The patient's perspective on recovery from depression
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Chapter 7

General Discussion
The present thesis explored the depressed patient’s perspective on self-management and professional treatment. This concluding chapter summarises the major findings of those investigations, followed by a general discussion and methodological considerations. It closes with implications for clinical practice and directions for future research.

Summary of the main findings

This thesis addressed several questions:

PART I
Depression self-management

1. What self-management strategies do patients consider to positively contribute towards their recovery from depression?

In chapter 2, we explored the experiences of 20 participants who recently recovered from a depressive episode using the mixed-method concept mapping. In the qualitative stage, the participants generated 50 unique helpful strategies in focus group discussions. In the additive quantitative stage, they individually sorted and prioritized these 50 strategies, which after statistical analysis resulted in the following eight main themes, ranked in order of perceived importance: 1) Proactive attitude towards depression and treatment, 2) Daily life strategies and rules, 3) Explanation of disease to others, 4) Remaining socially engaged, 5) Engaging in activities, 6) Structured attention to oneself and 7) Contact with fellow sufferers. With the help of the group process, participants encouraged each other to bring up several ideas. Although, in general, depressed patients lack motivation and self-confidence, these participants who recently recovered from a depressive episode illustrated elaborate ideas and strategies about how they can contribute to their own recovery.

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?

Next, in chapter 3, we studied to what extent the strategies that have been found suitable from the patients’ perspective as contribution to their recovery from depression (chapter 2) are actually used by patients and which they found helpful or very helpful. Therefore, based on the previously identified 50 self-management strategies, we developed an online survey that aimed to measure the most used and perceived most helpful strategies, to distinguish common themes within the strategies and to measure any differences between patient clinical and demographic characteristics. In a sample of
193 participants, who mostly have had recurrent and severe depressive episodes, forty-five of the 50 strategies were used by more than 50% of participants. In addition, thirty percent of all participants perceived almost 50% of all strategies as helpful or very helpful if they had used the strategies. Exploratory factor analyses resulted in four themes: 1) Accepting depression and actively coping with the disease (e.g. discussing changes in role within the family/relationship), 2) Engagement in social and working life (e.g. explaining depression to colleagues), 3) Daily life coping (e.g. setting realistic short term goals), and 4) Daily routines and activities (e.g. healthy eating). Two significant group differences were present: compared to men, women significantly perceived ‘daily life coping’ to be more helpful, and participants living with others significantly perceived ‘accepting depression and actively coping with the disease’ more helpful than participants living alone. No significant differences were found regarding self-management strategies in other subgroups such as age, family history with depression or depression severity. Although avoidance behaviour is a coping pattern that is often seen in depression, patients used and experienced many different strategies that promote the acceptance of depression and engagement in physical and social activities as the most helpful. These strategies may now be introduced in clinical practice to individual patients, to self-help groups, to carers and professionals in order to support and empower patients. Furthermore, the results form a basis for the further development of a comprehensive self-management tool.

3. What do patients believe they can do themselves to cope with enduring depression besides professional treatment?

In chapter 4, we explored the perspectives of 25 patients suffering from enduring depression who had received at least two different professional treatments for depression with a poor or unsatisfactory response. We were interested to learn what they do themselves to cope with their enduring depression, and which self-management strategies they perceive as being most helpful during their depression. Using concept mapping, we identified 50 helpful strategies that were combined into three main-themes, each comprising two sub-themes: 1) A focus on the depression (Active coping with my depression and Active coping with professional treatment), 2) An active lifestyle (Active self-care, structure and planning and Free time activities) and 3) Participation in everyday social life (Social engagement and Work-related activities). The most important strategies from the patient’s perspective were ‘take the signals of my depression seriously’, ‘maintaining long-term professional support’, ‘acknowledging that depression is a disease’, ‘leaving the house regularly’ and ‘finding a therapist with whom I feel connection’. These results suggest that, although current developments in eHealth are occurring, patients emphasise face-to-face treatments and long-term relations with professionals, being engaged in social and working life and involving carers and professionals in their disease management.
PART II
Professional treatment for depression

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

In chapter 5, a total of 27 patients who had recovered from a depressive episode were individually interviewed in-depth about their experiences regarding impeding characteristics of professional treatment for depression. Analysis of the interviews identified four major themes: 1) A lack of clarity and consensus about the nature of the participants’ MDD and the content of their treatment, 2) Precarious relationship with the clinician, 3) Unavailability of mental health care and 4) Insufficient involvement of significant others. The findings resulted in a comprehensive overview with examples of impeding characteristics of treatment. The results may help professionals to understand how patients experience MDD treatments, what professionals should not do considering treatment and to incorporate patients’ perspectives about treatment into their joint decision making with the aim to increase treatment adherence, motivation and finally success.

