# **BMJ Open** Starting antidepressant use: a qualitative synthesis of UK and Australian data

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#### ABSTRACT

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Professor Claire Anderson; Claire.anderson@nottingham. ac.uk **Objective:** To explore people's experiences of starting antidepressant treatment.

**Design:** Qualitative interpretive approach combining thematic analysis with constant comparison. Relevant coding reports from the original studies (generated using NVivo) relating to initial experiences of antidepressants were explored in further detail, focusing on the ways in which participants discussed their experiences of taking or being prescribed an antidepressant for the first time.

**Participants:** 108 men and women aged 22–84 who had taken antidepressants for depression.

**Setting:** Respondents recruited throughout the UK during 2003–2004 and 2008 and 2012–2013 and in Australia during 2010–2011.

**Results:** People expressed a wide range of feelings about initiating antidepressant use. People's attitudes towards starting antidepressant use were shaped by stereotypes and stigmas related to perceived drug dependency and potentially extreme side effects. Anxieties were expressed about starting use, and about how long the antidepressant might begin to take effect, how much it might help or hinder them, and about what to expect in the initial weeks. People worried about the possibility of experiencing adverse effects and implications for their senses of self. Where people felt they had not been given sufficient time during their consultation information or support to take the medicines, the uncertainty could be particularly unsettling and impact on their ongoing views on and use of antidepressants as a viable treatment option.

**Conclusions:** Our paper is the first to explore in-depth patient existential concerns about start of antidepressant use using multicountry data. People need additional support when they make decisions about starting antidepressants. Health professionals can use our findings to better understand and explore with patients' their concerns before their patients start antidepressants. These insights are key to supporting patients, many of whom feel intimidated by the prospect of taking antidepressants, especially during the uncertain first few weeks of treatment.

#### Strengths and limitations of this study

- While much has been written about adherence, compliance, and patient meaning-making in relation to taking antidepressants over the full course of treatment, researchers have neglected the critical period of when patients start treatment with antidepressants.
- This paper focuses attention around the time people experience being given their first antidepressant prescription and when they contemplate taking their first dose. Our paper seeks to illuminate patient experiences in a manner that encourages health professionals to better consider what patients go through explicitly, so that better decision-making and care in the crucial early stages of antidepressant treatment can be advanced.
- While our study contributes important information, it must be considered in the light of a number of study limitations. Only people willing to talk about their depression or taking antidepressants were interviewed and many of the participants regarded themselves as being in 'recovery', and so were doing relatively well.
- While the study does not claim numerical representation (this is not the purpose of maximum variation sampling), our sample reveals a wide range of experience and complexities about experiences of taking antidepressants in the UK and Australia.
- Full details about individual's prescribed medicines in this study were not available as they were not originally collected.

### **INTRODUCTION**

Receiving a prescription for antidepressants for the first time is a significant event and frequently a worrying time for patients. During a consultation leading to an antidepressant prescription, patients may experience difficulty absorbing the information given,<sup>1</sup> and they may hold preconceptions about the treatment based on their own and other people's beliefs, their past experiences with medicines, and the quality of their relationships with healthcare providers.<sup>2</sup> Patients may be concerned about side effects they might experience well before they experience any therapeutic effects.<sup>3</sup> The extent to which patients accept their diagnosis and prescription of antidepressants at the early point of consultation with health professionals is critical in determining their ongoing adherence to medication in the future.<sup>4</sup> Factors thought to explain whether a patient starts or continues to take antidepressants include: beliefs about illness; resistance to viewing depression as an illness and the associated lack of belief about the need for antidepressants; and concerns about addiction and dependency.<sup>5</sup> <sup>6</sup> Patients' resistance to medicines for chronic physical conditions such as diabetes, hypertension and epilepsy is founded partially on the threat medication poses to selfintegrity,<sup>7 8</sup> and the difficulties surrounding acceptance of medication for psychological disorders involves additional complexities, for example, fears about loss of an 'authentic' self.<sup>9</sup><sup>10</sup> Equally, if a meaningful decisionmaking relationship between practitioners and patients is routinely difficult,<sup>11 12</sup> these and other difficulties may be exacerbated by symptoms of depression, for example, impaired cognitive ability to engage in decisionmaking.<sup>13</sup> While much has been written about adherence, compliance and patient meaning-making in relation to taking antidepressants over the full course of treatment,<sup>14-16</sup> researchers have neglected to examine in-depth the critical period of start of treatment with antidepressants.

