

Patients' ambivalence about taking antidepressants: a qualitative study

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AIM • To understand patients' views and experiences of taking antidepressants.

DESIGN • Qualitative semi-structured interview-based study.

SUBJECTS AND SETTING • 32 primary care patients recently diagnosed with mild to moderate depression who had received care from one of 19 GPs or two practice counsellors at general medical practices in Shropshire.

RESULTS • Respondents had a range of attitudes towards antidepressants initially. These were not fixed and changed over time in response to their experience of

treatment. Uncertainty about the usefulness of antidepressants prompted some patients to test their efficacy by stopping their tablets. Others were afraid to stop even after finishing the course of treatment in case their symptoms returned. Psychological dependency became a concern for some patients. Although antidepressants could prove helpful in the short term many respondents were uneasy about taking them long term.

CONCLUSIONS • Health professionals need to be aware of patients' changing and varied views about taking antidepressants when advising them on treatment options for mild to moderate depression. In particular some patients discover antidepressants can hinder rather than facilitate the possibility of recovery.

Depression is a common diagnosis in Britain.¹ Most of the medical care of patients with depression is carried out in primary care¹ and 75 per cent of the time treatment includes an antidepressant.² Selective serotonin reuptake inhibitors (SSRIs) are the most commonly prescribed antidepressants. Between 1996 and 2001 prescribing of these drugs in primary care rose by 143 per cent amounting to £55.5m in the quarter to June 2001.³ Tricyclics are the other main group of antidepressants prescribed at a cost of £10.8m in the same quarter.³ Non-compliance with treatment is estimated to be in line with other medication at 50 per cent.⁴ The professional response to non-compliance centres on engineering change to patient behaviour through education and information programmes such as medication counselling or the provision of information leaflets.⁵⁻⁷ This approach assumes the superiority of professional models of treatment for depression. However, the notion that patient non-compliance results primarily from an easily rectifiable information deficit,⁸ is increasingly challenged in recent government policy documents,^{9,10} by some professionals¹¹ and also by the rapidly growing and diverse body of user organisations and self-help groups.^{12,13} A radical change in professional culture is advocated through a shift from the outmoded paternalism of compliance to concordance as a more effective and progressive model for the relationships between health care workers and their patients.¹⁴

Concordance recognises that both professionals and patients bring different but equally valid knowledge and experience to the consultation. The success of clinical encounters depends on how well these different understandings can be shared and used as the basis for negotiation and joint

decision making about treatment. Concordance recognises that patient defined health care outcomes may not correspond to those of professionals, and that they may be informed by different goals and values.

Patient understanding of illness and aspirations regarding treatment are under-researched topics across the whole spectrum of illness. However, this deficit is particularly marked in relation to conditions involving mental distress such as depression.¹⁵⁻¹⁷ Although non-compliance with antidepressants has been extensively studied,^{4,18} little has been written about patients' initial attitudes to treatment or how their experience of taking antidepressants influences their medicine taking behaviour. This is despite recognition that patients' beliefs and attitudes are probably a greater cause of non-compliance than their experience of side effects.^{2,19}

This article reports findings from an extensive qualitative investigation of how patients and health professionals recognise depression and the extent to which these different groups share an understanding of depression and its treatment.

METHOD

Design The patient data reported in this paper are part of a larger qualitative study²⁰ which compared the perspectives of three groups of respondents:

- Thirty-two patients diagnosed with mild to moderate depression who were

being treated in primary care — the paper draws predominantly on these data

- Thirty experienced and self-help oriented sufferers from depression who were recruited from the regional membership of the Depression Alliance, a leading voluntary organisation supporting sufferers from depression
- Nineteen GPs and two practice counsellors

Data were collected through qualitative interviews. The patient respondents were interviewed twice: a follow up interview was carried out six months after the first. The research was approved by Shropshire Research Ethics Committee.