5. What are helpful factors of professional treatment of depression from the patient’s, carer’s and professional’s perspectives?

In chapter 6, we unravelled the helpful factors of depression treatment based on the experiences of patients who recently recovered from a depressive episode, carers and mental health professionals. In six brainstorm sessions, the three participant groups generated 795 ideas. We removed ideas that overlapped or that were not related to our focus. A total of 256 ideas remained. Next, ideas were further condensed by combining similar ideas to formulate the quality demand statements with an abstraction level that was neither too specific nor too general. This resulted in a final set of 55 unique statements. Subsequently, 100 participants sorted and prioritized these statements, which were then analysed by using concept mapping software. Ten clusters emerged, grouped into four main-clusters: 1) Professional therapist, 2) Treatment content, 3) A structured treatment process and 4) Treatment organisation. The clusters we found to be helpful were considered as almost of equal importance among the three groups of patients, carers and professionals. The groups only differed on one cluster (‘Treatment organization’) with patients and carers rating this of higher importance than professionals. We found that not only patients and carers, but also professionals considered aspecific factors, such as a good therapeutic relationship and hope, the most helpful about treatment. Future studies might show that the factors we found to be helpful in the treatment for depression, can be generalized to mental health treatment in general.
Self-management

Helpful strategies include active coping
Findings in the present thesis show that patients have the experience to self-manage their depression with a variety of helpful strategies. Interestingly, although avoidance behaviour is a coping pattern that is often seen in depression,¹ and in general, patients often feel to be out of control and some experience a particular type of ‘weak’ or ‘flawed’ personality in themselves,² the strategies perceived helpful by patients are quite clearly the opposite of avoidance behaviour. Instead, patients appear to have quite elaborate ideas about how they can contribute to their own recovery. Patients experienced strategies that promote engagement in physical and social activities as the most helpful, such as ‘leaving the house regularly’ and ‘engaging in social and working life’ (chapter 2, 3 and 4). Whether these results are a result of effective (previous) treatment experiences of the patients or not, these results underscore the helpfulness of behavioural activation as used in many depression treatments.³

Engagement in social and working life
In order to effectively self-manage a depressive episode, patients mentioned they need to participate in everyday social life (chapter 2, 3 and 4). Social engagement (e.g. sharing the depression with carers and involving carers into treatment) and work related activities (e.g. engage in an occupation or explaining the depression to colleagues) were perceived to impact the patient’s capacities for self-management. These findings suggest that patients may benefit by being invited by professionals to bring their carers into treatment and to remain socially engaged rather than trying to self-manage in isolation.

Acknowledging depression is needed for self-management
In the studies described in chapter 2, 3 and 4, patients mentioned ‘acknowledging depression is a disease’ (ST 42 and ST 22 respectively) in their top 15 of most important self-management strategies to recover from, and cope with, depression. In order to adequately realize self-management, patients not only need to acknowledge the disease, but also to acknowledge the "self" as a problem: altered self-experience, decreased autonomy and impaired agency are core parts of depression.¹ According to patients, hope, confidence and motivation are important agents of the self in managing depression. In addition, the recovery movement - called 'Peer Support' - (equivalent in Dutch: Herstelbeweging)⁵ also supports the idea of acknowledgement of the self, which is needed for self-management. Empowerment of the self is needed for patient’s to make self-selected choices in their daily depression care.⁶ Future studies will provide more insight under what conditions patients with mental health problems such as depression can take responsibility for their disease,
since their self-experience is often severely disturbed. In addition, psycho-education may be a helpful approach to gain knowledge about the depression and its consequences in order to achieve acknowledgment.

Ian suffers from chronic depression and received various professional treatments such as cognitive-behavioural therapy and medication. He fought vainly against his depression for years, until he discovered he had to embrace his enemy: he started to accept the depression in his life. Acceptance caused a big change for him because, to his regret, he realised that his depression had taken over his life. Due to acceptance, he considered the pros and cons of being depressed and he realised he had been devoted to his depression as a victim. He now started to take responsibility for his life and self-manage his disease, or what he calls ‘personal leadership’. Although the depression is still part of his life, he discovered a way to gain back the control over his life. *(Peter Oostelbos, expert by experience)*

However, acceptability of self-management has to be discussed for some patients, such as ambivalent and poorly motivated patients. Ambivalence can be based on the patient’s past experience with self-management, their reaction to fellow-sufferer’s experience or their attitude to self-management in general. Also, socially isolated patients may be truly ambivalent because social support is perceived to be needed in self-management of the disease (chapter 2, 3 and 4). During treatment consultation, ambivalent feelings may be nurtured by a careful exploration of the patient’s perspective and the development of a therapeutic relationship in order to open opportunities for change and discover the specific patient’s needs.

