

How patients with depressive symptoms view their condition: a qualitative study

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Background. Depressive symptoms are common in primary care, yet considerable professional controversy exists about appropriate management including the effectiveness of treatments. In addition, avoiding prescribing antidepressants at least initially is recommended. Views of patients themselves should therefore be particularly important in agreeing management strategies.

Objective. To examine lay beliefs about depressive symptoms in primary care.

Method. A total of 23 semi-structured interviews were conducted with patients scoring positively for depression on the Hospital Anxiety and Depression Score in a primary care setting.

Results. Differentiating 'depression' from understandable reactions to adversity was difficult for patients. The wide range of consequences discussed included adverse effects on others, difficulties coping with feeling out of control and loss of self-identity. Negative images of depression, such as depression being a 20th century phenomenon, were pervasive. Views about medication varied. Various management strategies described included strategies of detachment, engagement in activities and 'blotting out' symptoms.

Conclusions. Patients' views about depressive symptoms are significantly different from conventional medical views. A 'disease management approach' fits uncomfortably with patients' experiences. Acknowledging feelings of loss of control and loss of self-identity in consultations may be useful. The wide employment of techniques patients use to control their disorders, such as support from others, engagement in activities and working at relationships, may be useful to encourage in consultations as alternatives to the use of antidepressant medication.

Keywords. Attitude to health, depression, primary care.

Introduction

Depressive disorders contribute greatly to the global burden of disease,¹ the majority of which will be managed in primary care. Much of this burden is unrecognized or inadequately treated.^{2,3} As a result, primary care professionals are encouraged to improve their recognition skills and adopt a more proactive chronic disease management approach.^{4–6}

There are difficulties with this strategy, not least because educational interventions to change GPs' behaviour for patients with depression are ineffective⁷ and disclosure of undiagnosed patients may not result in improvement.⁸ The natural history of depressive symptoms in primary care is poorly understood⁹ and

there is no good evidence that treatment, at least for 'minor' depression, is effective.¹⁰

With these controversies it is particularly important to understand how patients with depressive symptoms view their experiences. In addition, the recent National Institute for Clinical Excellence (NICE) guideline in the UK emphasizes a more systematic approach in primary care, including watchful waiting, self help and exercise on prescription.⁶ The lay beliefs of people with depressive symptoms may well influence the acceptability and likelihood of success of such an approach, and if more effective management is to be provided, it is particularly necessary to understand how patients themselves view their condition.¹¹

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Qualitative work to-date has emphasized different aspects of views of people with depression. For instance, a study of narratives of 11 people self-diagnosed with depression from a mental health patient organization group in Finland emphasized three accounts of causes—those with traumatic child events, those with traumatic adult life events and those ‘burnt-out’ by excessive demands.¹² Another qualitative study of people with long-term depression, the majority of whom had at some stage been admitted to hospital argues that a patient goes through a depressive career¹³—a stage of ambiguous feelings, a phase of realization that something is wrong, a phase of crisis when professional help is obtained, a phase of coming to terms with the illness identity including stigma and coming to terms with taking medication and then finally either accepting the problem as long term or feeling the depression will be overcome. Another account of the volunteer participants¹⁴ emphasizes three different themes of coming to terms with the disorder—receiving the diagnosis (either with relief, critically or with rejection), trying to explain depression to others (often with difficulty) and trying to explain the causes to oneself. Interference with social roles and functioning with other people seemed to be the reason for consulting and accepting medication.¹⁵ Various studies confirm the wide range of attributes people make about depression, from biochemical causes, hereditary influences, personality traits, multiple demands and social problems.^{13,14,16–18} Negative views about depression seem to be widespread,^{15,16,19,20} as do reluctance to accept medication for treatment compared to talking-type therapies^{15,16,21–24} though patients who have received treatment may be more positive.²⁵

Although literature examining such beliefs exists, most work focuses on those with a long history of depression, those identified from voluntary groups, those patients identified through professionals or those admitted to secondary care. We aimed to obtain the accounts of people with a range of presentation including those not necessarily ‘diagnosed’ by doctors. We used the Hospital Anxiety and Depression Scale (HADS)²⁶ to identify patients for semi-structured interviews, using a depression subscale score equal to or more than 11 to indicate probable presence of a mood disorder. The HADS is a well-established brief self-report instrument with 90% sensitivity and 86% specificity for depression in primary care compared to a gold standard diagnostic interview²⁷ and is also a reliable measure of severity.²⁸ Qualitative methods were chosen because they are particularly appropriate to investigate how people make sense of illness.^{29,30} Our theoretical approach was interpretative phenomenological,³¹ assuming for instance the existence of multiple realities and that the lived, contextual experience is important.

