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Patients' perspective on self-management in the recovery from depression

Roos A. van Grieken MD,*[1] Anneloes C.E. Kirkenier MSc,†[1] Maarten W.J. Koeter PhD,‡ Udo W. Nabitz PhD§ and Aart H. Schene MD, PhD¶

*Resident in Psychiatry, †Research Psychologist, ‡Associate Professor, ¶Professor of Psychiatry, Program for Mood Disorders, Department of Psychiatry, Academic Medical Center, University of Amsterdam and §Senior Research Psychologist, Department of Research, Arkin, Amsterdam, The Netherlands

Correspondence
Rosa A. van Grieken, MD
Program for Mood Disorders,
Department of Psychiatry
Academic Medical Center, University of Amsterdam
Meibergdreef 5
1105 AZ Amsterdam
The Netherlands
E-mail: r.a.vangrieken@amc.uva.nl

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Abstract

Background Self-management appears to be a promising approach in the case of depression, which helps to stimulate patients' autonomy. However, a good and systematic description of the concept self-management from the patients' perspective, to our knowledge, has not yet been performed.

Objective To determine: (i) what strategies patients think they can use themselves to recover from depression, (ii) which main themes of self-management strategies can be detected, and (iii) which of these strategies patients perceive as being most helpful.

Methods We used concept mapping to explore the experiences of patients who recently recovered from a depressive episode. Patients generated self-management strategies in focus group discussions. The strategies were clustered on a two-dimensional concept map by a hierarchical cluster analysis.

Results Patients generated 50 strategies that formed eight clusters: (i) proactive attitude towards depression and treatment, (ii) daily life strategies and rules, (iii) explanation of disease to others, (iv) remaining socially engaged, (v) engaging in activities, (vi) structured attention to oneself, (vii) contact with fellow sufferers, and (viii) other. Behavioural and cognitive strategies and a proactive attitude towards treatment were considered as the most helpful.

Discussion and conclusion From the patients' perspective, there is a wide range of self-management strategies that they can use – and perceive as helpful- to contribute to their own recovery. Professionals could encourage patients to take an active role in achieving recovery. Further research could open new roads to improve patients' active contributions to current treatments for depression.

Introduction

Major depressive disorder (MDD) has a high lifetime prevalence (16.2%), and for two-thirds of the cases, MDD has an episodic recurrent course that is often severe.[1,2] It is well-known that by the year 2030, depression is estimated to be the leading cause of burden of disease in

high-income countries.[3] Although evidence-based treatments such as pharmacotherapy and psychotherapy are available, not all patients seek, accept or continue treatment and if they do, remission is partial for many, even in case of sequential treatment.[4–7] This clearly indicates a need for improvement. One approach is the addition of effective self-management strategies.

Over the last decade, self-management approaches have become of growing interest due to increases in individualism, empowerment, patient participation and decreasing health-care budgets combined with a growing number of patients who have to cope with the consequences of chronic diseases. Self-management refers to 'the training, skill acquisition, and interventions through which patients who suffer from a disease or chronic condition may take care of themselves and manage their illnesses'.[8] Although self-management in general medicine is mostly related to coping with a chronic disease, it is interesting that in the case of depression, information on the Internet and in (self-help) books suggests that self-management could help in particular in the 'recovery from' instead of 'coping with' the disease.[9]

Self-management appears to be a promising approach in the case of depression.[10] However, individuals who manage difficult emotions prior to receiving a diagnosis, who suffer from depressive symptoms but will never fulfil the criteria of depression, who reject the concept of depression for reasons of culture or health beliefs, who avoid treatment or who have previously had treatment but now want to do something themselves may potentially also benefit from self-management.

Previous studies have mainly focused on 'mild' subthreshold depression[11] or depression in primary care patients.[12] Generally, self-management approaches in these patients are without contact with therapists, with the aim of successful prevention and reduction of health-care costs. However, in 'full blown' depressed patients, who lack motivation and confidence, self-management may not be effective if there is no contact with therapists. Therefore, in this study, we focus on self-management in patients who also have received treatment from mental health-care professionals.