**Comparison with previous research**

To our knowledge, only one other study examined the patient’s perspective on self-management for chronic depression, however, that study had a different and broader study design which also included the overall depression experience. Nevertheless, the results from this qualitative study, obtained by in-depth interviews and focus groups, revealed comparable helpful strategies such as regular exercise, being creative and gaining information about depression (see chapter 2 and 4). Even so, engaging in activities was cited as important for all of the patients in both studies.

Interestingly, substantial overlap also exists between the strategies we found and the strategies identified in existing literature that are perceived to be helpful for sub-threshold depression, including strategies identified for other mental disorders including anxiety.
and bipolar disorders\textsuperscript{11,12} and chronic somatic diseases\textsuperscript{13-15}. For sub-threshold depression (depressive symptoms that fall short of meeting diagnostic criteria, also called ‘minor’ or ‘sub-clinical’ depression), Morgan and Jorm (2009)\textsuperscript{9} identified 48 self-management strategies by asking clinicians, researchers and consumers about strategies they employ, as well as examining the current literature. The perceived ‘most helpful’ strategies included (physical) activities and psychosocial strategies (such as rewarding oneself for reaching a small goal). Spending time alone was perceived as ‘least helpful’. For mood and anxiety disorders, Villagi et al (2015)\textsuperscript{11} identified 60 self-management strategies, ranging from breaking isolation and maintaining social relationships, implementing strategies to instil hope for recovery by having a positive outlook, engaging in sports activities and seeking professional help.

For chronic somatic diseases, such as asthma, key self-management strategies include dealing with medication, increasing education and awareness, and goal setting.\textsuperscript{13} Moreover, in a review by Barlow et al (2002)\textsuperscript{16} considering chronic diseases in general, self-management strategies mostly include (psycho-)education, changing life habits, behavioural activation, improving communication with the professional, family and friends, monitoring symptoms and adherence to treatment.

**The same basic strategies across different chronic diseases**

Lorig et al (1999)\textsuperscript{17} created a self-management programme for patients suffering from any chronic somatic disease, postulating that the same basic abilities are needed to efficiently manage one’s diabetes or arthritis. Although today, many self-management strategies are identified- and programmes are developed for specific diseases, strikingly similar themes occur reviewing these self-management strategies that are perceived helpful and that are used across different chronic diseases. For example, behavioral and cognitive strategies do not target a specific disease, but could apply to any kind of chronic disease. The same applies for engaging in activities and (psycho)education. If ‘depression’ would be replaced by ‘disease’ in the strategies we found (chapter 2 and 4), the strategies may be applied to and used with other diseases. Only a few strategies may be unique for the specific diseases, such as pain-management for some somatic diseases. For depression, the strategy ‘acknowledging that depression is a disease’ may be specific and may be related to stigma (chapter 2 and 4). Also, ‘making sure you have a good day-night rhythm’ may be a specific depression strategy.

**Timing of self-management regarding the phase of the depression**

It is not only suggested that there is an overlap of helpful strategies across different diseases, but there also seems to be an overlap across the different phases of depression,
such as sub-threshold depression, recovery from (non-chronic) depression (chapter 2) and with enduring (chronic, treatment-resistant) depression (chapter 4). With respect to recovery from depression (chapter 2), activity-related strategies were considered slightly more important, while coping with chronic depression (chapter 4) the emphasis was more on social engagement. Even so, as results show in chapter 3, with the exception of some differences in the perceived helpfulness of certain self-management strategies in men versus women and people living with others versus people living alone, there are very few differences in the perceived helpfulness of self-management strategies between clinical and demographic characteristics. Because our study was a first modest exploration to assess for differences, further research is needed. As a result, the introduction of the strategies may be used in primary care as well as secondary or tertiary care treatments. Depending on the phase of the depression, strategies could be carried out with a gradual intensity of support by professionals.

**Personalized mix of strategies**

Although self-management strategies may be shared across different diseases and may be used irrespective of the severity of the phase of the disease, we must consider that the patient’s perspective is not static and can change over time. In the end, each patient uses a unique personalized mix of strategies, that suit their particular needs, interests and depend on the resources available. The mix of strategies may change according to circumstances and time for each patient and between patients. Therefore, professional treatment requires exploration of the most suitable and preferred strategies for each patient at that moment.

