

# Patients' view on screening for depression in general practice

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**Background.** In general practice, depression is often not recognized. As treatment of depression is effective, screening has been proposed as one solution to combat this 'hidden morbidity'. The results of screening programmes for depression, however, are inconsistent and most studies do not show a positive effect on patient outcomes. Patients do not always accept this diagnosis and hence do not receive proper treatment. Nothing is known about the tendency of those patients who screen positive for depression to accept treatment for their 'disclosed' disorder.

**Objective.** In this study, we aimed to better understand the views of patients who screened positive in a screening programme for depression.

**Methods.** We performed a qualitative study with semi-structured in-depth interviews with 17 patients. These adult patients (nine females), all suffering from major depressive disorder, were disclosed by a screening programme for depression performed within 11 Dutch general practices. The transcripts were independently analysed by two researchers using MAXqda2.

**Results.** All patients appreciated the active way in which they were approached for screening. Fifteen of the 17 patients recognized the depressive symptoms but nine of them did not accept the diagnosis. The first explanation for resistance to the diagnosis of depression is fear of stigmatization and scepticism about the usefulness of labelling. Secondly, patients experienced their depressive symptoms as a normal and transitory reaction to adversity. Thirdly, patients had doubts about the necessity and effectiveness of treatment. Depressive symptoms, such as feelings of guilt, self-depreciation and fatigue, hamper help-seeking behaviour.

**Conclusions.** We conclude that some patients with undisclosed depression, who took the trouble of going through a complete screening programme, felt aversion to being diagnosed as having depression. In the context of screening for depression, we recommend that the patients' view on depression be elicited before diagnosing and offering treatment.

**Keywords.** Depressive disorder, primary health care, qualitative methods, screening programmes.

## Introduction

In primary care, depression often goes undiagnosed.<sup>1</sup> Some clinicians plead for screening to disclose this hidden morbidity.<sup>2</sup> Conversely, others report that screening and disclosure of unrecognized depression does not have a positive effect on patients' outcome.<sup>1,3–6</sup> So far, the patients' view on screening for depression has been missing in this discussion. Patient

participation is a cornerstone of successful screening and as such one of the indispensable conditions described by the UK National screening committee.<sup>7</sup> A complete screening programme (test, diagnostic procedures and treatment/intervention) has to be clinically, socially and ethically acceptable to health professionals as well as to the public. Gilbody<sup>4</sup> has reported that the acceptance of screening tests for depression is generally low: 30–60% of patients in

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primary care decline to participate in screening questionnaires or interviews.

Studies have shown that patients experience difficulties with being diagnosed as having depression.<sup>8</sup> A remarkable difference exists between the conventional medical view and the patients' view of the concept of depression.<sup>9</sup> This probably has to do with patients' views that depression is not the right label for their problems, a negative view of depression related to fear of stigmatization,<sup>8</sup> doubts about the purpose of labelling, feelings of shame and scepticism about the benefits of therapy, in particular drug treatment.<sup>9-12</sup> Additionally, patients may have difficulties in differentiating depression from understandable reactions to adversity.<sup>9</sup> Nothing is known about the tendency of those patients who screen positive for depression to seek treatment for their 'disclosed' disorder. A negative view on being diagnosed with depression will probably reduce the chance of acceptance of the diagnosis within a screening programme.

In this study, we aimed to better understand the views of patients in a screening programme for depression. We focused on primary care patients who were willing to participate in such a programme, subsequently screened positive for depression, but who had not yet been diagnosed by their GP. In order to learn more about the views of these patients on screening as well as on the diagnosis of depression, we performed a qualitative study.

## Methods

### *Sample selection*

This qualitative study was part of a larger project on disease management for depression in which the first step was to screen patients in 11 general practices. The population was ethnically mixed and consisted of three groups of adult primary care patients at risk for depression. The first group of patients were frequent attenders; they had the 10% highest consultation rates over the previous year adjusted for age and sex. The second group of patients had presented with psychosocial problems and the third group had unexplained somatic symptoms, both during the previous 3 months. All patients known to be suffering from a depressive disorder, a psychotic disorder, a bipolar disorder, a cognitive disorder or who had major problems with the Dutch or English language were excluded.