#### **STUDY DESIGN AND METHODS**

This paper combines data from three qualitative research studies that we conducted in the UK (studies (1—UKa) and (3—UKb)) and Australia (study (2); total sample size n=114). We conducted all three studies using an agreed set of rigorous strategies and guidelines, based on methods developed by the Health Experience Research Group (HERG) at Oxford University.<sup>17</sup> The main focus of (1) and (2) was 'Experiences of depression'. Interviews were conducted (1—UKa) in the UK in 2003–2004 (n=38) by DR and (2) in Australia in 2010–2011 (n=40) by RK and colleagues. In (3—UKb) interviews were conducted in 2012 in the UK by SK (n=36) with a specific focus on 'Experiences of using antidepressants'. For demographic details (age and ethnicity) please see tables 1.

Ethics approval for the original studies was granted by Berkshire Research Ethics Committee (multi site recruitment) in the UK, and in Australia by Monash University Human Research Ethics Committee (MUHREC).

The overall aim of the study was to examine in detail the ideas about start of antidepressants of a broad sample of antidepressant users and not to compare UK and Australian data as treatment is similar in each country. The combined narrative data from three UK 
 Table 1
 Demographic details (age and ethnicity) of people we interviewed

	UKa (n=38)	UKb (n=36)	Australia (n=40)
Age group in years			
20–29	3	17	5
30–39	12	15	6
40–49	9	5	13
50–59	8	5	9
60–69	4	1	4
70–79	2	2	3
80–89	0	1	0
Gender			
Male	16	13	16
Female	22	23	24
Ethnicity			
White British	33	27	1
Anglo Australian	0	0	26
Black	1	0	0
Asian	1	0	0
American	1	0	0
British Indian	0	1	
Jewish	0	1	1
British Iranian	0	1	
White European	2	1	2
White Irish	0	2	
Chinese	0	0	1
European Australian	0	0	2
Hispanic	0	0	1
Malaysian	0	0	1
Rwandan	0	0	1
Vietnamese	0	0	1
Chinese Anglo Australian	0	0	1
Anglo Canadian	0	0	1

and Australian narrative data collections provide a rich source of qualitative data for secondary analysis. Our paper expands on the original work by focusing solely on narrative accounts relating to the views, emotions and experiences of people on start of an antidepressant. Initial comparisons of the interview data during group email exchanges revealed similarities across all three studies, relating to narratives about initial use of an antidepressant and the profound impact this may have had on participants' ongoing experiences of managing depression. Our analysis aims to explore these predominant themes and to synthesise similarities and commonalities in experiences.

#### The original research

Participants were recruited for the original studies through a variety of routes including newsletters, websites, support groups, word of mouth and via health practitioners. Each study aimed to capture a wide variation in experiences and social demographic variables.<sup>18</sup> We conducted most interviews in participants' homes with just the interviewer and participant present, using a narrative style with subsequent prompting on topics including

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responses to a diagnosis of depression and being prescribed an antidepressant. Initial interviews served as pilots and the interview guides were pilot tested with the study advisory groups which included people with depression. Participants were interviewed until no new themes arose. The original interviews were conducted in person by authors DR, RK and SK who are experienced

qualitative researchers, were digitally recorded and transcribed verbatim. Transcripts were returned to participants for comment and/or correction.

#### Analysis

Both the original studies, and the analysis for this paper used a qualitative interpretive approach combining thematic analysis with constant comparison.<sup>19 20</sup> For this analysis, CA explored relevant coding reports from the original studies (generated using NVivo, a qualitative software package) relating to start of antidepressants in further detail, focusing on the ways in which participants discussed their experiences of taking or being prescribed an antidepressant for the first time.

By means of an iterative process, data extracts from the coding reports relating to initiation of medicines identified by CA were subsequently discussed and reviewed jointly by all authors through email exchanges and online conference calls. In the final round of analysis, CA synthesised the analysis and findings relating to participants' uncertainties, anxieties and concerns about start of treatment.

