International Journal of
Depression and Anxiety

A Patient Perspective on the Self-Management of Chronic Anxiety and Depression: A Mixed-Methods Study

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Abstract

Background: Self-management is considered relevant and effective for people living with chronic diseases, with studies showing that individuals with persistent anxiety and depressive disorders apply a wide range of cognitive and behavioural strategies to cope with their symptoms. But what is the patient perspective of such interventions?

Methods: In a mixed-methods design, we used two patient focus groups and concept mapping to elicit and cluster self-management strategies in chronic anxiety. Based on these and earlier outcomes on chronic depression, we developed the Assessment of Self-management in Anxiety and Depression (ASAD). Adults with chronic, treatment-resistant anxiety and depression under the care of 12 Dutch outpatients mental health care settings were subsequently invited to complete the questionnaire to assess which strategies they used and which of these they perceived as most and least helpful.

Results: The focus groups generated 91 strategies, which they sorted and prioritised. Analysis of the rank-ordered data yielded 45 unique strategies, which were included in the ASAD. Of the 141 patients invited, 71.6% (n = 101)
completed the questionnaire. Although subgroup strategies varied somewhat, the top three were comparable for the anxiety, depression, and comorbid group.

Limitations: Our subgroup comparison needs to be interpreted with caution given the limited number of participants.

Conclusion: Respondents perceived a diverse set of self-management strategies as helpful in coping with chronic anxiety and depression, with patient groups employing similar techniques across different stages of the disorder. We recommend discussing those self-management strategies that were deemed most helpful with patients as part of their treatment.

Keywords

Self-management, Anxiety, Depression, Chronic, Patient perspective

Abbreviations

ADF-stichting: Angst Dwang en Fobie stichting (English: Anxiety, Compulsion and Phobia Foundation); ASAD: Assessment of Self-management in Anxiety and Depression; CL: Cluster; ZemCAD (English SemCAD): Self-management for Chronic Anxiety and Depression

Introduction

Anxiety and depressive disorders are highly prevalent worldwide [1], are often comorbid with each other [2], and frequently become recurrent or chronic [3-6]. Penninx and colleagues estimate that 25-57% of anxiety and depressive disorders run a chronic course (no remission in > 2 years) [7], which is associated with a marked decrease in quality of life [8]. In anxiety there is a recurrence rate of 24% in a two-year period following recovery [9] and in depression 60% will experience another depressive episode within five years following recovery [10].

People with recurrent or persistent symptoms will have to learn to live with their disease and may benefit from chronic-disease management approaches [11-14]. Self-management is considered such a relevant approach [15]; the technique has proven to be effective [16,17] and is recommended in guidelines as a complementary intervention [18,19]. It is beneficial for individuals living with chronic mental-health disorders in general [20,21], while for those with persistent anxiety and depressive disorders it has been found to mitigate symptom severity, enabling them to handle their condition better [22].

However, there are multiple interpretations of the concept of self-management that may overlap with concepts such as recovery approach, self-help and self-care [23,24]. The Mental Health Foundation states: *"Self-management is about the methods, skills, and strategies we use to effectively manage our own activities towards achieving certain objectives. For those of us who live with long-term mental health conditions, this means concentrating on interventions and developing training and skills to take care of-and gain direct control over-our lives"* [25]. In other words, self-management includes all cognitions and activities that someone adopts and undertakes to deal with the disease, such as optimising their health, managing symptoms, and avoiding relapse [16,18], which efforts can be supported by a mental-health professional.

Studies investigating self-management in anxiety and depression show that participants use a wide variety of strategies [26,27]. However, while the nature and role of self-management strategies in the recovery from these disorders have been studied abundantly [28-32], the techniques individuals actually employ to cope with chronic, treatment-resistant anxiety and depression have not been delineated. Very little is known about how patients themselves perceive self-management and the effectiveness of cognitions and behaviours [28,33], and whether the interventions individuals with chronic anxiety and those with chronic depression use are similar in nature and perceived benefit.

Against this background, we asked ourselves the following questions: 1) What self-management strategies do individuals with chronic anxiety and depressive disorders use? 2) Which self-management strategies do they perceive as being most and which as least helpful? and 3) Is there a difference in the nature, use, and perceived usefulness of self-management strategies in anxiety and depression?