Studies focusing on self-management for depression so far mainly use professional developed *treatments*, such as booklets,[12] cognitive behavioural therapy (CBT) chapters[13] and e-health programmes,[9,14] which are transformed into self-management approaches. Considering the fact that patients need to manage the illness on a day-to-day basis, they may in particular benefit from self-management strategies that are helpful from the patients' perspective.[15] To our knowledge, no study has systematically investigated what specific self-management strategies depressive patients need and perceive as most helpful in their recovery. If we know more about what patients themselves believe they can contribute – and perceive as helpful – towards their recovery from depression, this could be used in the development of new or adjustment of existing therapeutic approaches including self-help programmes.

Aims of the study

The aim of our study was to explore the patients' perspectives towards self-management in their recovery from depression. In an explorative study, we addressed the following research questions: (i) What strategies do patients believe they can use themselves to contribute towards their recovery from depression? (ii) Which main themes of self-management strategies can be detected? and (iii) Which of these strategies do patients perceive as being most helpful?

Methods

Concept mapping

We used concept mapping to explore patients' experiences with and perceptions about their own contribution to recovery in a systematic and structured way. We have chosen this method for two reasons: First, because in a

group process patients encourage each other to bring up more ideas than would appear in individual approaches like interviews. Second, because concept mapping combines a qualitative method with quantitative methodology in the analysis stage.

Concept mapping consists of three stages: (i) generating, (ii) structuring, and (iii) analysing data.[16] In the first 'generating' stage, (ex-) patients were encouraged to discuss in three focus groups their perceptions on recovery enhancing behaviour and initiatives and to generate strategies answering the central question: *What can people do themselves to recover from depression?* A trained researcher (ACEK) guided the 1.5-h group sessions. All strategies were visualized for the group via a digital projector. The researcher (re)formulated the strategies with the help of the patients till they were clear for everyone. Next, two researchers (ACEK and MWJK) combined the strategies from the focus groups and removed overlapping strategies, resulting in a final list.

In the second 'structuring' stage, each individual patient was asked to sort the strategies of the final list based on their own meaning of whether they belonged to the same category in 4 to 10 groups, each containing 2 to 15 strategies. In addition, each patient had to prioritize the same strategies by dividing them into 5 groups of equal size. Group 1 was defined as 'the least important' for the recovery from depression and group 5 as 'the most important'. The final strategy list was presented to patients in a word document, and sorting was conducted using a computer.

In the third 'analysing' stage, we used the 'Ariadne' software package.[17] First, the strategies were positioned in a two-dimensional map, based on multidimensional scaling. In this map, the distance between the strategies represents how often the patients sorted them together in one group. Secondly, the individual strategies were clustered based on a hierarchical cluster analysis.[18] This cluster analysis offers solutions with 2 to 18 clusters. Three researchers (RAvG, ACEK and MWJK) independently reviewed each of these 17-computer-generated cluster solutions, and the best interpretable cluster solution was selected. Subsequently, the relative importance of the strategies was calculated based on the patients' prioritizing score. The percentage of the strategies prioritized 4 (important) or 5 (very important) was calculated. Then, each cluster received a descriptive name based on the content and importance of the items comprising a cluster.

Finally, the researchers (RAvG, ACEK and MWJK) positioned two axes based on the location of the clusters and on whether or not there was a thematic distinction in the location of the strategies.[16]

Patients

To be eligible for the study, patients had to meet the following criteria: (i) At some point during the year preceding participation, patients had met the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) criteria for depressive disorder, confirmed by the structured psychiatric diagnostic interview (SCID-I),[19] achieved by ACEK, (ii) At the time of participation, the depression was in full remission as indicated by a score of less than seven on the Hamilton Depression Rating Scale (HDRS)[20], (iii) Experience with professional treatment for depression. Exclusion criteria were as follows: age younger than 18 years, insufficient command of the Dutch language, a terminal disease, mental retardation, bipolar disorder, suicidality or disorders classified higher in the hierarchy of the DSM-IV-TR.

We chose to recruit 50% of the patients from the Program for Mood Disorders at the Academic Medical Center (AMC) Amsterdam, because they had been treated as an outpatient, day patient or inpatient, and to recruit 50% of the patients via requests on Internet with various treatment experiences.

Results

Twenty patients participated in the first two stages (nine men, eleven women), a number

advised and in line with the protocol for concept mapping.[18] Their mean age was 42.6 years (range 25–57). Nine patients were recruited at the AMC; five had received outpatient treatment, three had received day treatment with group therapy, and one had received both types of treatment. The remaining eleven patients had responded to our requests on the Internet. These patients came from different parts of the Netherlands and had a variety of treatment experiences, ranging from medication contacts to various types of psychotherapy.