**Approaches to support patients in self-management**

Various approaches are described to support patients in self-management strategies: the settings in which self-management are delivered can be the home environment, primary care settings or mental health institutions. Self-management is mainly delivered by professionals (e.g. psychiatrists, psychologists, nurses, occupational therapists), but also non-professionals, such as lay tutors with chronic diseases, may be trained to deliver self-management. The mode may be either group-based, individualized sessions or a combination of both. Finally, the format may include written materials (booklets and manuals), (online) lectures or educational videotapes and can be combined. Considering the focus of this thesis is the patient’s perspective, their perspective should also be explored when considering the treatment approach. One example of an existing form of self-management support for patients irrespective of the type of disease is The Patient Action Communication (PAC)-Card. The PAC-card contains a checklist of essential support questions to use in any interaction with a health professional. This instrument
may be a valuable contribution to support patients in their self-management of depression whenever they seek treatment.

Oddly, although rapid developments in eHealth occur nowadays, in the above described studies as well as in our studies (chapter 2, 3 and 4), the use of eHealth is mostly not mentioned as an important approach to deliver self-management. A recent study on the acceptability of e-mental health showed negative perspectives of participants about online self-help intervention and low likelihood of use in the future.20 Although participants were aware of the potential advantages of online interventions, including convenient access, they preferred not to replace face-to-face contacts to meet their needs. Considering the studies in this thesis, one could hypothesize that selection bias might have caused this ‘anticlimatic’ result; that the participants in these studies did not have experience with eHealth. On the other hand, this finding is also quite consistent with our findings that patients emphasize long-term relations, face-to-face contacts with professionals, family, friends and colleagues. Ehealth is a form of isolation, potentially. So far, eHealth has mainly been investigated and used to deliver psychological treatments, such as cognitive behavioural therapy (CBT),21,22 rather than the delivery of strategies that may be helpful in the day-to-day coping with the disease. However, because of the rapid developments in both fields, self-management and eHealth, it is suspected that eHealth will become an important delivery approach for self-management strategies in the near future. Nevertheless, an effort should be made in improving the image and acceptability of eHealth.20

**Self-management as a complementary intervention to treatment**

Up to 50% of depressive patients do not seek treatment when treatment is appropriate.23 According to the Netherlands Mental Health Survey and Incidence Study (NEMESIS),24 28% of depressed patients exclusively use primary care services, 45% uses specialised mental health care, and 27% have never received any professional help. There are several reasons for not seeking help, including the stigma, financial costs, the idea that treatments do not work, not knowing where to get help, or the longing to manage the symptoms on their own or together with their carers, especially in the case of a first depressive episode.25 Often people try to manage their depressive symptoms by exploring strategies by themselves, such as consuming healthy food, taking more rest or seeking alternative medicine options.

Although for these patient groups the availability of online self-management programmes may seem to be an acceptable solution, there are risks of accessing non-evidence based and unreliable information. Additionally, there is risk that the patient struggles too long
with self-managing the disease, because they are not adequately signalled about the worsening of the symptoms by a professional. Therefore, self-management can be used after receiving psycho-education by a professional. It may further be offered in conjunction with professional treatments and may be administered by different kinds of professionals, such as general practitioners, nurses or psychologists.  

To support this statement, the patients in our studies regarded maintaining contact with a professional as quite important (chapter 2, 3 and 4). They perceived adequate support when using medication, completing treatment, believing that a therapist is accessible and discussing information with a professional as helpful. Furthermore, in other studies focussing on depression, the need for professional support was emphasized. In order to be able to self-manage depression, a patient first needs to accept and understand the disease. Therefore, professional support is needed for psycho-education, to achieve acceptance and to subsequently understand how to use self-management adequately. The same applies for other chronic somatic diseases, such as diabetes: a professional first needs to explain the aetiology of the disease and the patient needs to recognize and accept the disease to ultimately be able to use strategies that promote a healthy diet.

**Implementation of self-management in today’s mental health care**

The health care system must be prepared to integrate self-management. Many mental health services have yet to embed self-management in routine care, possibly because numerous barriers to implementation in our existing health care services for depression continue to exist. In many mental health care organisations, either clinics or general doctor practices, there is little or no structure to support self-management. There are only a few professionals with specific specialized training to support patients in self-management and the systematic documentation in terms of quality standards and guidelines lack. Self-management is seen as an adjunct to the main purpose of the system instead of central to the system’s mission. Further, the results of studies about patient’s perspectives with (chronic) treatment suggest that there are substantial impeding factors in the actual level of patient engagement in terms of therapeutic relationship, engagement of carers and shared-decision making (chapter 5). Therefore, the involvement of patient’s perspectives into the further development of self-management implementation in chronic care would be an important step forward.