Selected patients received a self-report screening instrument by mail, the Patient Health Questionnaire (PHQ).<sup>13</sup> Patients with a positive score on the PHQ module for depression were subsequently interviewed by telephone using the Structured Clinical Interview for DSM-IV Disorders (SCID)<sup>14</sup> and the Hamilton Depression Rating Scale (HDRS).<sup>15</sup> Following the interview, the diagnosis of depression was notified to the

patients who fulfilled to the DSM-IV criteria for major depressive disorder. The first 17 patients with undisclosed depression were included in this study. We continued including patients until the data were saturated. In accordance with the Medical Research Involving Human Subjects Act (WMO) and with a local Medical Ethics Committee, formal approval for this research project by the Medical Ethics Committee was not necessary.

### *Data collection*

The semi-structured in-depth interviews ( $n = 17$ ) were performed by one researcher (KAW) at the patients' homes and each interview took about 40 minutes. The aim of the interview was to provide an in-depth viewpoint based on personal experience, centred around the topic of the recent diagnosis of depressive disorder. In the first six interviews, the following topics were explored; emotions and cognitions related to this diagnosis, previous experience of depression, consequences of the diagnosis, acceptance of the diagnosis, need for help, willingness to follow treatment and, if applicable, experience with different types of treatment in the past.

Initially collecting data was alternated with analysing the transcripts i.e. sequential analysis or interim analysis.<sup>16</sup> The transcripts of the first six interviews were read with a view to extracting topics that could be missing from our primary topic list. Based on this initial analysis, we added the topic 'feelings about the screening programme up to now' because most of the patients referred somehow to this topic. This adjusted topic list was then used in successive interviews.

The questions were open-ended and the answers were further explored by the interviewer. With the patients' consent, interviews were recorded on audio tape and were fully transcribed. Patients were assured that all views expressed would remain anonymous and that their participation would be kept confidential. Patients were also told that the outcome of the interviews would not have any effect on the post-screening phase (treatment) of the programme.

### *Data analysis*

The transcripts were analysed by two researchers (KAW and MvZ) using MAXqda2.<sup>17</sup> The analysis consisted of multiple phases largely based on Pope's recommendations.<sup>16</sup> First, to discover what the patients had said about these topics, one researcher (KAW) worked through the interviews deductively using the primary topic list: this is also known as the familiarization phase. Later on, the analyses continued in a more inductive way to include other aspects like the definition of depression and perceptions of and experiences with depression, as these subjects were frequently brought up by the patients. In this phase, a thematic framework was identified.<sup>18</sup>

Secondly, recurrent themes within the transcripts were selected and text fragments were sorted according to the thematic framework. This consisted of the following themes: (i) patients' definition of depression; (ii) acceptance of the diagnosis of depression; (iii) patients' view of causes of the depressive disorder; and (iv) physical symptoms and physical co-morbidity related to the patients' complaints. Next, the second author (MvZ) independently analysed all the interviews and added the theme 'reaction to being screened'. Consensus meetings between all authors led to the rearrangement of themes which is presented in the results section.

## Results

### Patient characteristics

The study group consisted of nine females and eight males with a mean age of 47 years (range 29–65) of three different ethnic origins: Dutch ( $n = 10$ ), Surinamese ( $n = 6$ ) and Indian ( $n = 1$ ). None of the patients invited declined to participate. According to the SCID, all patients were suffering from a major depressive disorder. The severity of the depressive disorder expressed by the HDRS score varied between 13 (mild) and 32 (severe), with a mean score of 21 (moderate depression). Six of the 17 patients had a recurrent depressive disorder and the co-morbid psychiatric diagnoses in seven of the 17 patients were specific

phobia, social phobia and alcohol dependence. Six of the 17 patients had been treated for depression in the past.

### Patients' views on screening for depression

We identified six consecutive themes related to the main subject of our study: patients' views on screening for depression. These six themes were (i) reaction to being screened; (ii) recognition of dysfunction; (iii) ideas about depression; (iv) differentiation of problems; (v) acceptance of the diagnosis of depression; and (vi) consequences of the diagnosis of depression (Fig. 1).