Strategies and clusters

Patients were allocated to three focus groups, which produced a total of 84 strategies. The third session generated only four new strategies, indicating that saturation had appeared. After removal of overlapping strategies, a final list of 50 strategies remained for structuring and prioritizing in stage two.

Figure 1 shows the 50 strategies positioned in a concept map and combined into eight clusters. Table 1 lists the eight clusters with the corresponding strategies, sorted by patients' priority score. The eight-cluster solution was considered the best interpretable and most meaningful. Solutions with more clusters were more difficult to interpret and less meaningful. Solutions with fewer clusters resulted in few heterogeneous clusters and the loss of clinically relevant clusters. Names given to the clusters were based on the content of the strategies within the cluster with most emphasis placed on higher priority strategies. The following clusters were identified:

1. *Proactive attitude towards depression and treatment* Activities in this cluster mainly focus on an active and critical attitude towards depression and professional treatment. Patients define quality requirements for health care. They emphasize an active attitude towards their disease by seeking good information about depression and gaining insight into their own condition.
2. *Daily life strategies and rules* This is a set of practical and relevant strategies to overcome

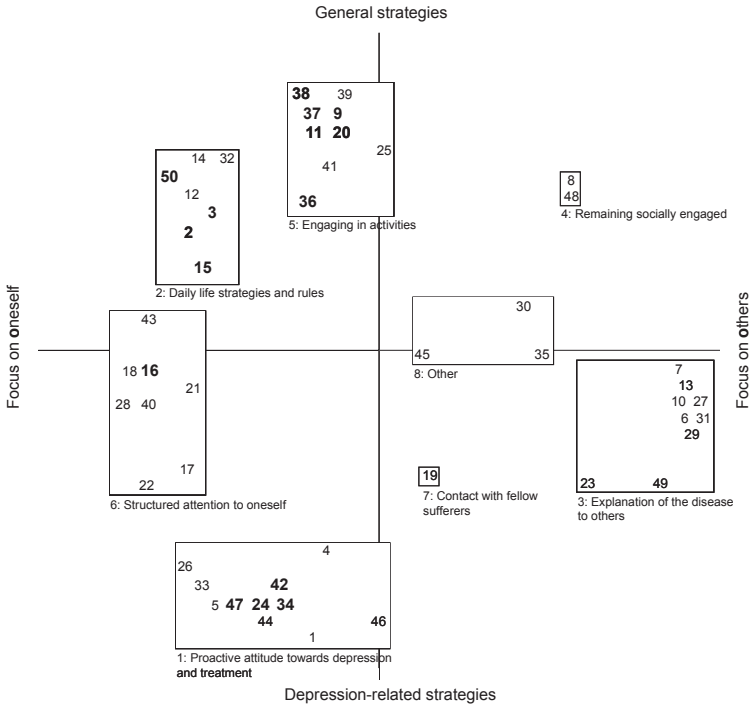

Figure 1 Concept map. Bold values indicate the 15 strategies with highest priority.

