PEP self-management programme with care as usual (CAU) in primary care showed no evidence for improved short-term outcomes and cost-effectiveness. However, some factors of this RCT may help explain why no support for self-management was found. The recruiting physicians in the CAU received a training on optimal treatment of depression and compliance with guidelines. This training may have contributed to high rates of antidepressant adherence in the control group and the training might have masked the beneficial effects of self-management in real world practice. Additionally, the PEP providers were not trained psychotherapists, the programme was characterized by minimal face-to-face and telephone contacts and the nature of the programme might have had too little intensity to attain major improvements.

In order to describe self-management approaches and to examine their efficacy to understand the potential of self-management, Houle *et al* (2013) performed a systematic review and included, among others, some of the above described studies. Houle concluded that overall, self-management seems to be associated with reduced depressive symptomatology and improved functioning, but the results are inconsistent with respect to reducing relapse and recurrence rates. However, these findings can be explained by
the fact that some of those studies are dated, two pilot studies were included in the review and most studies narrowed their target strategies on medication adherence.

Various reasons complicate effectiveness research which hampers conclusions in meta-analyses: The different conceptions of self-management as described earlier make it difficult to properly distinguish aims and outcomes. Self-management approaches are heterogeneous and use e-health, booklets, (peer-led) group interventions with or without professional support. Next, the target outcome of self-management is diverse and varies between prevention, sub-threshold or 'mild' depression and only a scarcity of research focuses on major depressive episodes (MDE) that fulfil criteria of DSM-IV. And although self-management was originally developed for chronic diseases, to our knowledge, no study thus far includes chronic depressive patients.

**Patient’s perspective on self-management**

As a consequence of the heterogeneous use of self-management, different parties (such as policy makers and health institutions) use self-management according to their own beliefs about good chronic care. Moreover, the majority of self-management approaches are led and designed by professionals. However, in order to be helpful and effective for use in clinical practice, self-management strategies should certainly also reflect the patient’s perspective. Specifically, professional support that considers patients individual needs increases effectiveness. Although the revised version of the Dutch professional guideline for depression cautiously recommends self-management as a new approach in the treatment of depression, little is known about what self-management strategies patients use and consider helpful.

**The patient’s perspective on treatment**

Despite major promising developments regarding chronic depression management and treatment, basic knowledge is still lacking not only about what patients perceive as helpful in coping with the daily problems caused by depression, but also about their different needs for treatment. There is emerging evidence that patient’s involvement and expertise about treatment of depression (e.g. patient preferences regarding treatment conditions, type of treatment or therapist characteristics) influence treatment outcomes. It is necessary to know whether and how professionals take into account the patient’s perspectives, preferences and diversity.
With the current extreme emphasis on biological psychiatry, most scientific approaches aim to discover helpful treatment factors by focusing on neurobiology and the application of the best pharmacological strategies. However, these approaches lose sight of the effectiveness of common factors in treatment such as the therapeutic alliance and hope.

In real-world patients, a professional has to focus on much more than the application of technical approaches. With the knowledge of the patient's perspective, professionals have an opportunity to develop personalized treatment by adjusting the specific needs of depression treatment for each individual patient, amalgamate shared goals, and consequently accomplish better coping and self-management of the disease.

**Patient's, carer's and professional's perspective on professional treatment**

Another way to broaden our view of helpful factors in the process of depression treatment is not to only focus on the patient's perspective, but to include the perspectives of professionals and carers. First, professional's perspectives about treatment often differ from those of patients. For example, findings indicate that professionals' occasional advice for pharmacological treatment strategies are not in line with what patients prefer (i.e., many patients tend to prefer psychological therapies). Second, the role of the carer is relatively invisible, but invaluable, because they are the daily witnesses in perceiving how treatment affects the recovery of a depressed patient. According to professional depression guidelines the carer's engagement into treatment is therefore highly recommended. Altogether, patients, carers and professionals are considered the experts to lead us in unraveling the helping factors in the treatment of depression.

Especially with the increased emphasis on engagement of patients in their own healthcare, shared-decision making (SDM), a joint venture between patients and clinicians, has become a topic of interest in today's health care. SDM is a gradual process and often involves more people than only the patient and clinician engaged in the decision making process, including carers, and is of particular value because it provides personalized treatment.

Overall, there seems to be a gap between professional-led treatments and vision on how to recover from depression, and the perspectives of patients about what is helpful for them. With the knowledge and the recommendations from the patient's perspective, mental health professionals have the opportunity to adjust the specific needs of depression treatment for each individual patient and thereby improve symptoms and functioning.
Aim and research questions

The general aim of this thesis is to gain profound insight into the depressed patient’s perspective on professional treatment and their day-to-day coping, using self-management as a strategy. Based on the results, we expect to make recommendations for clinical practice to pursue effective, efficient, personalized treatment and a truly joint venture regarding self-management between professionals and patients.

PART I

As shown above, it is not known what self-management strategies patients use and perceive as helpful in their recovery from- and coping with depression. The first part of this thesis therefore aims to explore the patient’s perspective on self-management strategies and this aim is divided into three general research questions:

1. What self-management strategies do patients consider to positively contribute towards their recovery from depression? (*chapter 2*)

2. Which of these self-management strategies do patients actually use, which do they perceive as being most helpful and are there differences according to clinical and demographic characteristics? (*chapter 3*)

3. What do patients believe they can do themselves to cope with enduring depression besides professional treatment? (*chapter 4*)

PART II

Little is known about what patients, carers and professionals, perceive as helpful, not-helpful or even harmful in the treatment of depression. The aim of this part is to explore the perspectives of those three groups with the following two general research questions:

4. What are the impeding, or even harmful, characteristics of professional treatment for the recovery of depression from the patient’s perspective? (*chapter 5*)

5. What are helpful factors of professional treatment of depression from the patient’s, carers and professional’s perspectives? (*chapter 6*)
Chapter 1

Outline of the thesis

PART I of this thesis consists of three chapters that explore the patient’s perspective on depression self-management. In chapter 2, self-management strategies perceived helpful in the recovery from depression are identified using a mixed-method design ‘concept mapping’. In addition, in chapter 3, the actual use and perceived helpfulness of those strategies are further studied with the use of a developed online self-report survey that was distributed in a large sample of depressed patients. Also, common self-management themes are identified and differences between patient clinical and demographic characteristics in the perceived helpfulness of self-management strategies are studied. In chapter 4, concept mapping is used again to explore self-management strategies that are perceived helpful to cope with enduring depression besides professional treatment.

PART II contains two chapters that focus on the patient’s, carer’s and professional’s perspectives on treatment. In chapter 5, impeding and hindering characteristics of professional treatment from the patient’s perspectives are studied in-depth by means of individual interviews with recovered depressed patients. In addition, chapter 6 describes helpful factors of treatment from the perspectives of patients, carers and professionals, using concept mapping in a large sample. Finally, the results of the different studies are reviewed and discussed in chapter 7. This chapter also includes recommendations for further research as well as practical implications.
References


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