*Reaction to being screened.* In this study, almost all patients were positive about the process of being screened for depression. They appreciated the active approach of their GP for screening, because it drew attention to their problems. This positive reaction to being screened is important because it illustrated that the patients did want attention. Some patients said they were unsure about their GP being the right person to go to with mental problems. Others said that they had difficulties in bringing up this subject during consultation (see Box 1).

*Recognition of dysfunction.* Following the positive reaction to being screened, patients said they knew something was wrong with them, i.e. they were aware

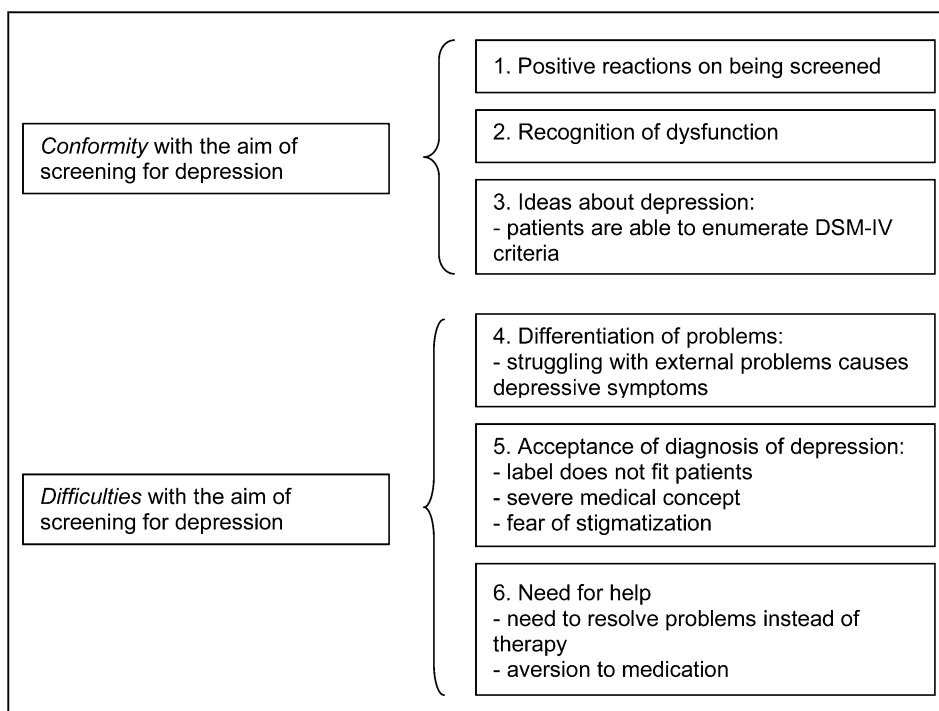


FIGURE 1 Patients' view on screening for depression

Box 1. *Reactions being screened*

I believe the time is ripe for it; it has been long enough now that I've been letting this prey on my mind. I just needed this prod. Now it's time to clear my mind. (Pt 6)

Well, it was funny because the invitation arrived just at the time I was going through a bad period, and I felt things were developing in the wrong direction. And exactly at that time the first envelope arrived. My husband read the invitation as well and said 'well, somewhere somebody must have sensed this', so that was quite peculiar! (Pt 8)

Box 2. *Recognition of dysfunction*

I knew something was wrong with me. People told me I was stressed, but I didn't know what it was exactly although I did feel something was wrong. When I got the results of the test I knew the test was right and now I hope it can be treated. (Pt 7)

I read about depression on the Internet and it all seemed familiar to me. Symptoms like sleeplessness, agitation, concentration problems and loss of interest I'm experiencing all this. (Pt 3)

For the last three years I have been feeling worse and worse. I don't feel like doing anything and I don't leave the house any more except to go to work. Even when I've planned to potter about the house, I just can't get myself to do it. (Pt 6)

that they were dysfunctioning. Recognition of dysfunction might make patients realize they were suffering from a mental disorder like depression. In fact, all patients were convinced they were dysfunctioning and 15 of 17 patients did actually perceive themselves as being depressed (see Box 2).

*Ideas about depression.* Ideas about depression probably influence patients' recognition and acceptance of the diagnosis of depression and their need for help. In general, most patients were well aware of the depressive symptoms and were able to enumerate most of the symptoms belonging to a depressive disorder. This is illustrated by the following answers to the interviewer's question of how to define depression (see Box 3).