**Depression guidelines**

The various professional guidelines for depression hardly describe self-management as a (new) approach in the treatment of depression. The only sentence the American
guideline for depression\textsuperscript{39} includes is in the case of incomplete recovery: ‘the professional should add a disease management component to the overall treatment plan.... such as developing self-management skills’. No further explanation about how to encourage and integrate self-management in clinical practice, nor examples of strategies, are mentioned. In the Dutch patient-version of the depression guideline, a section is described about self-care that includes some self-management strategies.\textsuperscript{32} The NICE guideline has a section with information for the public; however, it does not mention self-management strategies as an approach to be offered.

In contrast with other mental health disorders, guidelines for depression differ from one another and especially the most recent versions that include self-management as a recommended approach. For example, the recent Dutch professional guideline for bipolar disorders\textsuperscript{33} has a clear and comprehensive section on how to support patient’s and carer’s in self-management and what strategies are recommended. Also, the NICE guideline for bipolar disorders mentions self-management, although they only use a few words to describe it.\textsuperscript{34} For schizophrenia, the current Dutch guideline only refers to self-management initiatives that are promising and in development.\textsuperscript{35} Also, the NICE guideline for psychosis and schizophrenia\textsuperscript{36} mentions a few words about self-management. The APA guidelines for bipolar disorders and schizophrenia have not been revised since 2002 and 2004 respectively and have no section on self-management. In conclusion, current guidelines for depression need to be adjusted and include self-management strategies as an approach to support patients.

**Professional treatment**

It has now been explained profoundly how patients perceive they are able to recover from, or cope with, depression by using self-management. In addition, in clinical practice, patients have unique experiences regarding how they cope with depression and they also have different needs for treatment. Patients perceive various impeding and helping factors of professional treatment for depression and the knowledge from their perspective can help mental health professionals to adjust the specific needs of treatment for each individual patient and thereby improve symptoms and functioning.

**Impeding treatment factors**

The findings presented in chapter 5 indicate that in clinical practice, patients do experience some important impeding treatment factors, such as a precarious therapeutic relationship and a lack of consensus about the content of treatment. The results indicate an unmet need (by patients) to be much more informed about goals, methods, and evaluation of treatment, as well as for involvement of significant others in treatment. Some impeding
factors may easily be resolved by a more open and explorative type of communication from the professional to adjust and collaborate with patients in order to optimize treatment.

**Aspecific factors perceived most helpful in depression treatment**

Patient’s perspectives towards *inhibiting* treatment factors (chapter 5) are in line with their perspectives towards *helpful* factors (chapter 6), because similar themes appear to be important to patients, including the therapeutic relationship and the engagement of carers. In addition, Badger and Nolan (2007)\(^{37}\) identified similar factors of depression treatment perceived as helpful by patients, such as the therapeutic relationship, receiving information and family support. Despite the numerous studies and randomized controlled trials that have been conducted in the last decade on depression and treatment, patients, carers and professionals perceive aspecific factors still as the most helpful in the current psychiatric treatment of depression. Instead of the current emphasis on biological psychiatric and protocolled treatments with time-limits, where professionals have been taught to adhere to evidence-based guidelines and follow accurately the steps of protocols for treatment, aspecific factors such as a good therapeutic relationship, professionalism, understanding and hope are perceived as most important by the users of treatment.

Regarding psychotherapy, Lambert conducted an extensive literature review of over 40 years psychotherapy outcome studies, and found that *common factors* (e.g. therapeutic alliance and hope) account for the major part of the effectiveness of psychotherapy treatment, and that only 15% of treatment outcome is related to technical factors.\(^{38}\) Interestingly, given that our results regarding the current evidence-based treatments offered for depression align with Lambert’s results regarding psychotherapy for numerous mental diseases, it may be suggested that the aspecific factors we found and which are shared by different treatments for depression (such as medication consultations, psychotherapy or other treatments), are much more powerful than the contributions of specific techniques.

**Emphasis on the therapeutic relationship**

In *all* of the studies we performed, a key factor for helpfulness in the support of self-management and a successful treatment experience, is the quality of the therapeutic relationship. It is known that the quality of the therapeutic relationship is one of the most important aspects for successful treatment.\(^{39}\) Our studies show that there is room for improvement in the therapeutic relationship with depressed patients, because one of the ingredients such as empathy is not only a patients’ wish, but also an evidence-based communication strategy that contributes to the health of patients.\(^{40}\) Although individual patients have to self-manage depression on their own, a foundation of professional support
is perceived as important. The professional needs to be trusted and the relationship needs to be good, even with little face-to-face contact.