To answer these questions, we adopted a mixed-methods design, i.e. a combination of qualitative and quantitative research components [34]. In the first study phase, we sought to generate an overview of self-management strategies by means of patient focus group discussions, which outcomes would subsequently be clustered into a concept map to thus generate a list of factual strategies. In the second study phase, we would draft a self-report questionnaire, the Assessment of Self-management in Anxiety and Depression (ASAD), based on the strategies identified in study phase 1 and have patients with chronic and treatment-resistant anxiety and depressive disorders rate the perceived helpfulness of the various strategies they (had) used. The methods employed and results obtained will be described separately for each study phase.

Study Phase 1: Identifying and Clustering Self-Management Strategies

Methods

Recruitment and participants: We asked the *Anxiety, Compulsion, and Phobia Foundation* ("Angst, Dwang en Fobie stichting"), the Dutch patient association, to approach its members and invite them to participate in our research. We subsequently assessed whether eligible candidates met the inclusion criteria for our study, which were: Being 18 years or older, being diagnosed with a chronic anxiety disorder by a health professional, and currently receiving or having recently received treatment for at least two years by a specialised mental-health facility. Candidates were excluded from participation if they had a life-threatening medical condition, dementia, psychotic or bipolar disorder, alcohol or drugs dependence, cognitive problems, indications of a low IQ (< 80), and those not sufficiently fluent in the Dutch language.

Concept mapping: In order to generate self-management strategies from users, we used group concept mapping [35,36], a well-established method to conceptualise a specific subject and clarify complex issues with in groups [35,36], in our case patient's experiences with and perceptions of coping with chronic anxiety and depressive disorders. The method exploits dynamic group processes, encouraging participants to react to each other's input, thus eliciting new and more ideas than would have emerged in individual interviews.

Building on an earlier comparable study exploring strategies in chronic depression [37] and now focusing solely on chronic anxiety disorders, our concept mapping process comprised three steps.

Generating: In two independent 2-hour focus-group sessions, participants brainstormed about the central question: "What can you do to optimally cope with your non-recovered anxiety disorder?" All the strategies the participants but forward during these sessions were noted on a flip over and then reformulated until they were clear to all group members. The sessions were guided by two researchers (HS and MZ), who eventually removed the overlapping strategies generated by the two focus groups to compose a final list.

Structuring: The final list was sent to each participant in Word file format with the request to prioritise the strategies by dividing them into five categories of equal size, where strategies in category 1 were judged to be the least important/helpful to cope with a chronic anxiety disorder and category 5 the most important/helpful. Next, the participants were asked to sort the strategies into groups with common characteristics and instructed to create a minimum of 5 and a maximum of 12 groups with 2 to 20 strategies in each group. These numbers were chosen to guarantee sufficient heterogeneity between the groups [35].

Analysing: Two types of analysis were performed using 'Ariadne', dedicated concept-mapping software [38]. First, in a multi-dimensional scale analysis all strategies were projected in a two-dimensional concept map. Here, the distance between the strategies represents how often they were grouped together by the participants, thus depicting the similarity of the strategies. Second, in a hierarchical cluster analysis [36] the prioritised and sorted strategies were divided into clusters. This yielded different solutions, with the number of clusters ranging from 5-10. Next, the computer-generated clusters were reviewed by two researchers (HS and MZ), who jointly selected the cluster solution that could best be interpreted, labelling the distinct clusters in the concept map accordingly. Finally, the relative importance of the strategies was calculated based on the participant's prioritisations (mean score).

Results

We recruited 18 participants, whom we divided into two separate focus groups (n = 8 and n = 10). Fourteen participants were female. Mean age was 51.7 (range 26-79 yrs). All had experienced anxiety symptoms from a young age and had received various treatments, including ongoing long-term care provided by specialised mental-health services. Together, they came up with 176 strategies (95 in the first and 81 in the second group). Having removed overlapping techniques, we arrived at 91 unique strategies to help manage chronic anxiety disorder. Analysis of these 91 prioritised and sorted strategies yielded a best-fit cluster solution containing seven clusters.

Numbering and labelling the seven clusters based on the highest combined mean score for the strategies

within that cluster, we derived the following clusters: *Cluster 1: Day-to-day functioning; Cluster 2: Feeling safe and supported; Cluster 3: Acceptance; Cluster 4: Realistic and positive approach; Cluster 5: Taking care of others; Cluster 6: Having control of the situation, and Cluster 7: New perspective.*

Cluster 1, perceived as the most important, contained cognitions and strategies such as '*I can sleep well*', '*I have a good physical condition*', '*I use healthy food*', and '*I pay attention to my personal hygiene*', followed by Cluster 2 *(e.g. 'I have a safe place where I am accepted for who I am', 'I dare to ask for help')*, Cluster 3 *(e.g. 'I accept my limitations and adapt to what I can do', 'My anxiety symptoms are allowed to be there and are accepted')*, Cluster 4 *(e.g. 'I am kind to myself, not too strict, and do not set high standards', 'I reward myself or give myself a compliment')*, Cluster 5 *(e.g. 'I can mean something for someone', 'I have a pet')*, Cluster 6 *(e.g. 'I always bring my medication with me', 'I do not depend on others')*, and Cluster 7 *(e.g. 'I get a cognitive behavioural therapy booster session', 'Others show me another perspective on my symptoms')*. For a full overview of the focus group strategies, see Appendix 1.

