

# A qualitative study of patients' views on anxiety and depression

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## SUMMARY

**Background:** In the management of patients with anxiety and depression in general practice, the emphasis has been on improving detection and appropriate use of drug therapies by health professionals. Patients' own perceptions of their problems and what services they would prefer have not often been sought.

**Aim:** To explore patient perspectives in relation to their health-care needs in anxiety and depression.

**Design of study:** Semi-structured individual and focus group interviews.

**Setting:** A total of 27 patients from an urban four-partner group general practice who were identified as having anxiety and depression by a practice population questionnaire survey.

**Method:** All interviews were transcribed and the major themes were summarised using grounded theory analysis.

**Results:** Patients seek many different ways of coping with their problems but view their general practice as a focal point for help. Their experiences are dominated by the struggle to control unwelcome and intrusive thoughts and to live in a hostile and threatening world. They also have distinct preferences regarding their health needs and there is universal scepticism about drug therapies.

**Conclusion:** Patients describe personal and professional barriers to seeking help and have particular views on the treatment options. This perspective contrasts with the current professional emphasis on detection and drug use. This view is therefore central to informing the debate on management of neurotic disorders in primary care and on improving the care of these patients.

**Keywords:** anxiety; depression; drug therapies; patient preference.

## Introduction

ANXIETY and depression are two of the most common disorders in general practice. They often co-exist<sup>1</sup> and account for a significant workload in general practice.<sup>2</sup> A national survey<sup>3</sup> has shown a high prevalence of these problems (up to 10–15%) in the general population and yet there is continuing evidence of difficulties in the management of these patients. Controversy surrounds problems with detection of these disorders<sup>4</sup> and the appropriate use of drug and other therapies. Prescribing patterns show an over-reliance on benzodiazepines for anxiety disorders<sup>5</sup> and an increasing use of antidepressants but at sub-therapeutic doses.<sup>6</sup> Counselling as a specific therapy has increasingly been added to health care provision by general practices in the United Kingdom<sup>7</sup>, although the benefits remain unproven.<sup>8</sup> In recognition of these problems, initiatives have included the Defeat Depression campaign<sup>9</sup> and general practice education in mental illness.<sup>10</sup>

The perspective of the doctor on these problems has been considered in terms of detection and subsequent drug treatment. Yet in all these controversies the views of the patient have not been readily sought. This is surprising, given the vigorous debate on the contrast between biomedical and sociocultural definitions of these problems.<sup>11</sup> Since achieving objective and standard diagnostic definitions is problematic, one of the possible consequences is that neurotic problem definition or diagnosis relies on the personal experience of the individual patient or the individual doctor.

There have been studies seeking patient views in relation to various other health problems,<sup>12</sup> drug therapy,<sup>13</sup> and severe mental illness.<sup>14</sup> In neurotic disorders, such as anxiety and depression, there is a lack of such studies. The purpose of our study was to obtain the patients' perspectives regarding their illness and their expectations about how the primary health care team might meet their needs. Both individual interviews and focus groups were used to provide detailed information of experiences to obtain a collective picture of the provision of primary care services.

## Method

### Sampling patients for the qualitative study (Figure 1)

The interviewees for the study were derived from a larger quantitative questionnaire survey ( $n = 4002$ ) of a randomly selected 50% sample from an urban four-partner group general practice population. They were adults aged between 18 and 75 years, identified from the age-sex register of the practice. The project had ethical committee approval.

The Hospital and Anxiety Depression (HAD) questionnaire,<sup>15</sup> a validated instrument for use in the general population,<sup>16</sup> was sent to this population to self-complete. The

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Submitted: 15 December 1999; Editor's response: 27 June 2000; final acceptance: 30 January 2001.

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©British Journal of General Practice, 2001, 51, 375–380.

**HOW THIS FITS IN**

*What do we know?*

Anxiety and depression are common disorders in general practice and the current evidence-based emphasis in clinical management is placed on improving the detection of these disorders and the appropriate use of drug therapies.