**Hope**

The theme 'hope' appeared uniquely and highly relevant as demonstrated in chapter 5 and 6. Patients, as well as professionals, perceived 'creating hope during treatment' as one of the most helpful factors of treatment. Patient's hope and expectations have long been considered a key ingredient to the concept of personal recovery from mental disorders and for successful psychotherapy. Hope helps to initiate therapeutic change, willingness and motivation to start the recovery process and personal well-being. A more recent meta-analysis by Constantino et al (2011) demonstrated positive effects of patients’ expectations on their treatment outcomes. Moreover, the loss of hope has been described as a cause of depression treatment resistance. Although many psychotherapies include elements that address various expectations, specific strategies to support hope are rarely emphasized in clinical practice. Even so, professional treatment guidelines for depression remain relatively silent about this complex aspecific factor. This result indicates that the factor of hope has to be explored more profoundly, to discover the meaning and usage of hope in depression treatment.

‘Hope is incredibly important. That always has been a tremendously important basis for me. Therapists who have the balls to say that everything will be all right: that requires courage. Because there are also therapists who do not dare to say that, because they don’t know whether that’s true and they think it’s not right to say it then.’ (Chapter 5, ID20)

**Historic loop: from short term treatments back to long-term professional support?**

Our focus on helpful factors in treatment resulted in a broader view than common and aspecific factors only. In chapters 5 and 6, various specific factors were identified to be perceived as important as well. An example is follow-up care: although depression is characterised by relapse, recurrence and chronicity, and therefore it may require long-term treatment, there is a trend towards time-limited treatments aiming for short-term improvement of symptoms. This trend in time-limited treatments is probably driven by health insurance companies. Currently, few data exist on the outcome and appropriate duration of maintenance treatment, but results show that benefits of long-term follow-up care should be taken into consideration, to prevent recurrences and to enable help-seeking
behaviour. Additionally, long-term follow-up care may be cost-effective as well, given that even low frequency contacts with a professional can prevent decompensation and a new referral to the mental health care system, intake process, and thus the treatment of acute depression or relapse may actually rise in costs.

**Perspectives of patients, carers and professionals**

Although patients, carers and professionals generally agree on which factors they perceive as most helpful for treatment (chapter 6), clinical practice and other research findings show that the perspectives between those three groups often differ. Patients prefer psychotherapy rather than the occasional professional advice for pharmacological treatment strategies. Moreover, while 71% of primary care physicians report they made a shared decision with their patients about depression treatment, 54% of patients did not experience their perspective was taken care of. Therefore, shared decision-making is increasingly emphasized as an ideal approach for treatment in medical care, in which both patient and professional share ideas, build consensus and come to an agreement on treatment. Some important requirements for shared decision-making are identified and include trustworthiness, information quality and communication with patients and families. For example, although professional depression guidelines require the carer’s engagement into treatment, carers often feel frustrated about their exclusion from treatment. Their role in depression research and treatment is relatively invisible, but invaluable, since they are the daily witnesses in perceiving how treatment affects the depressed patient.

**Subjectivity of the patient’s perspective**

The perspectives of people are obviously subjective. With respect to professional treatment, it might be simplistic to relate decisions to perspectives only, because treatment for depression is a complex process where a number of variables must be taken into account, such as severity, comorbidity and patient’s history. However, consideration of patient’s perspectives for depression treatments is important because depressed patients are more likely to develop a therapeutic alliance, participate in decision-making and thereby adhere to treatment. Furthermore, supporting patients’ preferences as part of depression treatment results in more patients receiving the treatment that is most suitable to them. In addition, initial evidence supports the idea that patients who are able to gain personal control over their treatment decisions may experience improved outcomes, because the feeling of choice and control alters one’s subjective appraisal of treatment, which in turn affects treatment adherence and response.
Even though the patient’s perspectives about helpful treatment factors might not result in objective remission, there is still a question for future research to find out to what extent the patient’s perspective contributes to objective remission. According to our results, it is obvious that clinical judgment should stop concentrating on technical strategies as the only ‘cure’ of the disease and should enlighten perspectives to improve, for example, patient treatment commitment and support from carers.

Methodological considerations

A number of limitations need to be considered in interpreting the results of this study.