Our aims were to investigate lay beliefs about depressive symptoms and the ways in which a typical

group of patients attending GPs manage their conditions in a primary care setting.

Method

The study took place between July 2003 and November 2004 within three town centre general practices in Middlesbrough, an industrial town in the north-east of England ranked 811th most deprived of 7932 areas nationally³² according to the Index of Multiple Deprivation which is a ward-level index derived from six indicators.³³ The three practices have practice populations ranging from 6700 to 14 000.

Participants

General practice reception staff gave an information sheet about the study, the HADS and a reply slip indicating whether they would be willing to be interviewed to patients as they attended appointments in GP surgeries. Receptionists were provided with a card listing the exclusion criteria which were age less than 18, dementia, cognitive impairment, speech problems and those whose language would make interview and subsequent interpretation of meaning difficult. Different surgeries on a variety of days and with different GPs were selected. Patients who were willing to answer the HADS and reply slip put it in a sealed envelope and placed it in a drop box in the waiting room. The envelope was marked private and addressed to the research associate. The GPs were notified of all patients scoring ≥ 11 .

In total, 1273 patients were approached in waiting rooms, presented with information sheets, invitations to participate and HADS questionnaires. Of these, 113 expressed a wish not to participate. We excluded a further 225 with incomplete information. Of the remaining 935, the HAD score was ≥ 11 in 282 patients. Invitations to take part in the interviews were posted to 120 of these chosen at random, 54 of whom replied agreeing to be interviewed.

We recruited 23 of these at random in three phases to allow development of the analysis, all of whom confirmed agreement to be interviewed. An initial 12 patients scoring positively for depression in one practice were interviewed to refine the interview schedule and produce an initial analysis of data. For the second and third phases, patients in all three practices were selected, six for the second phase and five for the third. The research associate when contacting patients informed them that their HAD score indicated they were feeling ‘low’ on that day.

The average age of the participants was 41 (range was 21–58) of whom 13 were women.

The interviews

The participants interviewed were offered a choice of venue. Semi-structured interviews were carried out by

one author (AH) with no clinical involvement with the participants, and lasted up to 1 hour. The interview was introduced by explaining that they had a high score on the HAD that would indicate that they were feeling low on the day they completed the questionnaire and that the aim was to investigate their views about depression. The interview schedule included ideas about the causes of their low mood, the impact if any on their life, their family and their social networks and the role of others in coping with their condition. Also included were questions relating to treatment and other management methods used. Interviews were fully transcribed and returned to participants to obtain confirmation of the accuracy of the transcripts.

Data analysis

Analysis was carried out by two (CC and AH) of the three authors independently and followed the method described by Miles and Huberman,³⁴ p. 55. Each transcript was read and ‘codes’—labels that described ‘units of meaning’³⁴ (p. 56)—were identified. Codes included purely descriptive codes arising directly from the transcripts and more interpretive codes³⁴ (p. 57). After analysing initial interviews in this way, a ‘scatter diagram’ was made,³⁵ which involved writing all codes down on a large sheet and grouping-related codes in adjacent areas. This helped identify ‘pattern codes’ or themes bringing together groups of descriptive and interpretive codes³⁴ (p. 57). The authors discussed their emerging analysis at different stages. Constant comparative analysis²⁹ was used in two ways—firstly, the transcripts were read on a number of occasions to determine how the emerging analysis fitted in with existing data, and secondly, the emerging data were tested out in new interviews particularly relating to themes concerning management strategies and ‘feeling out of control’. We continued to interview until we felt saturation had been obtained during the third phase of the recruitment strategy. After writing up, all transcripts were re-read looking deliberately for disconfirmatory data.

Results

Although not all the participants had consulted the GP because of emotional problems or had been diagnosed as having depression, all recognized that they had some emotional problem and none were surprised to be contacted. From the 23 transcripts accounts of patients with a HADS ≥ 11 , 19 had discussed their emotional problems with the doctor (though not necessarily for the most recent consultation) and four had not.