*What does this paper add?*

Patients describe personal and professional barriers to seeking help and have particular views on the treatment options. There is particular scepticism of drug therapy but a preference for counselling and complementary therapies. These views contrast with the current professional emphasis in anxiety and depression management, and need to be considered if there is going to be an improvement in the care of these patients.



questionnaire consists of seven questions relating to anxiety and seven to depression, with scores ranging from 0 (non-case) to 3 (case) for each of the questions. Subjects were selected on the basis of two groups:

1. high anxiety score  $\geq 11$  and depression score 0 to 7, and
2. depression score  $\geq 11$  irrespective of the anxiety score.

There were 217 such case responders to the questionnaire. The case responders were sent a postal invitation for an interview.

There were 82 patients who agreed to an interview (a response rate of 37.8%). A total of 29 randomly selected patients completed interviews, either in an individual interview or a focus group format. However, two individual interviews were excluded because of audiotape-recording failure. Therefore, 18 individual interviews and two focus groups with a total of nine people (six in one group and three in the other group) were completed overall.

**Characteristics of the study practice and the study patients**

At the time of the project, the study practice had an on-site established counselling service that was accessed through referral by a GP. In terms of anxiolytic and antidepressant drug use, the study practice was prescribing at an annual rate of 10% lower than the district average; however, its trends were increasing annually (personal communication 2000).

In terms of age and sex the study group who consented to interview was comparable to the initial total sample of cases, although with a slightly higher median age (Table 1). Study subjects who gave consent for their computer records to be accessed had the records reviewed for the 12 months prior to the questionnaire survey. These records showed that the selected patients were frequent users of primary health care in terms of practice contacts and only one patient had had no contact in the 12 months prior to the survey. Out of the 27 subjects interviewed, the clinical data for the 12-month record review showed that 13 (48%) patients had a prior diagnosis of anxiety or depression disorder, 7 (26%) were had been on anxiolytics, 7 (26%) were on antidepressants,

and only two (7%) patients had seen a practice-based counsellor.

**Qualitative methodology**

*Researchers.* The co-ordinating researcher (UTK) was a general practitioner associate attached to the practice for two clinical sessions a week, who was not readily known to the patients. MH was a non-medical researcher who conducted the individual interviews (apart from one interview done by the UTK) and the focus groups were lead by JM, with UTK as the facilitator.

*Interview pilot.* A separate pilot stage was carried out prior to the actual study. A semi-structured postal questionnaire (response rate = 6/20), one focus group (six people) and two individual interviews (open-ended questions) were used to select the best method for interviews. The final method selected for the study was a semi-structured approach to individual interviews and an open-ended approach to the focus groups (Box 1).

**Interviews**

Interviews were audiotape-recorded with the patients' consent and were fully transcribed. Patients were assured that all expressed views would be anonymous and their participation would be kept confidential from the practice. At the time of actual interviews, neither the interviewers or the patients were aware of the HAD survey questionnaire scores. A combination of individual and focus group interviews was employed to enable the widest range of patient views to be expressed, and in particular to facilitate collaborative constructions of meaning around the topic of service provision.

*Individual interviews.* The aim of the individual interview

**Individual interviews**

1. If you can think of an occasion when you have felt 'stressed', please tell the 'story' of what happened — what lead up to the problem, what you felt during this time and who or what was involved? The word 'stress' could mean feelings of tension, wound up, anxious or mood which was low, tearful, or depressed.
2. When you had this problem, how did you cope with it or what help did you seek?
3. What sort of things made the problem worse or were not of any help?
4. In an ideal world what sort of help should be available? Are there any new ways of coping with problems that you have heard about and might want to try out, particularly in relation to the type of problem you described on the previous page?
5. At the time of your own 'stress' how could your own General practice have possibly helped?
6. Have you any comments or observations on this study?

**Focus groups**

We are here to discuss what sort of services, a general practice could provide for you, if you suffered from stress. The word stress could mean feelings of tension, wound up, anxious or mood which was low, tearful, or depressed.

Box 1. Interview questions and topics.