Table 1 Strategies per cluster with priority

Number	Cluster strategies	Mean (SD)[1]	Priority ≥ 4[2] (%)
Cluster 1	Proactive attitude towards depression and treatment		
42	Acknowledging that depression is a disease	4.00 (1.50)	65
24	Finding a different therapist when there is limited progress	3.95 (1.45)	80
47	Making sure there is adequate support when using medication	3.80 (1.86)	80
34	Finding someone new when the relationship between therapist and patient is not compatible	3.50 (1.45)	60
33	Changing the negative aspect of daily routines	3.45 (1.55)	60
4	Finding information about depression	3.45 (1.25)	50
1	Identifying the cause of the depression	3.25 (1.29)	45
5	Completing treatment	2.75 (1.49)	25
44	Organizing that a therapist is accessible	2.45 (2.25)	20
26	Becoming aware of daily routines	2.10 (1.19)	20
46	Discussing information found about depression with therapist	1.40 (0.24)	0
Cluster 2	Daily life strategies and rules		
15	Setting realistic short-term goals	4.50 (0.65)	80
50	Healthy eating	3.70 (1.01)	65
2	Overcoming problems with concentration by creating to-do lists	3.60 (1.44)	65
3	Finding strategies to create pleasurable distractions	3.50 (1.05)	40
12	Creating a timetable of activities	3.10 (2.39)	35
32	Making plans for the future	2.40 (1.84)	35
14	Taking every opportunity to tidy the house	2.00 (0.40)	0
Cluster 3	Explanation of the disease to others		
29	Discussing depression with those you trust in order to have support nearby	3.20 (1.66)	45
31	Explaining depression to partner/family	3.20 (0.56)	40
6	Explaining depression to friends and family	3.00 (0.50)	25
49	Including partner/family in the treatment	2.80 (2.16)	35
13	Explaining depression to colleagues	2.70 (1.91)	20
10	Explaining depression to manager	2.50 (0.65)	5
23	Being able to explain depression yourself	2.25 (2.39)	20
7	Discussing changes in role within the family/relationship	2.15 (0.63)	0
27	Adjusting the discussion about depression allowing for what the partner/friend can cope with	1.80 (1.36)	20
Cluster 4	Remaining socially engaged		
8	Meeting up with friends regularly	3.30 (1.21)	50
48	Meeting up with people who are not aware of the depression	2.65 (2.03)	25
Cluster 5	Engaging in activities		
38	Leaving the house regularly	4.40 (0.64)	80
36	Recalling positive memories	4.15 (2.53)	80
37	Gradually resuming responsibilities that had been taken over by others	4.05 (0.05)	100
20	Engaging in sports activities	4.00 (1.80)	65
9	Engaging in leisure activities	3.95 (1.45)	80
11	Engaging in moderate physical activity (cycling, walking, etc.)	3.55 (0.45)	45
25	Finding meaningful occupations (e.g. volunteering)	3.10 (1.79)	40
39	Exploring new hobbies	3.05 (1.45)	20
41	Finding out which activities are achievable	3.05 (2.35)	40

Table 1 Continued

Number	Cluster strategies	Mean (SD)[1]	Priority ≥ 4[2] (%)
Cluster 6	Structured attention to oneself		
16	Making sure you have a good day/night rhythm	3.90 (1.09)	50
18	Ensuring enough rest to avoid exhaustion through over-exertion	3.45 (2.45)	60
40	Restricting the time spent on worrying	2.75 (1.39)	30
43	Using a positive mantra	2.70 (2.41)	40
22	Observe alcohol intake	2.50 (0.85)	10
17	Engaging in a structured form of meditation (e.g. yoga, mindfulness)	2.40 (2.04)	20
21	Keeping a diary	2.40 (1.64)	35
28	Ignoring the tiredness associated with depression	1.80 (0.56)	0
Cluster 7	Contact with fellow sufferers		
19	Seeking contact with fellow sufferers	2.25 (1.49)	15
Cluster 8	Other		
35	Asking for support at work	3.15 (2.03)	60
45	Searching out your family background	1.70 (1.41)	20
30	Writing a weblog	1.25 (0.19)	0

[1]Mean priority per strategy with standard deviation (SD)
[2]Percentage of patients that prioritize the strategy as important/very important (4 or 5)

the depression. Patients indicate that for successful recovery, it is important to set goals and plan strategies to achieve them. Examples are activity schedules, to-do lists and distraction strategies.

3. *Explanation of the disease to others* This cluster emphasizes the value of explaining what it means to suffer from depression to family, friends and colleagues. With this explanation, support needed for recovery can be obtained.
4. *Remaining socially engaged* Patients consider it important to continue to meet with friends and people who are unaware of the depression for recovery to occur.
5. *Engaging in activities* This cluster refers to activities related to fun, sport activities and hobbies. It is also considered important to determine what kind of work or (voluntary) work is still possible. Finally, responsibilities that have been taken over, for example, by family members, gradually have to be taken back.
6. *Structured attention to oneself* All activities in this cluster are about individual strategies that have to do with maintaining a fixed structure (day–night rhythm), regular moments of contemplation and a focus on oneself.
7. *Contact with fellow sufferers* This cluster comprises the single activity that sharing experiences with fellow sufferers is considered as helpful.
8. *Other* Unlike the above seven clusters, it is more difficult to attribute a specific label to this cluster. Strategies in this cluster range from requesting coaching at work, searching out family background and maintaining a weblog.