The fact that these patients were able to enumerate most of the criteria for depression might imply they saw the similarity between their own symptoms and the diagnosis of depression. However, in their causal explanations for their symptoms, patients did not attribute their symptoms to depression.

*Differentiation of problems.* On being asked their view on being diagnosed with depression, patients started to talk about the problems they were struggling with, which had resulted in their dysfunctioning. They did not experience the disease depression as being their main problem, but rather focused on the situation either related to or causing their depressive symptoms. Recurrent problems were difficulties in relationships with spouse or partner, loneliness, trouble at work and physical problems. Other problems included financial problems, parenting problems, divorce, traumas in childhood (abuse, misuse and betrayal), climacteric symptoms, bereavement, anxiety and personality problems. Patients frequently expressed the need for help to resolve these 'major' problems. They appeared to experience their depressive state as being a consequence of their struggle with these problems and not as the cause (see Box 4).

Box 3. *Ideas about depression*

For me it's like, when I'm depressed, I feel very sober and negative about everything. Things like shopping or being at home, everything's negative, even the things that would normally cheer me up. Like my little nephew, normally he would cheer me up, but not when I'm depressed, like this weekend, I was feeling so depressed that even he couldn't get me out of this. (Pt 17)

Then I don't have the energy to do anything, I'm forgetful and I feel life's pointless when I'm depressed. (Pt 10)

Box 4. *Differentiation of problems*

My whole future has collapsed since all my investment plans failed absolutely. Every single plan that I worked so hard for went wrong and the world around me is falling apart, and that's what's making me depressed. (Pt 16)

It started after my first relationship ended, but it wasn't that bad at the time. It only got worse after my last relationship broke down; then I couldn't handle it anymore, it was really too much. (Pt 7)

I don't think I can explain it, no, but I know what is bothering me, I can explain that to you. What you want to call a depression has more to do with everything I went through before it all finally became too much for me. So really, it's more a question of all the things I didn't deal with over the years catching up with me. When you are trying to deal with everything at once and then yet another setback occurs, well, that's the last straw. (Pt 9)

*Acceptance of the diagnosis of depression.* Although the vast majority of patients was positive about being screened and did recognize their own dysfunctioning, this did not automatically result in accepting the diagnosis of depression. When we kept on asking about their views on being diagnosed as depressed, nine of 17 patients said they felt some resistance to the diagnosis, as if it was going too far. Admitting to being depressed was seen as a failure and as the point of no return. Patients also expressed a fear of stigmatization (see Box 5, Example 1). The last quote, like some of

Box 5. *Acceptance of the diagnosis of depression*

Example 1: Seeing that diagnosis in the letter makes me want to fight against it. (...) Not even for myself, but because of others. (...) I don't really want to admit it, being afraid of others thinking 'you see, she didn't make it after all ...' (...) I'm afraid of becoming one of the people on that list at work, who have been ill, and can't handle it. (Pt 8)

Example 2: I really don't think that what I'm experiencing should be called a depression. People with a depression who I've seen just don't know what they're doing anymore; they just give up, or else start drinking. I have to admit that I've been drinking more lately, but anyway. These people behave differently, stop going to work, stop looking after themselves, you know, these kinds of depression. For me it's more a matter of 'where will this end?' It's all useless, hopeless, helpless ... (Pt 16)

Example 3: When I read the letter I thought it was referring to the depression I experienced in 2002. At that time I was suffering from real depression. I was feeling much worse then; I didn't have any energy and didn't feel like doing anything and slept the whole day through. I couldn't control my appetite. Now, I'm having some of these symptoms but not to the same extent as before. The word 'depression' really doesn't suit the way I'm feeling today; that's got more to do with the past. (Pt 4)

Example 4: Well, I think it's something in my character, but yet I'm not sure about it. (...) But a depression, I don't I know. I don't think so, and I don't want myself to stay like this. I feel like I'm going through a bad patch, a very bad patch. (Pt 13)

Example 5: Well, it depends what is meant by depression, but to me depression is something very severe. Last year I had burn out, that's what the doctor said. That, I felt, was severe as well, but that was easier to accept. And also, I don't feel that I should need to take antidepressive medication yet. (Pt 8)

Example 6: It's just a word you people have invented for people feeling like I do, and that's what you call depression. They've just made up a name for it. (Interviewer: So do I understand you correctly that it doesn't help you?) That's right, I don't feel connected to that word at all. I could never imagine myself, saying, 'I'm depressed'. No, I just know for myself that I've not been feeling very well lately. (Pt 9)

the preceding ones, illustrates that depression is perceived as a stigmatizing disorder. Patients also compared themselves with people suffering from more severe psychiatric symptoms (see Box 5, Example 2).