#### FINDINGS

#### Attitudes to taking antidepressants

Participants expressed a wide range of ideas and feelings about contemplating taking antidepressants. Some had few qualms about taking antidepressants, and pragmatically saw them as a means to an end:

I actually didn't have an ideological or philosophical position about medication. For me medication was a means to an end. (Catherine, Aus, F, 39)

Although people frequently argued that it was no different to taking medicines for other health conditions, such as using insulin for diabetes, others reflected on the way antidepressants are considered to be in a different class to other medicines:

I don't put my hands up in horror with psychiatric drugs...there's a lot of people turning against them... they wouldn't have the same attitude towards insulin or other drugs that were lifesaving. (Jean, UKb, F, 71)

Others disliked the 'mind-altering' potential of antidepressants, or potentially becoming dependent on a chemical substance to improve their mood. Taking medicines that were thought to 'mess with the mind' was perceived particularly negatively. This was particularly so when the reluctance to take antidepressants was tied

into the idea that they might get better without the medical intervention anyway:

I think taking medication is something I really struggled with because I didn't want to take it. I didn't want toyou know I thought I could just get better on my own. (Nicole, Aus, F, 27)

I obviously knew that there was antidepressants available but they've kind of got a stigma and I was worried that I didn't want anything I could get addicted to. (Maggie, UKb, F, 44)

Some people resisted taking antidepressants because they saw it as a sign of weakness that proved "that something's wrong and a lot of people don't like to admit that something's wrong". Ellie (UKb, F, 30) felt that men were particularly inclined to see using antidepressants in this way. Nevertheless, participants felt that the stigma around taking antidepressants was unjustified.

People also feared that antidepressants might mask their problems but not actually resolve it, and that they should manage it themselves, free of medicines, rather than 'papering over the cracks'.

#### Information

In the past, it was difficult for people to find information about the medicine they were prescribed, but these days the internet is routinely used by people to look up health information. People we spoke to in study UKb and Australia (carried out later than UKa) had routinely used the internet to find information, including about different types of antidepressants and side effects, as well as to find out about others' experiences with them:

Years ago I kind of just accepted what I was given and didn't really ask any questions but now I know to kind of do research on the internet and to you know, which websites are good to look at and which ones are not too good. (Esther, UKb, F, 31)

Others used internet forums where witnessing others' experiences helped them appreciate their own experience better:

Ah I've also seen a lot of other people on the internet as well that have been through far worse than me. They've trialled different medications and I've been fortunate that the medication I've been given hasn't had any, to my knowledge, any major effects. Because if something don't get ya something else will, something else will. (Joshua, Aus, M, 51)

#### The initial consultation

#### Getting to the doctor

Our participants had often felt depressed for a long time, only seeing a doctor and being prescribed an antidepressant after reaching a crisis point. They often described trying to 'manage' on their own, long before seeking help. Some went to the general practitioner

(GP) only after family and friends urged them to do so, others because their behaviour was obviously affecting other people. Charlotte (Aus, F, 51), for example, went to her GP when her husband was threatening to leave her. Both Scott's (Aus, M, 46) and Spencer's (UKb, M, 52) wives made them go to the doctor after they broke down at work. It can be difficult for people to recognise the signs and symptoms of depression themselves, and certainly, for our participants, there was not always awareness that treatments for their ailments existed that might help.

#### The consultation

Some people recalled very positive initial experiences of concordant consultations involving shared decisionmaking, including a good discussion about their views, fears and apprehensions and previous experiences of taking antidepressants. For these participants, being listened too and given sufficient time and information was universally recognised as positive and valuable, and key to the trust and rapport established between them and their health practitioner:

If she hadn't been able to turn my thinking around in that first appointment in the way that she did, you know, I'm not convinced I would have been motivated to take the medication. And certainly, you know, knowing now that it does take sort of four to six weeks to really start to have an effect I might have—even if I had started taking it—I may well have given up after two weeks, you know. But her, her influence was powerful enough that, you know, it changed everything about the way I was looking at the illness and subsequently at myself...So she then spent the time explaining about depression and different causes and, and then the medications and all of that. (Scott, Aus, M, 46)

These initial dialogues appear to be key to people developing a sense of agency with respect to their decision-making about taking antidepressants. If people trusted and respected their doctor and felt guided and informed, they also reported initiation of treatment as less problematic. In these instances, people more happily accepted the treatment option as suggested by their doctors, which fitted with their view of what treatment was needed.