We next rotated the axes in the concept map to obtain maximum meaning in Fig. 1; first, a thematic distinction became apparent in the location of the strategies and secondly, a meaning could be given to these locations. Strategies at the top of the vertical axis were related to 'general strategies' and those at the bottom to 'depression-related strategies'. The strategies on the horizontal axis expressed 'focus on oneself' on the left and 'focus on others' on the right side.

Priority of the strategies

Table 2 displays the 15 strategies that had a mean priority score ≥ 3.5; important/very

Table 2 Top fifteen strategies that on average were found important/very important

Cluster	No.	Mean (SD)	Strategies
2	15	4.50 (0.65)	Setting realistic short-term goals
5	38	4.40 (0.64)	Leaving the house regularly
5	36	4.15 (2.53)	Recalling positive memories
5	37	4.05 (0.05)	Gradually resuming responsibilities that were taken over by others
5	20	4.00 (1.80)	Engaging in sports activities
1	42	4.00 (1.50)	Acknowledging that depression is a disease
1	24	3.95 (1.45)	Finding a different therapist when there is limited progress
5	9	3.95 (1.45)	Engaging in leisure activities
6	16	3.90 (1.09)	Making sure you have a good day/night rhythm
1	47	3.80 (1.86)	Making sure there is adequate support when using medication
2	50	3.70 (1.01)	Healthy eating
2	2	3.60 (1.44)	Overcoming problems with concentration by creating to-do lists
5	11	3.55 (0.45)	Engaging in moderate physical activity (cycling, walking, etc.)
1	34	3.50 (1.45)	Finding someone new when the relationship between therapist and patient is not compatible
2	3	3.50 (1.05)	Finding strategies to create pleasurable distractions

important. Six of these strategies are in the fifth cluster 'Engaging in activities', four in the first cluster 'Proactive attitude towards depression and treatment', four in the second cluster 'Daily life strategies and rules' and one in the sixth cluster 'Structured attention to oneself'.

Discussion

Patients remitted from a recent depression believe that there is a wide range of helpful strategies with which they can contribute to their recovery from depression. The spectrum ranges from more cognitive strategies like setting realistic short-term goals, to more active strategies like engaging in sports activities. These strategies can be categorized into seven themes: Proactive attitude towards the depression and treatment, ensuring daily life strategies and rules, explaining depression to others, remaining socially engaged, engaging in activities, structured attention to oneself and contact with fellow sufferers.

Considering our third question, the relatively 'important/very important' strategies are concentrated in four of the seven themes, namely engaging in activities, proactive attitude towards the depression and treatment, ensuring daily life strategies and rules and structured attention to oneself. Although depression is often characterized by avoidance behaviour,[21] patients in our study have experienced that the focus for recovery must be on behavioural and cognitive strategies. Our study identified several unique strategies that can be applied by patients in their daily lives.

To our knowledge, this is the first study to systematically investigate what specific self-management strategies MDD patients need and perceive as most helpful in their recovery.

However, we found one study that also identified self-help strategies by asking professionals and consumers the likeliness that these strategies were helpful.[22] Although this study was based on sub-threshold depression, whereas our focus was MDD, it is interesting to see that there is substantial overlap with the strategies we found (e.g. the themes engaging in activities and lifestyle).

However, one new theme which came up in our study was a 'proactive attitude towards depression and treatment', which certainly has to do with our focus on self-management in patients who had experience with professional mental health treatment. This new theme in which patients consider a proactive and empowered attitude towards treatment as important and helpful is an interesting finding because this is not an 'obviously common' element in therapy. It includes an attitude demanding high-quality treatment and looking for another therapist should there be insufficient progress in recovery or an unsatisfactory therapeutic relationship.

Although we know that the quality of the therapeutic relationship is one of the most important aspects for successful treatment,[23,24] therapists possibly may actively support this important theme much more. On the other hand, some of the important/very important strategies mentioned by patients in our study (e.g. 'recalling positive memories' or 'engaging in sports activities') certainly do coincide with elements of therapies such as cognitive- and behavioural therapy.[25,26] Possibly, patients may have learned those strategies during their treatment and have acquired them now by maintaining those strategies in their daily lives.