Next, we compared the 91 self-management strategies for anxiety with 50 strategies to cope with chronic depression from a previous, comparable concept-mapping study [37]. We (HS, RvG, and MZ) first independently identified and removed overlapping strategies and merged duplicate ones. Next, during several consensus meetings we created a final list of 45 cognitions and techniques reflecting strategies that all agreed were applied both for chronic anxiety and depression.

Study Phase 2: Composing and Administering the ASAD

Methods

The ASAD: We used the 45 self-management strategies identified in study phase 1 to compose the ASAD (see Appendix 2 for the full questionnaire) which asks individuals living with chronic or treatment-resistant anxiety and depression to indicate the degree of helpfulness of these strategies on a 5-point Likert-type scale. To determine the most and least helpful strategies we exclusively looked at scores 1 (Not at all helpful) and 5 (Most helpful).

Survey participants: Candidate ASAD respondents were enrolled from twelve specialised mental-health outpatient services in the Netherlands within the framework of the ongoing ZemCAD (or SemCAD: Self-management for Chronic Anxiety and Depression) study [39,40], a multicentre, randomised controlled trial into the effectiveness of a self-management training programme. They were invited to complete the ASAD approximately one year after their inclusion. All were 18 years or over, had been diagnosed with a current

or lifetime anxiety or depressive disorder according to the DSM-IV, had received specialised (outpatient) treatment for at least two years that included at least one psychological treatment and at least three medication trials in accordance with the national multidisciplinary treatment guidelines for anxiety and depressive disorders. Their attending health professional had classified their condition as treatment-resistant, meaning that (s)he judged that further (specialised) treatment was unlikely to improve their clinical outcomes. Some of the respondents had no current disorder as established during a MINI interview but had been found eligible for the ZemCAD study by their health provider given their lifetime diagnosis and high levels of symptoms. The participants had supportive contacts with a community psychiatric nurse. All gave their written informed consent prior to their participation in our survey. Candidates were excluded from participation if they had a life-threatening medical condition, dementia, psychotic or bipolar disorder, alcohol or drugs dependence, cognitive problems or indications of a low IQ (< 80), or were insufficiently fluent in the Dutch language.

Analyses: We first analysed the ASAD data for all participants including the respondents without a current disorder (denoted as the 'Full sample' group) to determine which strategies were overall perceived as most and least helpful, after which we compared the data for three subgroups: The participants with an anxiety disorder only ('Anxiety'), those with a depressive disorder only ('Depression'), and those with both an anxiety and a depressive disorder ('Comorbid').

We next performed a Chi-square test on each of the six self-management strategies perceived as most and least helpful according to the full sample to determine whether these differed across the three subgroups. Due to the many values below 5, we used Fisher's Exact Test for the subgroup analyses. The results were considered significant at p < 0.05. All analyses were conducted using the Statistical Package for the Social Sciences (IBM SPSS, version 26) for Windows.

Results

Of the 141 participants in the ZemCAD sample 101 (71.6%) completed the ASAD, of whom 65.3% were female. The mean age of the respondents was 47.7 ± 8.9 years; 12.9% had a lifetime but no current disorder, 18.8% had an anxiety disorder, 31.7% a depressive disorder, and 36.6% both a depressive and an anxiety disorder. An overview of participant characteristics is provided in Table 1.

In the Full sample group, the top three strategies perceived as most helpful were: '*Make sure I regularly take my medication, for instance by carrying them with me and taking them in a fixed place and tim*' (47.5%, p 0.224), '*Take care of my personal hygiene*' (21.8%, p

0.408), and '*Seek or maintain daily activities, such as voluntary or paid work*' (13.9%, p 0.604). The top three strategies perceived as least helpful were: '*Express my feelings by writing in a journal or weblog*' (61.4%, p 0.462), '*Talking with peers*' (42.6%, p 0.980), and '*Learn to focus my attention, for instance by meditation, yoga, mindfulness, or breathing exercises*' (39.6%, p 0.059). Fisher's Exact Test showed that the top six self-management strategies were not significantly different for the various subgroups.