Concept mapping

For the exploration of the patients’ perspectives of recovery and coping with depression (chapter 2 and 4) concept mapping was used, which is considered as a suitable mixed method for both qualitative and quantitative data analysis. For the qualitative stage, 20 (chapter 2) and 16 (chapter 4) participants - this number is advised and in line with the concept mapping protocol - took part which was sufficient to reach data saturation. This stage resulted in a comprehensive overview of self-management strategies. However, the same amount, 20 participants in chapter 2 and 25 participants in chapter 4, was used for the quantitative stage. Because of this relatively small sample, we subsequently performed a survey (chapter 3) to widen our view about the external generalizability of the use and helpfulness of each strategy.

Concept mapping was also used for the exploration of the patient’s, carer’s and professional’s perspectives combined (chapter 6). In this study we chose a much larger participant group in order to reach the maximum input in the exploration of ideas. However, in this study, one has to be careful with conclusions based on comparisons between groups because the number of participants within each group differs.

Generalizability of study results

Regarding the exploration of self-management strategies in chapter 2 and 4, we may have missed specific subgroups with depression, such as elderly, patients with different cultural backgrounds or during different stages of a depressive episode. However, we purposefully sampled patients with a wide diversity in age, treatment history and experiences to enhance the external generalizability. In addition, the last focus group in both studies generated only a few new strategies and we therefore doubt whether including more patients would have resulted in very different results. Moreover, our samples were
appropriate for our purpose; to explore helpful strategies. Regarding the exploration of perspectives on treatment in chapter 5 and 6, this study included participants who were ethnic Dutch adults. Therefore our results are generalizable to adult patients from countries comparable to the Netherlands in terms of population and (mental) health care system.

**Distorted patient’s perspective due to depression**

In chapter 4, we explored the perspectives of patients suffering from enduring depression, it is important to note that these clinically depressed patients’ experiences may have led to biased appraisals due to depression, where distorted cognitions of patients may be more negative. Therefore, results of this study may be coloured because of this negative bias. However, if so, our results are striking because patients show to have a rather positive view about what they can do themselves to recover from and cope with depression (chapter 2 and 4). The strategies the patients mention to be helpful in chapter 4 are not negative about their coping possibilities. We think the patients were able to give us their opinion about self-management and treatment of depression without the negative cognitions about their own capacities. Moreover, if patients have distorted perspectives about what strategies work for them or not, our results are relevant because if patients believe in strategies that are contrary to clinicians’ views or evidence, this information must be used by clinicians to find connection with their patients and must become a target of conversation between patient and clinician.

**Lessons and future directions**

**Implications for clinical practice**

**Use of self-management strategies in clinical practice**

The wide range of self-management strategies which patients can use and perceive as helpful while coping with, and in their recovery from, depression may help professionals to improve their knowledge and understanding about what patients consider beneficial to cope with depression in their daily life. Professionals may discuss these strategies with their patients during treatments and emphasize those strategies perceived as most helpful by other patients.

**Union of self-management strategies**

In order to create a simple overview for patients and professionals to use self-management strategies in clinical practice, it would be helpful if the strategies would be united into a core generic set of strategies for all chronic diseases. An addendum with some unique
strategies for the specific diseases may be necessary, such as pain-management for some somatic diseases. For depression, some strategies may be unique, such as ‘making sure you have a good day-night rhythm’ which may be specific to depression, and ‘acknowledging that depression is a disease’ may be related to stigma. Especially for depression, union may help diminish the stigma due to the realisation that depression is a disease like others.

If accomplished for depression, the same set of strategies could be offered to patients by the general practitioner, in the ‘Basis GGZ’, second- or third-line care. Patients could be encouraged to start self-managing the disease during waiting periods, after referral by a general practitioner, if the general practitioner could be available for professional support.

**Personalized selection of strategies**

No simple package or recipe suits every patient. Therefore, a personalized strategy selection may be needed for every patient which must be made in close collaboration with the patient and the professional. Furthermore, to adapt the strategies to the specific circumstances and needs of each patient, patients may select the strategies that they are motivated to undertake.

**Integration of self-management in depression health care**

In order to integrate self-management into depression health care, self-management education needs to become a central mission of the mental health organisation. Professionals must be trained to support patients in self-managing and self-management programmes for depression must be established. To support patients with improving their self-management skills requires new communication- and psychological techniques which should be developed.

**A new role for the professional**

To integrate depression self-management in various clinical practices, professionals will need to assume a new role that reflects a partnership model of treatment, based on the principles of empowerment, patient-centred approach, choice and control. The development of new skills for this new role is therefore necessary. Professionals need to say “I want you to learn about your depression and its management” and need to become enablers and educators and encourage patients in developing their own self-management strategies.
Chapter 7

**Adjustment of guidelines**
Guidelines should be adjusted to include a list of recommended self-management strategies and should inform the professional how to consider the patient's perspective in the use of self-management.