Sample GP practices were purposefully sampled to cover a range of rural, suburban and urban settings. Nineteen GPs and two counsellors from nine practices agreed to take part, and recruited the 32 patient respondents whose experience of taking antidepressants is reported in this paper. Details of patients' ages, sex, socioeconomic status are given in Tables 1 and 2. At the first interview 25 of the 32 patients were taking antidepressants. At the follow-up interview, 16 out of 30 patients were taking antidepressants (two follow-up interviews were not completed — one patient died and another moved out of the area).

Research interviews All interviews with patients took place in the respondents' homes. Most of these lasted about one and a half hours, with a range from 40 minutes to two and a half hours. Interviews were loosely structured around a topic list, which served as a prompt for the interviewer to cover a range of core issues relating to respondents' ideas about the causes and

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diagnosis of their problem, and their experience of treatment. Neither the order of topics nor the wording of questions was standardised. This paper presents findings relating specifically to the patient group of respondents.

Analysis All but three of the patient interviews were taped and fully transcribed for content analysis using the NUD*IST qualitative data analysis software program. One patient did not want either of the interviews to be taped. One other interview was not recorded owing to technical failure. These interviews were transcribed from extensive notes made during and immediately after the event, and the notes were subsequently incorporated into the NUD*IST database.

Coding categories were developed initially from identification of themes arising from scrutiny of the interview transcripts and field notes and refined subsequently through an iterative process of reflection, scrutiny of the transcripts and discussion between the researchers.

RESULTS

Initial views and responses of patients towards antidepressants Patients had a wide range of views initially. In some cases, respondents had anticipated or readily accepted a diagnosis of depression and had expected or even desired that antidepressant treatment would be offered.

[When I was prescribed Prozac] it gave me a bit more of a lift really. I thought good, I was pleased. I didn't ask for Prozac. I didn't go in and say I think I need Prozac, I wouldn't have dared to do that. (Patient 301: first interview)

Other respondents had not anticipated a diagnosis of depression and the prescribing of antidepressants. Some were relieved to be taken seriously by their GP, and to be given a clear diagnosis for their problems and told that there was a non-addictive, effective treatment for their illness.

I thought he [GP] might laugh at me and say: "Clear off and pull yourself together." But he didn't, he was highly sympathetic. He's obviously had cases of it before. I burst into tears in his surgery by the way. Anyway once I'd taken the first couple [of antidepressants] — I took two at a time to start with — after I'd taken the first couple I thought, "Well, I'm going to get better now aren't I?" and that was reassuring as well. Now that's psychological isn't it? (Patient 405: first interview)

Others were not so sure, and resisted or even rejected the diagnosis of depression and treatment with antidepressants, at least in the short term.

*A: I thought that he [orthopaedic specialist] would offer me some more physiotherapy.
Q: Right and he was also the one at this point that said you were depressed?
A: Yes. Here's some Prozac. Like, you know, how could he tell I was depressed? I don't know*

TABLE 1: AGE AND SEX OF PATIENTS

	<20	20-29	30-39	40-49	50-59	60-69	>70	Total
Male	0	1	2	2	1	3	0	9
Female	2	3	3	8	5	2	0	23
Total	2	4	5	10	6	5	0	32

because he never asked me any questions. (Patient 403: second interview)

You hear different rumours about antidepressants. We [patient and wife] weren't too sure whether that was the right way to go. (Patient 409: first interview)

The prescription was there [in the house] thinking you are depressed. I think that it was, I didn't want to accept that I was maybe erm — and I was [laugh] — it is difficult to describe how I felt but yes I held on to it for a couple of weeks before I decided to go [to the pharmacy]. (Patient 404: second interview)

Changing attitudes in light of experience

Whatever their starting position, respondents' initial attitudes were often modified in the light of further knowledge and experience of antidepressants. Some patients, even if initially they had felt reluctant, were quite positive in their assessments of antidepressants as an effective and acceptable treatment in the short or more rarely in the longer term.