Table 1. Patient demographic characteristics and clinical contact in the 12 months before the HAD questionnaire survey.

	Distribution of females (males)	Age range in years (median)	Number of all practice contacts (median)	Number of GP contacts (median)
HAD survey cases (n = 217)	137 (80)	18–75 (48)	0–96 (10)	0–60 (6)
Consent to interview (n = 82)	52 (30)	18–72 (49)	0–96 (11)	0–60 (6.5)
Interview sample (n = 27)	18 (9)	31–69 (53)	0–79 (17)	0–28 (10)

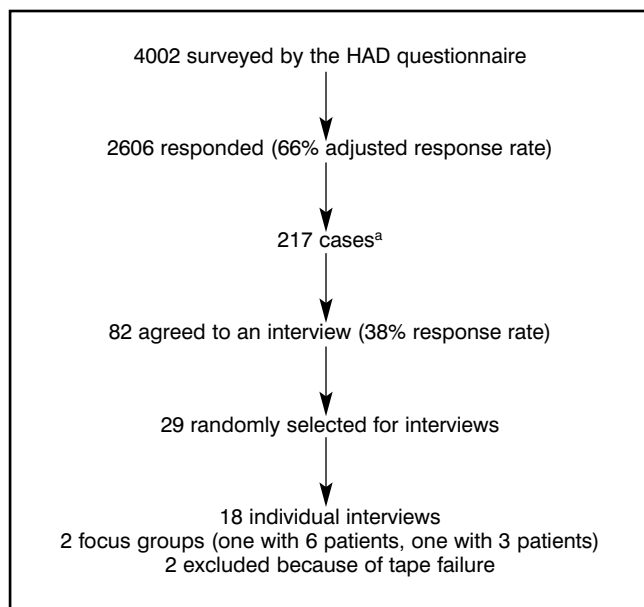


Figure 1. Sampling of patients for the qualitative study. <sup>a</sup>Cases as defined by (a) high anxiety score  $\geq 11$  and depression score 0 to 7 and (b) depression score  $\geq 11$  irrespective of the anxiety score.

was to provide an in-depth viewpoint based on personal experience, using an example of an event that made the patient suffer psychologically, and the factors which helped or hindered them at the time. In the postal invitation patients were asked to state their own choice of location for the individual interview, which could take place either at the patient's home or at the surgery. All those who agreed to interview (n = 18) chose to come to the surgery and the average length of each individual interview completed was 45 minutes.

**Focus groups.** The aim of the focus group was to obtain a clearer picture of the type of general practice-based services that a group of patients with anxiety and depression might want. There were two focus groups — one consisting of six, and one with three patients — and the interview length for both was approximately one hour.

### Analysis

Qualitative analysis using grounded theory methodology was used.<sup>17</sup> This involves detailed coding of transcript material leading to the identification of core categories that can be employed as a conceptual framework for understanding the views and experiences of research informants. In addition, the themes were identified as a result of an initial independent assessment by the three interviewers who subse-

quently reached a consensus agreement for these themes.

### Results

The interview and focus group formats were effective in enabling most of the research participants to talk openly about their perceptions of their problems and mental health needs. Only two of the interviewees appeared to be unwilling or unable to talk in detail or at length.

Our findings seek to explicate the most central themes, or core categories, emerging from analysis of the material. In this study using grounded theory analysis, the recorded individual interview material could be assigned to three main categories:

1. the struggle to control unwelcome and intrusive thoughts and feelings;
2. living in a hostile and threatening world; and
3. searching for sources of help.

The focus group material informed primarily on the last aspect of the three main categories: searching for sources of help.

### Core problems

All individual interviewees located external sources for their difficulties; for example, conflict with work colleagues, chronic illness or events in childhood. They were clear that the challenge in their everyday life was not that of dealing with the cause of their problem, but of coping with the thoughts and emotions associated with it.