Nevertheless, many people whom we interviewed were resistant to being prescribed antidepressants due to the strong stigma attached to them:

The first mention of medication and antidepressants. And um I don't think she'd even finished saying the word before I said 'not a chance.' I said 'do you know who you're talking to here? I'm a detective. I think—this is—you can't do that.' And there was no way I, I'd entertain um just the label of the drug. Just the term antidepressant to me was ah you just can't hack it. Um and I thought 'well that's what I think so everybody else must think that.' So I said 'nup, not a chance.' (Sean, Aus, M, 39) While 'shared decision-making' is increasingly valued as a necessary part of clinical care in consultations with GPs, we interviewed both younger and older people who told us that this was not something they had encountered. Some older people in particular described one-way conversations which involved them simply acceding to their doctors wishes, saying they had always believed that the 'doctor knows best'. Malcolm, (UKb, M 2=72), for example, had taken an antidepressant most of his adult life on the advice of his doctors. For him, the overwhelming impact of his depressive symptoms meant that not taking the treatment was not an option.

Others raised concerns about the way that their consultations unfolded, particularly where they felt like there was a lack of discussion and negotiation. Some people believed they were completely excluded from the decision-making:

Well, yeah, on her notes I think she wrote depressed and I think she said to me, "I think you're suffering with depression and need antidepressants"...And she put me on antidepressants straight away, and on sleeping tablets as well I think. She didn't even ask me! (Belinda, UKa, F, 33)

Rosey (UKa, F, 40) described not being told the reason for her antidepressant prescription and how she had never been given an explanation of what they would do, nor the side effects.

People typically linked their experiences with antidepressants to their interactions with doctors in their consultations. Having a good relationship with a doctor was an important indicator of whether people would discuss their need for information about adverse effects. Others mentioned that being able to talk to their doctor enabled them to reflect on their difficulties, and to better understand or reframe their experiences.

People described dissatisfaction with the doctorpatient interaction in terms of lack of attention to or acknowledgment of the patient and/or issues they may be encountering or experience. Apparent dismissive reactions or preoccupation with note taking or prescription writing, and superficial or glib responses from doctors to patients were commonly described and experienced as negative and disempowering. Examples included thinking that the doctor did not communicate well or, listen to them, did not spend enough time with them, did not supply them with sufficiently up to date information, or did not behave as if the patient had expertise too:

I'm just thinking, 'My God, you know, they [doctors] don't believe me,' but that's what I felt, they just don't have time to listen [about side-effects]. (Anne, UKa, F, 39)

Even more difficult for patients was feeling that they were being coerced into taking antidepressants, or that they do not have a choice in the matter: This GP was particularly um insistent that I take her prescription. And I had said, 'no,' I had said 'no' about three times. In the end she said to me, 'um I don't know what's wrong with depressed people, why they always refuse to take um my prescriptions. I think depressed people like being depressed.' I felt like she'd shamed me into taking her um prescription. (Vanessa, Aus, F, 35)

Others were surprised and even frightened by some of the things doctors said about what antidepressant taking would mean for them in the future, for example, that it would take a long time to get better, or that they would be dependent on them for life.

#### Being prescribed an antidepressant

Many people were relieved to be diagnosed with depression and be prescribed an antidepressant:

Once that was done it was like such a relief because I knew what was wrong and I could see there was now a way of fixing it. I have to say my father had depression a few years ago so I knew that there was a 'fix' because he was recovered he got treatment and he got better which helped me a lot. (Spencer, UKb, M, 52)

Being offered a prescription for an antidepressant brought significant relief, as it helped people to feel that their symptoms were recognised as a legitimate illness. A sense of agency and, in turn, empowerment often accompanied the receipt of a prescription as people felt they were being proactive, acknowledging they were depressed, and beginning to 'tackle the problem':

I think the first doctor I ever saw was absolutely fantastic. You know, he noticed the signs, he asked the questions. He diagnosed me, treated me, when the treatment didn't work so well, you know, we adjusted it and got me back on track within a couple of months. (Nancy, Aus, F, 26)

There were, however, also less positive reactions. When Tony (UKb) was first prescribed an antidepressant he said he felt it signified his depression as 'official', likening it to a defeat, as though he had 'surrendered'. Seeing it written in his notes felt, 'almost like having a criminal record'. It had affected the way he felt about himself as he felt designated to a denigrated category; now he was someone who was 'mentally ill'. People said they would prefer to 'manage' without antidepressants, wanting to come off them as soon as possible, or that it was important to them for there to be 'an end in sight'. They talked about preferring to be 'in control' of their own emotions and saw antidepressants as a temporary 'crutch' to lean on rather than a permanent solution.