I feel very good, very positive. I am actually amazed the effect it [antidepressant] has had and I think it has been helped because I was taking St John's wort. (Patient 401: second interview)

A few were put off by unpleasant side effects even if initially they were optimistic about the potential benefit of taking antidepressants.

I'd read about this Prozac and he [GP] talked to me about antidepressant tablets for quite some time. Well I thought after 14 days I was going to start and feel better and after six months I thought I was going to be a new man. But after nine days of taking them and I just knew that I couldn't manage to take them for a 14 day period. So I thought I couldn't stand that, I never ate anything for about five days and I mean I am only skin and bone as it is. (Patient 402: second interview)

This experience was the trigger for this respondent to decide against drug treatment and use self-help methods. Other respondents were perplexed by the lack of any noticeable effect, therapeutic or otherwise after taking antidepressants.

You can't feel them working in a sense. I've not experienced any euphoria or anything like that, so I don't really know if they are working. I just know that I'm getting better and I'm wondering what's causing it. (Patient 407: first interview)

Consequently, when people began to feel better it was often hard for them to pinpoint the cause of their recovery or disentangle the effects of antidepressants from other factors, such as changes or improvements in their personal circumstances, or

TABLE 2: SOCIAL CLASS OF PATIENTS

Social class	Number of patients
1 (professional occupations)	2
2 (management and technical)	12
3 (skilled non-manual and manual)	10
4 (partly skilled)	6
Student	2
Total	32

even simply the recuperative passage of time. This left them uncertain about whether, or how much, antidepressants had contributed to their recovery.

I felt they [antidepressants] were [effective] to begin with. It is just recently I am beginning to think is there any benefit in taking them any longer — what would happen if I didn't take them? (Patient 409: second interview)

Some people experimented to discover the effects of stopping antidepressants. This may start as "forgetting" and become more deliberate if they found they suffered no adverse effects or it may be stopping with intent from the outset.

Others began to worry about what would happen when they ceased treatment, and even if they wanted to stop treatment preferred to play safe and keep taking the tablets, rather than risk a relapse after giving them up.

I sort of changed the way I was thinking about it because I didn't want to take them initially, and I wanted to stop taking them as soon as I started to feel better. But then I think I was feeling so much better, was feeling so good and I was coping and everything. I am thinking this is fine and if I stop taking them I might not feel like this and that was the quandary really. (Patient 312: second interview)

Overall there was a wide range of responses to antidepressant treatment and many were characterised by shifting perspectives, ambivalence and uncertainty.

Attitude to length of treatment Respondents were often able to accept the short-term use of antidepressants to provide a temporary support and "kick start" the process of recovery.

I have a natural aversion to taking medicines but by the same token I had no hang up about taking this [antidepressant]. But you don't live your life taking tablets — so there will come a time when I won't be taking them and that's fine. They've been a bit of a crutch for now. (Patient 304: first interview)

However, few were entirely sanguine about the prospect of remaining on tablets long term or even indefinitely.

I suppose I didn't feel happy taking them really, you know perhaps I thought I didn't know how much control they were having over me. You know: how effective were the other [self-help] things that I was doing or whether it was the tablets that were making me feel better. (Patient 309: second interview)

Even within the small group that were more accepting of long-term use there was still a degree of ambivalence.

Having a higher dose of the tablet than I had been taking works and it works so brilliantly and it is like almost [in] the instant. And I really know if I miss one and, as I say, I find that scary in a way because I would like to think that I have actually got the power myself to make those changes and that it doesn't have to be drug dependent. But then if it works I am not going to knock it. (Patient 306: second interview)

Respondents' anxieties centred on uncertainty about their future ability to cope independently without the use of antidepressants.