Onset and causes

The participants were asked during the interviews about the causes of their condition. Beliefs were complex and multifactorial. They commonly had problems

differentiating the onset of the disorder from ‘normal’ reactions to adverse events, for instance, from ‘normal’ grief following a bereavement. Although a few precisely dated the onset of their depressive symptoms, for many the onset was insidious, growing from a number of reversals and difficult to recognize distinctly. In retrospect, some recounted earlier similar episodes for which they had not sought help. Several participants noted that it was others who recognized the problem, as in this example:

Friends ... they told me I was depressed, they noticed a real change in me. Oh ... and the girlfriend, well she is training to be a nurse, so she was quite aware of depression and other types of mental illness. I thought I was okay, but everyone else said I was not, so I went to the doctors and she agreed that I might be suffering from depression. Participant 15

Some recognized a particular type of ‘weak’ or ‘flawed’ personality in themselves or others which meant they were more prone to their condition—as described by this participant:

I think that it's to do with personality as well, 'cos if you have a strong personality I think you can cope with most things, but if you are weak, well in personality I mean, then you collapse at every hurdle don't you? Participant 4

There were also beliefs about a variety of triggers that had precipitated or could precipitate their condition, including bereavement, relationship problems, poor support from others, domestic violence, unemployment, money problems, world events, work problems and physical health problems.

Negative meanings

Participants gave many examples of negative images including ideas that depression was not a real illness lacking, for instance, physical attributes. A further example was of depression being a ‘modern’ phenomenon—although it might ‘really’ be more common because of increased stress, there was a suspicion that it was simply a new label for problems of daily living within the range of normal experiences:

well I suppose it is depression, just feeling low and lifeless all the time, I think they just give these things a name, well in the past I don't think they had a term for it, you just got on with it didn't you, I remember people saying oh just pull yourself together, and that was it, people never said oh I am depressed or things like that did they? Now everyone is depressed all of the time, any excuse and oh I'm depressed, I think sometimes people feel down and they automatically say 'oh I'm depressed' of course you do get depression

everyone does, don't they, but some just say it without actually being depressed. Participant 7

There were occasional clear examples where others, through negative views concerning their condition, had engaged in discriminatory activities, as for this participant:

When I was off with depression their whole attitude seemed to change. Suddenly they needed extra supporting documentation off my consultant, sick notes from my GP weren't good enough. Respondent 17

Much more common were more subtle worries about potential negative impacts of others being aware of their condition. Examples included unwillingness to receive medication in case information in medical records would adversely affect applications for life insurance or work and worry that other people would treat them differently if they knew the 'diagnosis'. This raises, however, some of the problems interpreting accounts of people while suffering from depressive symptoms. The following example of reluctance to access treatment was probably an example of hypersensitivity to beliefs that depression is not a 'real' illness—but might reflect a 'real' situation of the practice having insufficient time or being unwilling to provide sufficient time, or might simply reflect the negative cognitions that are part of the disorder:

Well they say if it's urgent you can come straight down, well then if you say okay, they ask you what the problem is, well I don't wanna tell them I am depressed. Bet they would love that. Depressed, hardly an emergency is it? Participant 01

Feeling out of control

The participants described restriction in social activities and adverse effects on family members. Some were concerned about imposing further worries on partners and felt partners themselves had become depressed as a result of their illness.

However one of the most difficult aspects mentioned was the feeling of being out of control. They could not predict how they were going to feel from day-to-day, as for this participant:

cos it's just awful being so down, so out of control as well, I think that's the scary thing ... you can't control how you are going to feel each day ... you just can't ... and you can go to sleep feeling okay and wake up feeling like shit ... and for no real reason, I mean what could happen while you are sleeping to turn everything to shit? ... it's just so debilitating. Participant 04

Some, such as this participant, were worried that though apparently resolved, it might resurface at any time:

Long term, I mean it will always be there won't it, in the back of the mind it must sit and wait, like an entity, I suppose, it's like a break in a bone, it weakens it afterwards so you need to be a bit more careful don't you? Participant 10

Other worries about loss of control included breaking down emotionally in socially unacceptable ways in front of people.