Sam (UKb, M, 31) had felt it was taking the 'lazy' option when he was first prescribed an antidepressant, and said it felt like avoiding responsibility for his own well-being. Others saw taking antidepressant as signifying either to themselves or others that they were a 'failure'.

Those people who had not been prescribed an antidepressant straight away appreciated the time to think about it:

I didn't really want to go on medication but I thought that I was at the point where I needed something to help me. They were very, very good in that they didn't just immediately give me a prescription. Actually, we went through the options of what kind of medication...what they do, what they're designed for. And they said that they would rather monitor my situation before letting me go onto them, which I think was very responsible of them. I did eventually, because I wasn't getting any better, did go onto antidepressants. (Patrick, UKa, M, 30)

#### Taking an antidepressant for the first time

Even after deciding to start antidepressants, actually contemplating swallowing the tablet for the first time could feel like a momentous occasion:

I left them on my top shelf for ages and I just didn't want to take them because I was a bit confused as why I; he's prescribed me that after like a really short chat, just me saying I was down and maybe at the time they were handing them out left right and centre, I don't know. (George, UKb,M, 34)

Other participants wanted to find out more information before taking their first tablet. In the absence of information from their doctors:

He said go home and take these Prozac but as a person with a scientific mind as myself, I look up Prozac, I didn't take any, because so many side effect, I was so worried. I just threw it away, threw them away... (Phuong, Aus, F, 59)

Maggie (UKb, F, 44) got her prescription dispensed but took time to read through the information leaflet before deciding whether or not to take the first dose. She worried that the antidepressant might make her feel 'fluffy' or 'out of control':

Hilary (UKb, F, 28) spent a full week wondering whether to take the antidepressant and had second thoughts after reading an article online. She saw the GP for a second chat before deciding whether to take it. Others felt less autonomy in their encounter with health professionals:

I thought if I can be seen to be compliant to treatment it would make me less likely to be sectioned. (Tony, UKb, M, 34)

Our findings indicate that people can also feel unsure about what to expect once they take the antidepressant, and that it can be difficult to make decisions and think things through when very ill with depression:

Obviously the medication does what the, what the medication does but if, if she, I went home and I was, I read the thing and I was very scared too, and I took a tablet after—not straight away, a few weeks. I took a tablet, I took a tablet and it sort of made me so sick I retched the whole night in the toilet, just retching, and it made me feel like I almost died... (Phuong, Aus, F, 59)

People were uncertain about how long it would take for the antidepressant to take effect, the extent to which it might help, and about what to expect in the first few weeks. They were concerned that it could make them feel worse rather than better, and fretted over how long they would need to take an antidepressant for. Others did feel a lot worse, at least at first, and often took the antidepressants for 'a little bit' and then stopped:

And so I started taking the medicine, um and it was amazing. In, within two hours I could feel different. I felt, well, like there were side effects...there was my jaw would shake, and I would feel really sick, but within two hours I felt calm; that sort of anxiety wasn't there so much. I felt calm and tired, too tired. I slept for, you know, like 12 hours straight and then I had to go work. It was very difficult to go to work. (Laura, Aus, F, 55)

Others felt they benefitted in time, if not immediately:

One of the, one of the most striking things that struck me the first time I took antidepressants...is all of a sudden you realise how much colour is, there is in the world. But I think when I was depressed my, my perception of colour had diminished. (Craig, UKa, M 33)

Others variously described how they felt as spaced out, controlled, drunk, completely flattened and numb, although not depressed any more:

The first week of it I felt I'd been hit over the head with a sledgehammer. I found it really hard to have my bearings and, and ah cope. It was just the most bizarre feeling but I hung in there and after about ten days it, that got better. (Edith, Aus, F, 55)

For some just the fact that they were taking the antidepressant and doing something about their depression helped:

Straight away when you start taking it you feel great because somebody understands, somebody has listened to what's wrong with you because you're in this bubble the only way I can describe it is a bubble, the whole world is going on around you and nobody seems to understand you assume that nobody...it just takes a lot of weight lifted off your shoulders that you're starting medication and that you're starting on the road to get better... (Ellie, UKb, F, 30)