But I don't feel that I have been able to talk to him [GP] enough to say: "Look, okay I am going to have to accept that I do get these lows. And I know that once I start taking the tablets I start to feel better but I don't want to suddenly think, yes, there is going to be a crisis coming up in my life and I can't cope so I had better go and get these [antidepressants]". (Patient 410: second interview)

When starting to prescribe GPs often made a point of reassuring patients that antidepressants were not addictive. However, the GPs were largely unaware of the complexity of many patients' responses to antidepressants, or that their concerns over time were usually focused much more directly on psychological rather than physical dependency. Psychological dependency led to patients questioning their own identity.

I just feel it is not really you, is it, if you have to get through each day by taking pills really. It is not really me. Whereas if I had a physical thing I had got to take it for, I would need to take those to live sort of thing, just to keep the symptoms at bay or whatever. I know it is the same, but I cannot think about it the same. (Patient 312; second interview)

Feeling they were relying on a drug rather than themselves to get by was not positive. They were perched on the horns of a dilemma. On the one hand they wanted to carry on taking antidepressants if it kept symptoms at bay but on the other they felt themselves to be a weaker person in doing so and desired to "sort themselves out" without recourse to drugs. Because health professionals were not usually aware of psychological dependency they were unable to discuss this as a potential issue with patients at the time of prescribing or during follow up.

DISCUSSION

Summary of main findings Patient respondents being treated for mild to moderate depression had a range of attitudes

towards antidepressants initially. Their attitudes were not fixed and changed over time in response to the experiences they had of taking them. Uncertainty about the role of antidepressants in recovery led some patients to experiment by stopping treatment early and others to worry about what would happen when they finished treatment according to plan. Discontinuing an antidepressant could be undertaken as an experiment to test the efficacy of the medicine and to discover the extent to which the tablets were still needed. Rather than seeing such non-adherence as an obstacle to effective treatment¹⁸ it should be viewed in a positive light as evidence of patients trying to take control of their own recovery. Although antidepressants could be helpful in the early stages of depression few respondents were pleased at the prospect of taking them in the long term. Feelings of psychological dependency on the medication contributed to their ambivalence about sustained use.

Relevance to existing professional views

Patients' original concerns about becoming physically addicted to antidepressants often changed to anxiety about psychological dependency. Patients were not forewarned about the risk of this development and so could not anticipate how they might feel about it. The issue of psychological dependency has been raised by others^{16,21} but has not featured strongly in medical perceptions of patients' concerns about antidepressants.⁵ Respondents' feelings about psychological dependency concur with findings of other studies that report a similar fear of stopping the medication and of the need to restart it in the future not only if problems arose or symptoms returned but also in anticipation of these events.^{15,16} Antidepressant consumption takes place in the context of a cultural norm that tablet taking is generally undesirable. Psychotropic medication, especially taken in the long term, attracts particular suspicion. In signalling a personal fragility and incapacity to cope it undermines the personal autonomy that remains a fundamental attribute of adult status in contemporary society.²² Respondents assess their use of antidepressants in terms of their perceptions of the social acceptability of using these drugs, and for how long, and how they feel that other people will view them as a result. In this way the use of antidepressants could give rise to lingering doubts about the individual's capacity to cope in the future, and even place in jeopardy the prospect of "recovery".

Strengths and limitations of the study

The respondents in this study constitute a self-selected sample and we do not know if they differed substantially from those who did not respond. We assumed that patients who were more severely ill, had opted out of treatment or were of lower socioeconomic status were less likely to take part. As this was a qualitative investigation respondents do not constitute a representative sample, but their accounts illustrate the wide range of views and experiences of patients with depression.

It is likely that the patients who took part in the study would be oriented towards the more positive end of the spectrum of satisfaction with their GP and counsellors and with the treatment they had received. In this case, it is noteworthy that so many gave a clear expression of their uncertainty about the effectiveness of antidepressants and their ambivalence about taking them. Interviewing patients in depth for a second time after six months enabled us to see that experience of treatment with antidepressants gave rise to complex issues for patients that were not anticipated at the outset. Patients' doubts and uncertainties do not simply resolve as a result of professional reassurance and early experience, but may develop and intensify with the passage of time.