A few were frightened by the loss of control, worries about 'losing one's mind' and experiences of de-personalization—as if someone else had the condition, as described by this participant:

I just collapsed at work, crying, curled up in a ball, it was a real effort to get up, to think even. I was sort of detached from myself, I could imagine what I looked like, almost see myself from the outside, it was all fuzzy and strange ... it was hellish. Participant 17

It was apparent that some participants, though scoring ≥ 11 on the HADS, were improving and were even able to describe positive consequences of their condition. These included drawing strength from their experiences, knowing themselves more deeply, stronger relationships with partners and feeling better prepared if the condition returned, as for this participant:

it's actually had a positive effect ... made me a stronger person, they say what makes you bad makes you stronger ... Well I'm strong now, I look at that as a positive outcome I suppose, so yeah, a good impact really, and I think when you have felt so down, like suicidal and all that, then I think you appreciate being well again. Participant 22

Management strategies

The participants described multiple management methods; conventional medical treatment represented only one aspect. For instance, support from partners, family, doctors and other professionals was mentioned and involvement with others through work.

One important method in the view of the participants involved pushing oneself forward—putting effort into engaging with social events and with others. Sometimes others might do the pushing. Although some felt the need to withdraw and be alone, there was the sense that this was not entirely a good idea. Examples included forcing oneself to carry out responsibilities such as caring for children, like this mother:

Well having a child, a responsibility ... it makes you get up everyday, act in a certain way, you have to think about someone else, in many respects she stopped me feeling sorry for myself ... erm ... if she wasn't here, well maybe I would have gone further down hill, faster. Participant 04

Others described working at maintaining relationships with partners and others, caring for pets and exercise. Friends and partners provided support but also there was a sense that interacting with them involved forcing the depressed self to get out of itself, to become another, non-depressed, self.

'Blotting the experience out' was a further treatment accomplished in various ways. Sleep was understood to be a healing agent and while asleep the disorder is also blotted out:

I feel as though I am sleeping me life away
you know that's the only way I can feel as I can
compare it, its like somebody drinking to blot,
blot it out, I feel as though I sleep to blot it out.
Participant 02

Many participants believed that medication worked, at least partly, by blotting out or dulling the sensations and stopping the person dwelling on symptoms, as for this participant:

Well I know that they supposedly make you feel
better . . . err mask the emotional downs, you
know, a bit like a pain killer numbs the pain, then
I think the antidepressant numbs the depression.
Participant 22

Some, however, worried that antidepressants would blunt them too much with deleterious effects on function and cognition, particularly grieving. Other views on how medications worked included action on brain chemicals or hormones, as for this participant:

I think they help you to produce the happy hormone. I read about them a while ago, it was interesting. Well I think that's what they do, change your brain chemistry with that hormone. Participant 23

Some, already taking them, were happy to continue without questioning too deeply how they worked, or indeed whether they really worked at all.

There were differences in the extent of worries about antidepressant medications. Although some worried about addiction believing them similar to benzodiazepines, others thought them safer and non-addictive, as for this participant:

They are fine, I mean I felt okay after about four weeks. There used to be a bit of an argument that they were addictive . . . made you drowsy, made you suicidal I think they have all changed haven't they, I don't think they are like they used to be. Participant 15

The strong connection and difficult distinction many participants drew between life events and their condition helps explain the scepticism about effectiveness of various treatments. They acknowledged that drug therapy or talking therapy would not remove a problem

or resolve bereavement, though either or both might help. What was needed was a change in circumstances which was either impossible or difficult for the participant to visualize, or perhaps time for healing. There was a sense that professionals had little more to offer than pills which could not logically be the entire answer to their problems, as for this participant:

Well I think it's a waste of time really, he'll just give me yet another pill and I shall still be depressed because of all the other things that are wrong with me. Respondent 12

Medication also resulted in a dilemma. Managing the disorder involved being positive, optimistic and believing in a cure. Some participants who had improved did display this optimism, but 'cured' also meant being off tablets.

Discussion

Comparison with other literature

As described previously,^{12-14,16-18} a wide and mixed range of beliefs about causes was apparent, though in our study many participants had difficulty distinguishing their condition from normal reactions to life events. This may reflect our strategy of recruitment on the basis of symptoms rather than recruiting groups with defined diagnosis. The occurrence of a crisis has been suggested as the cause of seeking professional help¹⁴ but this was not apparent in all the respondents in our study and the difference may reflect our strategy of recruitment on the basis of HAD score rather than formal professional diagnosis. Like some previous work, interpreting beliefs about the benefits and disadvantages of antidepressants was complex,³⁶ though unlike other work,¹⁶ beliefs about medication were not all negative. The importance of the whole context of the person's life in recovery, including engagement with activities and with other people, is in keeping with self-help strategies described for people with severe mental health problems.³⁷ The participants' description of a need for a change in circumstances is supported by evidence that 'fresh start experiences' do in fact improve the chances of remission.³⁸

Strengths and limitations

Our recruitment strategy enabled us to interview some patients with depressive symptoms either before entry into an established 'illness career' or who had not received 'depression' as a formal diagnosis from a GP. Nevertheless, participants agreeing to be interviewed may have differed from those declining. The study took place in one relatively deprived area. The HADS does not necessarily diagnose or exclude depression, but rather assesses the presence and severity of depressive symptoms.