A woman who had experienced harassment at work reported that:

*'I couldn't get into the car to drive to work ... and even when I got to work and got into the office, I would just sit there and cry.'*

A male informant stated that:

*'I get terrible pains in my chest, and they build up, and the biggest problem is, same as coming here today, for the last hour waiting to come, it builds up in me and I get, you know, I get real, what I think is physical pain in my arms, my shoulders, my chest, I have headaches at the back of my head, and it just builds up.'*

Metaphors were often used to communicate these experiences: 'on edge', 'churned-up inside', 'boxed in', 'a volcano bursting', 'broken in half', 'shut in my own little shell', 'a wall of pain', 'prisoner in my own home'. These metaphors convey the sense of struggle that pervaded the lives of these people. Several talked about 'fighting' their unpleasant

thoughts and emotions. It was as though they were in a battle with parts of themselves.

The struggle generated individual strategies for controlling feeling. A common theme here was the use of distraction techniques to avoid thinking or feeling. One man, unable to sleep, worked late into the night on hobbies. A woman 'smoked her head off'. Another tried to 'think nice thoughts'. Several informants reported that there were particular places where they felt safe and in control — their garden, their car, and the countryside. The bathroom was experienced by some as an asylum and pets were regarded more as helpful 'friends'. Other forms of distraction described were reading, music, housework, and watching television. These methods were not seen as solutions but as forms of respite.

### Social context

Although many perceived close family members (e.g. their spouse) to be supportive, and several described their GP as 'marvellous' or 'has never let me down', there was nevertheless a strong sense that people in general were not sympathetic to their difficulties. Psychological problems were described as being invisible and hidden, in contrast to medical conditions that could be more readily admitted to others or even observed at first hand. Many believed that other people, even family members, just did not want to know. For example, a woman recounted that when she felt a panic attack coming on:

*'I go to the bathroom and then when I come back he says "where have you been?" I've been to the toilet. "You have been a long time." So trying to hide ... (the attacks). He thinks it's stupid. It makes you feel ashamed.'*

Many informants mentioned the experience of shame and embarrassment. They described their problems as 'trivial' in the eyes of other people. Over and over again responders described situations in which other people had told them to 'pull themselves together'.

One interviewee, reflecting the sentiments of many others, was clear that this kind of suggestion made her feel very angry:

*'...the worst thing you can say to someone is to pull yourself together ... because they don't know what they're talking about ... they just don't understand.'*

What is significant here is the experience of living with a troubled and painful inner world, but with little expectation that these thoughts, feelings, and images will be acceptable to other people, or understood by them. There was a pervasive theme of being different from other people — apart, isolated, and locked away.

### Sources of help

What was very striking was that most of these people had been active in searching out different forms of therapy. Apart from GP referrals to counselling, clinical psychology, hypnotherapy, and psychiatry, many of them had on their own initiative made use of a range of therapies: acupuncture, relaxation tapes, self-help books, exercise, self-help groups, reflexology, aromatherapy, and analytic psychotherapy. The

picture was not one of a group of people who were passively accepting their condition. The majority were doing their best to live a full life, and were open to suggestions (from their GP or elsewhere) regarding ways of making life better.

Within the broad category of searching for sources of help, it was possible to identify three subsidiary categories: (a) someone to talk to, (b) issues around access, and (c) attitudes to medication.

(a) *Someone to talk to.* All participants, both individual interviewees and the focus group members, believed that it was helpful to be able to talk to someone about their problem. It was widely regarded as desirable to be able to talk to someone outside of the immediate family situation; preferably someone who was not directly involved in the problem. The other advantage of talking to someone external was that this was seen as reducing the possibilities for gossiping. They were looking for someone who might understand them, might offer some perspective on their difficulties, and who might be able to suggest ways of coping. A number of interviewees specifically associated these qualities with professional counselling. However, others suggested that what they were ideally looking for was a person who could draw on personal experience of their type of problem, someone who had been through the problem and got better. The search for someone to talk to was seen as difficult. There was a wish that more could be done to make it easier to make the connection; for example, by the GP being more active in referrals or the counsellor checking on the progress made by their clients through 'phone calls, follow-up sessions, and home visits.