#### **DISCUSSION AND IMPLICATIONS**

The data from 108 interviews in both UK and Australia demonstrate the issues that people have when they are considering taking and starting to take antidepressants and provide some guidance for health professionals about how people feel and how to approach

consultations with them. The issues were similar across the data sets and there were no apparent differences between men and women's experiences nor between ethnic or cultural groups across the two countries. It was not the intention of the analysis to compare countries or time periods, as treatment for depression has not changed substantially over the past decades since the introduction of selective serotonin reuptake inhibitors (SSRIs),<sup>21</sup> nor are there notable differences between treatments in the UK and Australia. Participants were not asked specifically in interviews to comment at length on the complex issues surrounding the start of antidepressants. Thus, many such references to start were offered up spontaneously. While each study was found to be informative on the topic, no one study covered these issues thoroughly. However, combined in an analysis, it was found that the nuance of the analysis was increased substantially.

Many of these findings are similar to what have been reported elsewhere although those studies were derived from studies of adherence and compliance.<sup>14–16</sup> Although, medical encounters are only part of what influences antidepressant use. Once people have actually sought help from the GP, what happened at the initial consultation was critical for participants in their decisions to subsequently take their antidepressant or not. It is important that doctors take into account people's beliefs about medicines in general and medicines for treating mental health issues in particular.<sup>2</sup> <sup>22</sup> <sup>23</sup> When doctors took patients' beliefs and concerns about medicines into account, participants in our sample were much happier with their consultation and prescription.<sup>23</sup> <sup>24</sup>

Some people may have no qualms at all about taking antidepressants and clearly perceive them as being no different to other medicines. But even so, they may still experience effects like feeling spaced out, numb and so on difficult to accept because they impact on their persona.<sup>25</sup> Others struggle with the idea of taking antidepressants because they think that they can or should get better on their own. This is often compounded by the well-documented added burden of stigma and fear of dependency that antidepressants bring.<sup>9 15 25</sup>

Being offered a prescription for an antidepressant tells people that their symptoms are recognised by their GPs as an illness. It can be a relief to know that it might help the person feel better and give them hope for the future.<sup>24</sup> Sometimes just being given a prescription can help people feel more positive knowing that they are being proactive, acknowledging they are depressed, and beginning to 'tackle the problem'. For other people, it is hard to reconcile a pharmacological treatment with their understanding of personal and social problems, and even questioning of the depression diagnosis. Regardless, taking antidepressants for the first time can be a particularly anxiety provoking time, and people may reject the medicines at this time, particularly if they feel unsupported.

Side effects, especially on start of therapy, are another major barrier that people need support with and information about.<sup>3 26</sup> Our data suggest that people do want to know what to expect before they started taking an antidepressant. They felt reassured when they were provided with information and told that they can try different types of antidepressants if side effects were intolerable. Some participants wondered whether doctors were reluctant to give their patients too much information about side effects to avoid alarming them. If people do not realise or anticipate (or this was not explained to them by their GPs) that it can take a while to adjust to an antidepressant they may not recognise new symptoms as side effects of their medicine. Most people read the patient information leaflet, many finding it confusing, and often frightening given the list of possible side effects. Most people in the data set used the internet as a source of information about particular antidepressants, and what they found both in website sand on discussion forums influenced their subsequent decision-making. Conflicting congeries of information found online may be bewildering and health professionals could help by directing people to credible websites.

Studies have shown that around 40% of patients who start treatment with antidepressants fill only a single prescription at the pharmacy, apparently not accepting treatment and, as with other new medicines<sup>27</sup> stop taking them after 2 weeks.<sup>28–31</sup> Our data clearly show that once people have got their antidepressants from the pharmacy they often struggle with actually taking the first dose. Importantly, there was a significant silence in the narratives around experiences at pharmacies, with little mention of support when first or subsequent prescriptions were dispensed. Antidepressants would be a valuable additional group of medicines to add to the new medicines service that provides pharmacist support for prescription of a new medicine.<sup>32</sup>

Paramount in our data is the importance that people attach to being listened to, to have time spent with them considering the issues involved, and being treated as an individual. They wanted to be involved in decisions about their treatment and to understand the evidence for it. Having a good relationship with their doctor, which included being good communication, meant that they were more willing to trust the advice that was being given. Typically they wanted the opportunity to see the same person each time, so that their 'story' was familiar to the doctor. Some people were amazed at the speed with which they were diagnosed with depression and offered a prescription for antidepressants. Those who were given more time to consider whether or not to take them were much more satisfied. People also valued being given realistic expectations about side effects and being told that they do not work straight away. Doctors in Maxwell's study<sup>25</sup> found it hard to manage depression solely using a chronic disease model and were worried about medicalising problems of everyday living while

offering antidepressants was the single thing that they could do for the women.