Another patient had suffered from a depression in the past. She mentioned that her former depressive episode had been far more severe than it was this time (see Box 5, Example 3). Furthermore, patients tend to keep away from the diagnosis of depression by giving their problems other names. They prefer to label it as a 'bad patch', a 'big dip', 'burn out' or 'stress' (see Box 5, Examples 4 and 5). Some patients did not see the purpose of labelling their symptoms as depression and mentioned that using the label 'depression' did not clarify the situation (see Box 5, Example 6).

*Need for help.* The final theme that was drawn from the interviews was the need for help, the need for treatment and the kind of treatment preferred by these patients. The patients' needs differed greatly. Some patients doubted whether they really needed treatment because their symptoms were not severe enough for that. Others said that treatment would not help them. Few patients wished to solve their problems themselves without any help. They believed asking for help would confirm their failure (see Box 6, Example 1).

Of the patients who appreciated receiving some help, the majority did not think positive about treatment that included medication (see Box 6, Example 2). Taking medication was also not associated with an active approach they believed to be necessary for their recovery (see Box 6, Example 3).

## Discussion

In this study, we explored patients' views on being diagnosed as depressed in a screening programme by performing a qualitative study. We conclude that screening for depression detects a group of patients that appreciate the fact that they receive attention for their problems, but who also show resistance to being diagnosed as having depression. Three of the six themes that originated from the interviews are in accordance with the aim of screening for depression. First, patients in this study feel positive about being actively approached for screening. They express the need to talk about their problems but also describe themselves as being hesitant to ask for help.

Secondly, patients recognize that there is something wrong or that they are dysfunctioning or ill. This awareness of dysfunctioning is probably one of the main reasons why these patients participated in this screening programme. Third, patients were able to enumerate most of the DSM-IV criteria of depression and recognize these symptoms in themselves. This last aspect could be accounted for by the process of screening itself, which probably stimulated their awareness of illness by exploring all the symptoms of depression in a questionnaire and in the structured interview.

We conclude that these patients, who were willing to be screened for depression and who screened positive for depression, are aware of their dysfunctioning and depressive symptoms. Feeling ashamed or doubtful and feeling guilty about their dysfunctioning, probably in combination with apathy, hampers discussion of their problems with their GP. Therefore, screening

Box 6. *Need for help*

Example 1: I've thought about contacting my former therapist, but this feels like a difficult step. It's like admitting that I really need somebody to counsel me. (Pt 8)

Example 2: No, I don't believe that these pills that make you feel like a zombie would be helpful, because it's important to be active, and enjoy things and that's very hard when you feel numb like that. (Pt 15)

Example 3: Well, of course I'm just a lay person, but as soon as treatments concern pills I stop believing in it. I think it's you yourself that has to solve it, pills are not the solution. (Interviewer: 'Why not?') Because whenever you get depressed again, you think, 'well, the pills will solve this'. (Interviewer: 'You mean, you become passive?') It's pure laziness you'll get. I don't feel good, so I'll take a pill, while the problems are still there. You should deal with it yourself, and shouldn't take pills for that. (Pt 17)

might help to make contact with these patients about their symptoms.

Our last three themes illustrate that depression is seen as a medical concept that does not properly compare with patients' view and experiences. In this study, patients attribute their difficulties to external psychosocial problems. As a consequence, they find it difficult to accept that they had been diagnosed with depression, which they consider a disease-focused concept. Patients seemed to disagree with one particular view on depression, namely the bio-psychiatric view. This outcome is supported by earlier studies which found that patients with a depressive disorder or anxiety disorder are focused on external problems and their own reaction to these external problems, regarding this as the main cause of their depressive state.<sup>9,11</sup> In their causal way of thinking it are psychosocial problems that cause depression and not vice versa.