(b) *Issues around access.* Informants also raised a number of issues around access to a counsellor/listener. Some saw their GP as being willing to listen to their problems and refer you on to 'someone to talk to'. Quite a few others had reservations about approaching their GP with this type of problem. Many of them regarded their GP as being too busy to spend time on such 'trivial' matters. There were worries about taking the GP away from more pressing medical cases. Some, as mentioned above, had little hope that the GP would do any more than prescribe drugs. Several informants, particularly in the focus groups, observed that there was a lack of invitation or encouragement of disclosure of emotional or psychological problems. The importance of these sensitivities over access should be taken in the context of the sense that many of these people had of living in a hostile, threatening world in which other people would not take their problems seriously. One woman, referring to consulting her GP, summed all this up well:

*'It is as if you are making a fuss really ... and you don't have very long to actually speak to them, they have only got a certain time. So you haven't got enough time to actually, you know, make them understand and for it to come across exactly how you feel.'*

Another salient issue about access concerned waiting times. Interviewees argued that when they were feeling bad, they needed to speak to someone at that moment, and not wait days or weeks for an appointment.



(c) *Attitudes to medication.* All the interviewees had much to say about their attitudes to medication. All of them had, at some stage, discussed drug therapy for their emotional problems. Only one reported unequivocally that medication had been helpful. Some others acknowledged that tranquilisers and antidepressants had been useful in permitting them to cope with short-term crises. The majority, however, were critical of drug interventions. Some typical statements were:

*'I was prescribed Valium but didn't take it — it just suppresses the problem.'*

*'As soon as I stopped them I'd be ill again.'*

*'I don't want to be on tranquillisers ... don't mind now and again, just to calm me down if I do get a little bit over the top .... (but) it's not a remedy for anybody.'*

*'To me taking drugs is an admission of failure ... just mask the symptoms.'*

*'I don't want my wits dulled by medication.'*

*'They just dish out antidepressants.'*

*'Have never believed tablets do you any good at all.'*

These patients did not, in the main, perceive medication as an effective response to their distress. Moreover, some implied that they had felt 'fobbed-off' by their GP by being given a prescription. One woman said that she avoided her GP at the time of her greatest stress because he 'would only have given tablets'.

## Discussion

### Study findings

The patients identified to be anxious or depressed for this study were derived from a randomly selected population survey. The final qualitative sample were, on average, older and also more frequent users of practice-based services compared with all cases identified by the HAD survey. From the record review of the 12 months before the survey, at least half had had a diagnosis related to anxiety or depression and one-quarter had had a related drug treatment; however, only two patients had had counselling. The study thus reflects a broad patient perspective, among both those with and without a previously recorded medical history.

The individual interviewees, through their personal histories, describe the inner struggle that they face in dealing with the psychological distress they suffer from. This mind-state not only exacerbates their problem but also creates a 'barrier' to seeking help. It results in problems coping with the routines of everyday life, with the persistence of symptoms, and with the sense of failure in being self-sufficient. While they were active in searching for sources of help, interviewees found it difficult to summon enough courage to disclose their distress, as they perceive themselves to be a relative nuisance compared with people with physical problems.

The people interviewed in this study on the whole regarded their GP as an independent and key resource in their search for help in relation to their psychological problems. However, they often found it difficult to talk to their GP about

these problems and would have liked more proactive information and 'permission' to disclose mental health problems. These patients believed that they needed someone who would listen to their problems, and help them to gain understanding, to put their worries and fears in perspective. They were sceptical of the benefits of drug treatments for anxiety and depression while being open to the value of complementary therapies, such as reflexology and hypnotherapy. Most of the people interviewed held firm treatment preferences, and reported that they were unwilling to comply with interventions they perceived as unhelpful or irrelevant. The key attributes of treatment preferences were more time and faster access.

The findings of the study identified three practical issues that could be examined in further research and which also show the contrast between the health care that is available and recommended and that which the patients would prefer.