For those responsible for the primary care of people experiencing depression, this approach to patient care is considered apposite in facilitating shared decisionmaking as opposed to more paternalistic approaches.<sup>33</sup> As Greenhalgh *et al*<sup> $\beta$ 4</sup> explain, importantly, "real shared decision-making is not the same as taking the patient through a series of if-then decision options. Rather, it involves finding out what matters to the patient-what is at stake for them-and making judicious use of professional knowledge and status (to what extent, and in what ways, does this person want to be 'empowered'?) and introducing research evidence in a way that informs a dialogue about what best to do, how, and why." This tailored treatment to individual context and needs is consistent with research that has shown that people have a range of different responses both to diagnosis, treatment options and explanations thereof, and involvement in shared decision-making.<sup>34 35</sup> For example, Fullagar and O'Brien<sup>36</sup> and Dummit<sup>37</sup> found that neurochemical explanations of depression often offer comfort and reassurance to women experiencing emotional distress, and safeguard their access to medical care. In contrast, Givens *et al*<sup>88</sup> found that older people were resistant to both antidepressants and depression as a diagnosis because of its status as a medical illness.

The value of the shift from paternalism to shared decision-making tailored to individual needs has been well documented.<sup>33 39–41</sup> However, as Fosgerau and Davidsen<sup>42</sup> observe, "an essential question remains as to whether the requirements for shared decision making are actually met in clinical encounters." This is significant because health professionals are likely to encounter a patient population with a wide range of experiences of taking antidepressants that are often contingent on their interaction with health professionals and the relational process of decision-making at the time of prescribing.<sup>43</sup> Indeed, as for many participants in our study, Fosgerau and Davidsen<sup>42</sup> found that shared decision-making did not take place because doctors did not explore patients' perspectives in depth or take their perspectives into consideration.

The concept of shared decision-making and privileging of patient-centered care are perhaps especially important given that antidepressants are notoriously difficult for people to take.<sup>28–31 44</sup> The people whom we interviewed expressed strong views about the need to be able to make informed decisions about their diagnoses and medicines prior to starting treatment. If people's initial consultation experience was experienced as positive and they viewed antidepressants as essential to getting better they gladly accepted treatment options as suggested by their doctors. These people considered medicines as an important means through which they could gain a sense of having a 'normal life'. For some their first experience with medicines was unpleasant. Others were left still feeling concerned about whether they actually needed to take medicines.

#### Limitations

While our study contributes important information it must be considered in the light of a number of study limitations. Only people willing to talk about their depression or taking antidepressants were interviewed and many of the participants regarded themselves as being in 'recovery', and so were doing relatively well. While the study does not claim numerical representation (this is not the purpose of maximum variation sampling), our sample reveals a wide range of experience and complexities about experiences of taking antidepressants in the UK and Australia. Full details about individual's prescribed medicines in this study were not available as they were not originally collected.

#### CONCLUSION

This paper is the first to explore in depth the existential concerns of starting antidepressant use using multicountry data across two decades. There were no notable differences between the two data sets from the UK and the Australian data set, save for greater use of internet in the later studies. People need to feel supported by health professionals when they start taking antidepressants. Health professionals may be able to use these findings to better understand patients' potential concerns about starting antidepressants. Given the difficulties encountered at initiation of antidepressant therapy, healthcare professionals need to consider how they structure their consultations and about the information that they provide. These insights are key to providing appropriate support for people starting antidepressants.