Four explanations for difficulties with being diagnosed as having depression emerge from our study. First, the characteristics of the illness itself. Depressive symptoms, such as guilt, feelings of failure and fatigue, do hamper help-seeking behaviour. Furthermore, patients are not able to handle external problems because of depression. In fact, patients regard this as a weakness instead of a consequence of the depression.

For the second explanation, the course of depressive symptoms must be considered. Most patients in this study had already experienced that depressive symptoms are self-limiting and a normal reaction to life stress. Depressive disorder on the other hand is more and more considered to be a severe, chronic medical disorder. Patients could be afraid that labelling symptoms as a depressive disorder would imply that their symptoms are not self-limiting but chronic instead.

We assessed the diagnosis depressive disorder according to the DSM-IV criteria by a structured interview, the SCID I, which is an accepted reference standard to set the diagnosis in clinical settings.

Depressive disorder is, however, a syndromal diagnosis and as such not a diagnosis with a gold standard. It might be possible that patients who rejected the label are in fact correct, differ from the patients with a 'true' diagnosis of depressive disorder and have better outcome.<sup>19</sup> This standpoint suggests a rethinking of the validity of the clinical concept of depressive disorder in primary care.

The last explanation for the difficulties being diagnosed with depression is based on the fact that patients linked the diagnosis of depression to treatment and especially with medication. Patients seemed to be less familiar with other therapies which target the resolution of problems at work and home like certain psychotherapy for depression (cognitive behaviour therapy and interpersonal therapy) and are as effective as medication. As has been found before, patients are not convinced of the necessity and effectiveness of medical treatment.<sup>9-12</sup> In fact, recent systematic reviews have shown that medication effectiveness is overrated by drug manufacturers, researchers as well as prescribers.<sup>20-22</sup> It might also be possible that patients have former negative experiences with medication. This probably hampers patients to accept therapy for their problems based on the bio-psychiatric view on depressive disorder.

The implications of our findings are that screening programmes for depression are probably less successful because of the labelling of depression more by the psychosocial causes than by the syndromal symptomatology, the nature of the target disorder, the course of symptoms, the validity of depressive disorder in primary care and the limited effectiveness of (biological) treatment, which hamper the acceptance of the consequences of a positive test result.

## Strengths and limitations

This is the first study on attitudes and views about depression of patients who recently screened positive for major depressive disorder. Our recruitment strategy enabled us to interview patients who accepted the diagnosis as well as those who rejected the diagnosis. None of the patients, diagnosed as being depressed declined to participate in this study. As far as we are concerned, the ethnic variation within our sample did not influence the results because we could not find any recurrent themes that were specific to ethnic origin. Our results are valid for patients that cooperate with screening programmes for depression and who screen positive. They do not relate to all primary care patients and are probably too optimistic about the positive attitude towards screening for depression. The response rate to the screening programme was about 50%, which is not unusual in psychiatric programmes.<sup>23-25</sup> One limitation was our decision to use

convenience recruitment of consecutive patients rather than try to achieve maximal variation. On the other hand, the main implication is that the design was less efficient than if maximal variation were sought, because the data were collected until saturation occurred. For this reason, this is not a major limitation.

## Conclusions

From this study, we conclude that patients with undisclosed depression, detected by our screening programme, are experiencing difficulties in accepting the diagnosis of depression. Explanations for this are the nature of the target disorder depression and the negative views about the diagnosis and treatment of depression. We conclude that one important criterion for the viability of screening programmes, the complete screening programme (test, diagnostic procedures and treatment/intervention) is clinically, socially and ethically acceptable to the target population, is hard to comply within screening programmes for depression. In this context, we recommend that the patients' view about depression should be elicited before diagnosing and offering treatment for depression. Aversion to being labelled as being depressed can have a deterrent effect on the willingness of patients to accept help, even though they might benefit from care for their depressive symptoms.

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According to the Medical Research Involving Human Subjects Act (WMO), formal approval for this research project by a Medical Ethics Committee was not necessary. KAW had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

## Declaration

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Conflicts of interest: None.

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