We consider the combination of self-management with professional treatment necessary in more severe MDD patients, because they are generally poorly motivated. However, the overlap between the strategies Morgan *et al.*[22], and our study found, may signify that we can use a substantial amount of strategies for all phases of depression (subthreshold, mild, moderate, severe). Whereas our study is framed in terms of patients with depression, who accept the diagnosis and professional treatment, it would be interesting to study whether other individuals may also benefit from the strategies we found. For instance, those with symptoms or disorders related to depression (distress, sadness, adjustment disorder), or individuals who reject the concept of depression for reasons of culture or health beliefs, or those who have their particular reasons to want to manage difficult emotions or real depression by themselves and do not want to use professional treatment. Considering the overlap of strategies between the different phases of depression[22], we might assume that strategies within the themes ensuring daily life strategies and rules, remaining socially engaged, engaging in activities, structured attention to oneself and contact with fellow sufferers, could also be helpful in these individuals. The strategies in the other themes, proactive attitude towards the depression and treatment and explaining depression to others, might be too focused on the diagnoses and therefore probably less helpful. Nevertheless, this would be an interesting topic for further research in this area.

Not all phases require the same intensity of support within treatment. Depending on the phase of the depression, all strategies could therefore be considered to be carried out with a gradual intensity of support by therapists. We currently study to what extent the strategies that have been found important from the patients' perspective in this study are actually used by patients. Therefore, we developed a questionnaire, based on the concept map, and send this to a larger group of patients. This will enable us to assess for each strategy its prevalence, perceived efficacy, applicability and to identify the *most helpful* strategies in specific phases of the depression.

The most important strategies found where all concentrated on the 'focus on oneself', as the axis of the concept map illustrate. Somewhat surprisingly, 'focus on others', such as contact with fellow sufferers and explaining the disease to others, was considered relatively less important than other strategies by patients. It is possible that patients made a distinction between those strategies helpful for recovery and those that are relevant for coping with depression in a more chronic phase of the disease. In that case, this focus on others is perhaps important for the quality of life of those who respond less well to treatment and are faced with chronic symptoms.

Although many Internet forums promote contact with fellow sufferers[27] and the focus of current research is on Internet-based self-help programmes,[14] the patients from our study did not mention the role of Internet for their recovery at all to be helpful. The only exception was the writing of a weblog. On the other hand, patients did mention strategies like 'acknowledge that depression is a disease' and 'explain it to others', which may show that an open attitude towards this still often stigmatized disease is important and perhaps also supportive to create a validating environment.

Strengths and limitations

Our study has several strengths: the exploration of patients' perspectives, which is often a blind spot in treatment and other studies, and

the use of Concept Mapping, which has both qualitative and quantitative methodological components. However, it has also some limitations. First, our study sample seems small. We may have missed specific subgroups within depression. However, for concept mapping, 20 patients are considered sufficient to explore our research questions.[28] We included patients with a wide diversity in age, treatment history, and experiences to enhance the external generalizability. In addition, the third focus group generated only a few new strategies and we therefore doubt whether including more patients would have resulted in very different results. Nevertheless, the study should be replicated in patient groups with different (treatment) histories, cultural backgrounds, depression severity or comorbidity. Second, this study focused on contributions considered important for recovery by patients. Whether what patients perceive as helpful, really works in practice is a question for future research.

Conclusion

Our results suggest that from the patients' perspective there are a substantial number of different self-management strategies enabling patients to contribute to their recovery. Although motivation and autonomy in patients during a period of depression is supposed to be low,[29] our study shows that patients recovered from depression in hindsight stated that they are certainly able to contribute to their recovery. Further research on this issue could help to improve patients' active contributions to current treatments for depression.

Practice Implications

Our findings may provide information to aid in the further development of self-management strategies and programmes for the recovery from depression: First, the 50 strategies could simply be given to patients in a handout. Second, professionals could also present the 50 self-management strategies to their patients during their treatment consultations and subsequently incorporate *those* strategies that are considered *most helpful* based on patients' personal experiences. This may stimulate personal self-management goals, supporting autonomy and encourage patients to take an active role in achieving recovery. Integrating self-management into current treatments of depressed patients will require investments in training for the mental health professionals who will need to assume this new role. Third, a more structured self-management programme could be developed in close collaboration with patients. Such a programme could be investigated for efficacy in a randomised clinical trial.

For a further integration of treatment and self-management, we need to open new roads to organize and structure mental health-care organisations in such a way that they facilitate the use of self-management strategies.

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Conflict of interest

All authors declare that they have no conflict of interest.

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