We interviewed patients while suffering from depressive symptoms, though this raises interesting problems about interpretation. The accounts were sometimes more inconsistent than expected, which may reflect the effects of depressed mood on memory and concentration. For instance, patients sometimes expressed surprise when presented with transcripts of their interviews; some stated they were a true record of the interview but did not reflect their current views, and it appeared that those participants who came across in the interviews as being the most depressed had the most inconsistencies. At one level, this does not matter—it is important to understand how someone thinks and believes while suffering from depressive symptoms so that services adapt and respond in an appropriate manner.

Implications for further research

Our findings demonstrate the individual nature of understandings of depression, and the variety of self-management strategies used in a primary care population. Encouragement of self-help in a stepped care model as recommended in the UK's NICE guidelines may demand more than a blanket application of self-management tools; more systematic eliciting of these strategies may enable individuals to build on their existing strengths and move towards recovery more effectively. Further qualitative study in this population should focus more explicitly on self-management, and how the response of the primary care practitioner encourages or inhibits it. This may provide a basis for more targeted encouragement of self-help as part of a comprehensive approach in primary care. Secondly, it is likely that different belief patterns exist in groups not seen in this study, for instance, the black and minority ethnic population or those with chronic physical disease, so there is a need for study of beliefs in these populations also. A chronic disease management approach is becoming widespread practice for depressive disorder; qualitative study of how patients respond to this approach when first seeking help in primary care is important. The ambiguity of understanding symptoms as either a disease or a normal response may mean that an approach which is highly appropriate for those with established recurrent depression may be more problematic for those at first presentation, and chronic disease management strategies may need to be adapted in recognition of this.

Implications for practice

The research indicates the need to elicit patients' ideas about causes of depressive symptoms, ways of coping with them, difficulties caused by them, ideas about antidepressants and their ideas about positive aspects. We describe this in more detail in this section, assuming the interpretative phenomenological approach³¹ which underpins this study.

GPs are under increasing pressure either not to prescribe antidepressants for depressive symptoms or at least to delay prescribing⁶ but they also feel limited in alternatives.^{19,39,40} Eliciting patients' views about the causes of their depressive symptoms may be useful here, because the findings of the study suggest that often patients do not draw clear boundaries between their depressive symptoms and understandable emotional reactions to life experiences (which complements the known relationship between social factors in the cause and maintenance of depression).^{41–43} Having determined patients' views about causes, it should be easier to agree labels or diagnoses other than 'depression' which in turn should encourage the adoption of management strategies other than prescribing.

Listening to, and asking about, ways in which patients cope with their depressive symptoms in consultations should be helpful. For instance, eliciting ideas such as engagement with tasks and with other people, working at relationships and forcing oneself outwards may be appropriately encouraged in the initial consultations. Encouraging patients to talk about what is positive about their situation (such as support from partners, family or work mates), reinforcing any positive assessment and encouragement to work at positive aspects may also be an appropriate strategy.

Exploring particular aspects of what the patient finds difficult may also be important. For instance, listening to and acknowledging ideas and feelings about losing control, breaking down emotionally in front of others, losing one's mind and depersonalization could be helpful. In addition, asking about effects of the condition on others and listening to negative views about depression may be appropriate.

If antidepressants are being considered, then asking patients ideas about how they think they work, what worries they might have about them and the extent of the worries would seem important. The research would indicate that there is considerable variation between patients. Determining what an individual patient feels and believes about them should be important in decisions about treatment, particularly given the limited evidence for their effectiveness in primary care situations.

As patients begin to recover, exploring with them what they have learnt and other positive results of the experience—such as feeling stronger, knowing oneself better, being more aware of one's limitations, improved relationships and being better prepared for setbacks in the future—may be helpful and encouraging.

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