First, further research is needed on the degree to which patients perceive the GP environment as encouraging them to communicate mental health needs. Several studies have shown that GPs fail to detect a significant proportion of cases with psychological and psychiatric distress<sup>4,18,19</sup> and that GPs find such consultations difficult to address in routine consultation times,<sup>20</sup> with added difficulties in distinguishing between symptoms of somatisation and psychiatric illness.<sup>21</sup> In our study, patients revealed the extent of their problems through a self-report questionnaire, but often could not communicate them with their doctor. This finding has been supported by a recent study exploring patients' reasons for not presenting emotional problems in general practice consultations.<sup>22</sup> It may be that relevant information displayed in waiting rooms could increase reporting of psychological symptoms and referral to appropriate sources of help.

Second, research is needed on the way that counselling services are delivered in primary care settings, as patients perceive specialist counsellors to be more skilled than general practitioners in this activity and also able to give more time. Although only two patients in our study had had recorded experience of counselling, most participants perceived it as a preferred therapy despite their lack of actual experience of it. Most counsellors in primary care offer assessment and a restricted number of office-based sessions of individual counselling following referral from the GP. The evidence from the group of highly distressed patients surveyed in this study was that these arrangements do not meet their needs. Many of them have a sense of being 'imprisoned', 'different' and 'misunderstood' and seek services (telephone counselling, opportunities to meet with 'survivors' of their affliction, targeted groups, home visits) that do more to reach out to them. The concept of counselling seems to be an accepted and valued part of the patient's perception. Yet evidence-based studies suggest that the generic form of counselling is of uncertain value but that specific forms of psychotherapy, such as cognitive therapy, may be more preferable.<sup>23-25</sup>

Third, these findings highlight the need for further research into patients' perceptions and experiences of psychotropic medication. All participants expressed that drug therapy had previously been discussed with their GPs, although only one-quarter had had an actual prescription for

psychotropic drugs in the previous 12 months. Although there exists considerable evidence for the efficacy of drug treatments for psychological disorders,<sup>26,27</sup> many patients in this and other studies<sup>13,28</sup> are highly resistant to drug therapies. They appear to agree that drugs can be effective in helping to control symptoms, such as painful thoughts and feelings. However there are major patient concerns about the underlying meaning of drug use. This perception of drug therapy, particularly in the case of antidepressants, has a significant implication and poses a great challenge to general practice. While current guidelines recommend the use of effective drug therapy, patients may not be compliant with their treatment unless their role is explained fully. The reluctance of patients to accept drug therapy may perhaps explain why GPs frequently use suboptimal therapies<sup>6</sup> and why drug compliance is an issue.<sup>29</sup> Thus better patient education about drug therapy is required in addition to existing initiatives designed to improve GP use of psychotropic drugs. The possibility also needs to be explored that counselling, which is acceptable to patients, may offer an innovative role in drug therapy education of the patient as well as its conventional role in teaching life-coping skills.

### Study limitations

The views reported by the patients in our study reflect the experiences of people who live in a particular provincial city and have been influenced by contact with a particular set of GPs. In most qualitative studies, there is an element of self-selection and thus bias, as patient participation is dependent on voluntary consent. To minimise such an effect we chose to derive our study sample from a population survey, so that the study was not wholly dependent on patients who had been diagnosed or treated by GPs. Our investigation thus represents the beginnings of an attempt to capture the perceptions and 'voice' of primary care service users suffering from psychological and emotional difficulties. It is however plausible that those who agreed to participate in the research held views (for example, of drug treatment) that were not representative of all those who were invited to take part. The sample should be seen as providing insight into the perceptions of a significant group of users — but not necessarily all users.

### Acknowledgments

We are very grateful to all the patients who took part in the study and all the staff of the study practice. We would also like to thank Sue Hodgkinson for transcribing the interviews. Rob McCarney helped to develop and administer the population survey.

We are also grateful to the North Staffordshire Health Authority for supporting the Research Registrar post (UTK) during which the study was completed, and the Royal College of General Practitioners (Scientific Foundation Board Grant) for funding the qualitative study.

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