Implications for clinical practice

Patients lack opportunities to discuss antidepressants with GPs on an ongoing basis once treatment is initiated. Our study indicates the range of concerns that arise and how these may change over time throughout the period of treatment. Pharmacists are well placed to provide this kind of support, have been enjoined to do so, and are supposedly keen to extend their role in this direction. But as a related study²³ has shown, rather little discussion seems actually to take place in the pharmacy. Once a patient has received a prescription for antidepressants pharmacists confine themselves to reinforcing their perception of the GP's position, rather than engaging with or listening to and addressing patients' concerns. Findings like ours should help pharmacists as well as other health professionals to increase their understanding of patient experience of and concerns about antidepressant treatment, and to provide more effective advice and support as a result.

Greater awareness among doctors, pharmacists and nurses about the nature of patients' feelings about taking antidepressants would enable them to engage in a more focused and productive discussion with them about the pros and cons of taking antidepressants as opposed to other types of therapy and support.²³ This, in turn, would help patients to make a properly informed choice of treatment. Focusing on concordance between patient and doctor in relation to treatment decisions from a long-term perspective for mild to moderate depression, rather than on compliance with medication in the short term, offers the opportunity to develop treatment plans that will help patients recover on their own terms. This entails working from patients' perspectives in respect of their definition of problems, rather than those ascribed to them from a biomedical perspective.

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BRITISH PHARMACEUTICAL CONFERENCE

New ways of involving patients

One of the last sessions at the British Pharmaceutical Conference focused on concordance. Olivia Timbs reports

The session opened with Joanne Shaw, director of the Medicines Partnership, explaining why there was a need for a new approach to prescribing and medicines taking. It is established that as few as a third of patients with arthritis, for example, comply with their drug therapy. In addition, although patients' beliefs are a strong predictor of whether or not they take medicines, patients' views are rarely sought during a consultation. Ms Shaw pointed out that if prescribing and medicine-taking are based on a partnership between health professional and patient, then there is a greater likelihood that the patient will comply with the treatment, which is therefore more likely to be effective. Ms Shaw went on to describe some of the initiatives that the Medicines Partnership is supporting.

Professor Theo Raynor, of the department of pharmacy practice, University of Leeds, then spoke about the three steps to concordance: patients having enough knowledge to participate as partners; consultations that involve patients as partners; and, as a result, patients who are supported in taking their medicines. One way to improve

patients' knowledge is to improve the quality of information they receive both about their condition and their medication. The problem with current drug information leaflets is that they are too narrow, too negative and they are often pointless, as they are handed out at the end of the consultation and are likely to confuse patients rather than illuminate them. Involve patients in the compilation of guides and they are likely to be much more useful, Professor Raynor argued.

David Dickinson, of consumer information design consultancy, Consumption, gave an outline of what "Ask About Medicines Week" (12 – 18 October) is about and ways in which pharmacists could be involved. Mr Dickinson pointed out that the week should not be regarded as an end in itself, but rather as laying the foundations for lasting change by encouraging better communication between health professionals and people taking medicine.



David Dickinson: Ask About Medicines Week will lay the foundations for lasting change

The final speaker, Diane Harris, from Amber Valley Primary Care Trust, Derbyshire, described a project involving pharmacists from five different PCTs. Older people who were housebound and who had difficulty in managing their medicines were visited by a pharmacist to assist them in taking their medicines. Interim analysis of the project reveals that four months after a pharmacist's visit benefits were being seen.

Only about 10 per cent of patients were still having problems taking their medicines, three-quarters of patients or their carers were better at remembering to take them (both improvements on previous findings) and there were fewer problems with medicines hoarding. As one pharmacist involved in the project said: "Part of the reward is knowing that you have facilitated concordance by empowering the patients and making sure that you have listened to their beliefs or perspectives about medicines."