The subgroup analyses yielded additional strategies beyond those mentioned by the Full sample group, with the following strategies being perceived as most and least helpful:

Anxiety subgroup Most helpful: '*Seek monitoring from a professional for my psychotropic drug use*' (22.2%), '*Exercise regularly, for instance though sports, walking, or doing household chores*' (22.2%), '*Be in my familiar surroundings, where I am accepted for who I am*' (22.2%), and '*Eat and drink healthy*' (22.2%). No additional least helpful strategies emerged.

Depression subgroup Most helpful: '*Ensure a proper day-night rhythm*' (16.1%). As a least helpful strategy 43.8% mentioned '*Develop or use a talent*'.

Table 1: Participant characteristics of ASAD respondents.

	Responders (n = 101)
Gender, n (%)	
Female	66 (65.30)
Male	35 (34.70)
Age (years)	
Mean (SD)	47.74 (8.99)
Range	27-63
Education, n (%)	
Low	48 (47.53)
Intermediate	25 (24.75)
High	28 (27.72)
Employment, n (%)	
Paid	17 (16.83)
No paid	84 (83.17)
Nationality, n (%)	
Dutch	92 (91.10)
Other	9 (8.90)
Partner status, n (%)	
Single	24 (23.80)
Living with partner	77 (76.20)
Diagnosis according to MINI[a], n (%)	
Anxiety	19 (18.80)
Depression	32 (31.70)
Both anxiety and depression	37 (36.60)
No current anxiety or depression	13 (12.90)

[a]MINI: MINI International Neuropsychiatric Interview

Comorbid subgroup Most helpful: *'Maintain long-term professional help'* (18.9%), *'Seek monitoring from a professional for my psychotropic drug use'* (10.8%), *'Be in my familiar surroundings, where I am accepted for who I am'* (10.8%), and *'Seek a professional that suits me'* (10.8%). No additional least helpful strategies were identified.

Of the additional most helpful strategies, Fisher's Exact Test showed only *'Exercise regularly, for instance though sports, walking, or doing household chores'* (p 0.029) to be statistically significant in the Anxiety subgroup. None of the other above-mentioned strategies were found to be significantly different among the subgroups (p-values: 0.259-0.899). Appendix 3 provides an overview of all the strategies perceived as most (score 1) and least (score 5) helpful.

Discussion

Based on the input from our patient focus groups and the concept-mapping results, we developed the Assessment of Self-management in Anxiety and Depression (ASAD). Having patients living with chronic anxiety and/or depressive disorders rate the ASAD's 45 self-management strategies, we identified six cognitive and behavioural strategies that were deemed most and least helpful and found very few differences between the respondents with either anxiety or depression, or those coping with both conditions.

To our knowledge, this is the first study to specifically explore self-management strategies as described and used by patients with chronic and treatment-resistant anxiety and depression. Although other self-management studies focused on recovery from anxiety and depression, or just on anxiety or depression in general [27-32,37], and had other aims, it is worth mentioning that we see a marked overlap in the cognitions and behaviours reported on in this previous and our research, with strategies most frequently pertaining to day-to-day functioning, acceptance, and adopting a realistic and positive approach to one's symptoms. This concurrence might then also explain why we did not find meaningful differences in the strategies used by the respondents with chronic anxiety, those with persistent depression, and those with comorbid treatment-resistant symptoms.

Looking at our findings and those of other studies, we can pose that self-management strategies for anxiety and depressive disorders, other mental disorders [31,41], chronic somatic diseases [42-44], and chronic diseases in general [16] are quite similar. They all include elements of psycho education, behavioural activation, changing life habits, and cognitive strategies. Only a few interventions may be said to be more or less unique for a specific disease, such as 'Do my best not to avoid, by confronting the situation' for anxiety, and 'Ensure a proper day-night rhythm' for depression. Furthermore, approaches appear not to depend on disease stage. Irrespective of recovery or chronicity, the self-management strategies our participants identified as most helpful can thus be generalised and used during all phases of treatment. Yet, although the same set of strategies appears helpful for most, we must always consider that the patient's perspective can change over time and that it is recommended to monitor which strategies are perceived as most helpful in the course of the treatment process.