**Awareness of different perspectives regarding the treatment of depression**
During the treatment process, patients, carers and professionals should be aware that each person may have a different perspective of helpful and impeding factors in the treatment of depression. Therefore, it is recommended that professionals encourage patients and carers to make explicit their perspectives and to involve their perspective and concerns about treatment in decision-making.

**Emphasis on aspecific treatment factors**
Professionals might shift the focus of depression treatment to establish a good therapeutic relationship at first, with instruments such as the Helping Alliance questionnaire (HAq-II). Aspecific treatment factors and the creation of hope must be emphasized much more during depression treatment than in other treatments. Although this is common knowledge and recommended in professional depression treatment guidelines, these aspecific treatment factors are in conflict with current policy requirements that include limits on treatment duration.

**Engagement of the social support system**
If the patient agrees, carers should have the opportunity to be more fully involved in decisions about treatment than they are now according to their perspectives. Carers should also be given the information and support they need.

**Future directions for research**

**Evaluation of existing self-management strategies across different chronic diseases**
Considering the overlap of strategies across the different chronic diseases, there is a need to systematically evaluate the strategies to create a clear core generic set of strategies for all chronic diseases. Next, we need to investigate the effectiveness of the existing strategies.
**Development of a specific depression self-management programme**

With the help of the self-management strategies that patients use and perceive as helpful during their depressive episode (chapter 2 and 4), a structured depression self-management programme should be developed in close collaboration with patients.

**Randomized controlled trial for effectivity of self-management strategies**

Such a programme must be investigated for efficacy in a randomised clinical trial with a sufficient number of participants in order to determine whether the perceived helpful self-management strategies as a core actually help in clinical practice. Also, individual- and group approaches, including the combination of eHealth with face-to-face treatments (blended treatment), should be assessed and eventually compared in order to verify which approach improves the efficacy of self-management strategies.

**Depression subgroups**

More research is needed to gain knowledge about the use and perceived helpfulness of self-management strategies for specific subgroups, such as elderly, patients with different cultural backgrounds or during different stages of a depressive episode.

**Further elaboration of 'how' the strategies could be performed**

Now it is clear what strategies are perceived to be helpful (chapter 2 and 4), a further elaboration, in close collaboration with patients, could be explored about how the strategies could or should be performed in day-to-day life. For example, there might be some different examples of how patients can 'engage in leisure activities' (chapter 2), such as inviting friends over for dinner or making a cycle tour in the woods.

**Mixed methods research**

In order to gain an in-depth understanding and information from patient’s experiences, a mixed methods research approach combining qualitative and quantitative research is recommended for future studies that evaluate self-management strategies and professional treatment, for example, for other chronic diseases.

**Helpful and impeding treatment factors for other (mental) disorders**

Further research might show that the factors we found to be perceived most helpful in the treatment for depression (chapter 5 and 6), can be replicated to other mental disorders, such as personality- or anxiety disorders, or even other somatic diseases, and may be generalized to (mental health) treatment in general.
Chapter 7

Conclusions

From this thesis, it can be concluded that there are a substantial number of self-management strategies that patients can use and perceive as helpful to recover from and to cope with their depression. Most helpful strategies include active coping with depression and engagement in social and working life. Interestingly, substantial overlap exists between the strategies we found and the strategies perceived to be helpful for other mental or somatic chronic diseases. It may therefore be helpful for patients and professionals to create a core generic set of helpful strategies across different chronic diseases. There also seem to be an overlap across the different phases of depression and the introduction of strategies may therefore be used in primary care as well as secondary or tertiary care treatments. Depending on the phase of the depression and the patient’s perspective, strategies could be carried out with a gradual intensity of support by professionals. Self-management needs professional support and professionals need to adjust their role to engage patients to have an active role in their own healthcare with the use of these strategies. We expect that patients are more motivated to use the strategies that promote engaging in activities instead of avoidance behavior with the knowledge that other patients perceived them as helpful during their recovery.

Moreover, the patient perspective about helpful and impeding factors in treatment do not differ substantially from carers and professionals, and emphasize aspecific factors such as a good therapeutic relationship, understanding and hope. If professionals would encourage patients to involve their carers into treatment and make both their perspectives explicit, professionals could adjust the specific needs of depression treatment for each individual patient to develop personalized treatment, ameliorate shared goals, and consequently accomplish better satisfaction, treatment compliance and effectiveness.
References