Of note is that the widely promoted intervention '*Talking with peers*' [45] was perceived as one of the least helpful strategies by our participants. Although we did not inquire into the reason why, it is possible that they found talking to peers difficult because they are still strangers and they prefer to confide in close relatives or friends only. Also notable was the fact that none of our participants reported that they (had) searched for information on the Internet or for online interventions even though these are increasingly being mentioned in the literature as important treatment or support options [46]. In an earlier depression-management study, Van Grieken and colleagues [37] hypothesised that when participants only have experience with clinician-delivered treatments, they are less inclined to mention these options out of lack of personal experience with them, or that those who were familiar with them had a strong preference for face-to-face care over contacts via the Internet and decided not to put these options forward. Arguably, peer support (be it on- or offline) may be more relevant in the earlier stages of an illness and was therefore not considered beneficial or pertinent by our study population.

Finally, our participants deemed specific strategies associated with professional treatment effective, such as '*Recognize signals which indicate that things are not going well, for instance by using a relapse prevention plan*', '*Seek monitoring from a professional for my psychotropic drug use*', and '*Involve people close to me in my treatment*' which interventions are also part of Dutch multidisciplinary treatment guidelines. This shows that, despite the fact that they had not recovered from their illness, our respondents still applied recommended techniques they had trained in previous treatments and still valued and actively engaged in professional care.

Strengths and limitations

One of the main strengths or our study is that we looked at the helpfulness of self-management strategies from the patient's perspective. Second, although several recent studies also examined self-management strategies for anxiety and depression, to our knowledge ours is the first study to specifically focus on patients with chronic, treatment-resistant anxiety and depression. And third, we were able to include patients from all over the Netherlands who had had various guideline-recommended treatments and were under the care of expert mental-health services.

As to the study's limitations, we need to mention that, although still in line with the protocol [35,36] and relying on two instead of a single focus group, the number of participants we managed to recruit for our concept-mapping approach was limited. Also, the results of our comparison of diagnostic subgroups need to be interpreted with caution. Because the number of respondents per subgroup was limited, some statistical tests were less appropriate, for which reason we also used Fisher's Exact Test. Moreover, the ASAD research was exploratory and not guided by any prior hypotheses. The questionnaire was specifically designed to assess the usefulness of self-management techniques of patients with chronic, treatment-resistant anxiety and/ or depression and, due to the high comorbidity of the two disorders, it is not surprising that we found few differences between diagnostic groups. Finally, our focus on what patients themselves perceived as helpful or non-helpful and founding our ASAD on their input is both a strength and a limitation. Some respondents may have scored items without ever having actually used the strategies described, which would make their judgements 'theoretical' rather than rooted in personal experience. Moreover, some strategies that were perceived as most helpful may not be the ones that actually work best in practice or for all patients. These issues require evaluation in future research.

Implications

Self-management has gained an important role in the lives of people living with chronic illnesses. Our concept-mapping study and patient survey using the newly-developed Assessment of Self-management in Anxiety and Depression (ASAD) show that people with chronic, treatment-resistant anxiety and depressive disorders use a variety of strategies that help them cope with their long-term symptoms. In (clinical) practice, people with persistent symptoms may then use the ASAD to explore, possibly together with their health professional, which strategies would suit them best to help create a different mindset and effectively convert their hope for a cure (which has not proven feasible) into a sense of acceptance and good self-care activities.

Because the self-management approaches the patients described are very diverse, we suggest that clinicians become familiar with those that are reportedly the most helpful and include these in their treatment, for example, by way of psycho education, emphasising that it were peers that perceived these strategies as being helpful. By making their treatment more patient-centred, they can empower patients by helping them find the strategies that work best for them.

Conclusion

The self-management strategies patients with chronic, treatment-resistant anxiety and/or depression perceived as most helpful to cope with their symptoms

included pursuing an active lifestyle, engaging in social activities, maintaining (long-term) professional help, and involving significant others in dealing with their recurrent symptoms. Previous self-management studies showed that the same set of strategies are being used by various other diagnostic groups and in different stages of the illness. We hence recommend clinicians discuss these findings on self-management strategies with their patients and jointly look for those interventions that match the individual patient.

Declarations

Ethics approval and consent to participate

This study was approved by the Institutional Review Board of the University Medical Centre Utrecht (NL33674.097.10, registration number 10.218) for all participating sites, and was conducted according to the principles of the Declaration of Helsinki (version 2008) and in accordance with the Dutch Medical Research Involving Human Subjects Act (WMO) and other relevant guidelines, regulations, and acts.

Declarations of interest

None.

Author statement

MZ, RvG and HS participated in all steps of the development of the ASAD (study phase 1). MZ performed the statistical analyses (study phase 2) and drafted the manuscript. BK and JS supervised both study phase 1 and study phase 2, the statistical analyses, and helped draft the manuscript. FS helped draft the manuscript. All authors commented and contributed to successive drafts, and read and approved the final manuscript.

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