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#### REFERENCES

- Garfield S, Smith F, Francis SA. The paradoxical role of antidepressant medication—returning to normal functioning while losing the sense of being normal. *J Ment Health* 2003; 12:521–35.
- Dolovich L, Nair K, Sellors C, et al. Do patients' expectations influence their use of medications? Can Fam Physician 2008;54:384–93.
- Demyttenaere K, Albert A, Mesters P, et al. What happens with adverse events during 6 months of treatment with selective serotonin reuptake inhibitors? J Clin Psychiatry 2005;66:859–63.
- van Geffen ECG, Hermsen JHCM, Heerdink ER, et al. The decision to continue or discontinue treatment: experiences and beliefs of users of selective serotonin-reuptake inhibitors in the initial months a qualitative study. *Res Social Adm Pharm* 2011;7:134–50.
- Byrne N, Regan C, Livingston G. Adherence to treatment in mood disorders. *Curr Opin Psychiatry* 2006;19:44–9.
- 6. Hansen HV, Kessing LV. Adherence to antidepressant treatment. *Expert Rev Neurother* 2007;7:57–62.
- Campbell R, Pound P, Pope C, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experience of diabetes and diabetes care. Soc Sci Med 2003;56:671–84.
- Pound P, Britten N, Morgan M, *et al.* Resisting medicines: a synthesis of qualitative studies of medicine taking. *Soc Sci Med* 2005;61:133–55.
- Stevenson F, Knudsen P. Discourses of agency and the search for the authentic self: the case of mood-modifying medicines. *Soc Sci Med* 2008;66:170–81.
- Kokanovic R, Bendelow G, Philip B. Depression: the ambivalence of diagnosis. Sociol Health Ilin 2013;35:377–90.
- Cox K, Britten N, Hooper R, *et al.* Patients' involvement in decisions about medicines: GPs' perceptions of their preferences. *Br J Gen Pract* 2007;57:777–84.
- Kokanovic R, May C, Dowrick C, et al. Negotiating distress between East Timorese and Vietnamese migrants in Melbourne and their family doctors. Sociol Health IIIn 2010;32:511–27.
- Malpass A, Shaw A, Sharp D, et al. 'Medication career' or 'moral career'? The two sides of managing antidepressants: a metaethnography of patients' experience of antidepressants. Soc Sci Med 2009;68:154–68.
- Buus N, Johannessen H, Stage KB. Explanatory models of depression and treatment adherence to antidepressant medication: a qualitative interview study. *Int J Nurs Stud* 2012;49:1220–9.
- Buus N. Adherence to anti-depressant medication: a medicine-taking career. Soc Sci Med 2014;123:105–13.
- Leydon GM, Rodgers L, Kendrick T. A qualitative study of patient views on discontinuing long-term selective serotonin reuptake inhibitors. *Fam Pract* 2007;24:570–5.
- Ziebland S, Hunt K. Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. J Health Serv Res Policy 2014;19:177–82.
- Coyne I. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? J Adv Nurs 1997;26:623–30.
- Silverman D. Interpreting qualitative data: methods for analysing talk, text and interaction. Sage, 2001.
   Spearer I. Bitabia J. Compared M. Applysia. practices priority in the second sec
- Spencer L, Ritchie J, O'Connor W. Analysis, practices, principles, processes. In: Ritich J, Lewis J, eds. *Qualitative research practice:* a guide for social science students and researchers. Sage, 2007.
- Priebe S, Burns T, Craig TKJ. The future of academic psychiatry may be social. *Br J Psychiatry* 2013;202:319–20.
- National Institute for Health and Clinical Excellence. Depression: the treatment and management of depression in adults. NICE, 2009. http://www.nice.org.uk/guidance/cg90/resources/ guidance-depression-in-adults-pdf
- Stevenson FA, Cox K, Britten NM, et al. A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance. *Health Expect* 2004;7:235–45.
- Kokanovic R, Philip B. Emotional talk: depression, diagnosis and disclosure. In: Davis M, Manderson L, eds. *Disclosure in health and illness*. Routledge, 2014:56–71.
- Maxwell M. The influence of social and moral reasoning on patients' and doctors' decisions. Women's and doctors' accounts of their experiences of depression in primary care. *Chronic IIIn* 2005;1:61–71.
- van Geffen EC, Gardarsdottir H, van Hulten R, *et al.* Initiation of antidepressant therapy do patients follow the GPs prescription. *Br J Gen Pract* 2009;59:81–7.

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- Barber N, Parsons J, Clifford S, *et al.* Patients' problems with new medication for chronic conditions. *Qual Saf Health Care* 2004;13:172–5.
- McGettigan P, Kelly A, Carvahlo M, *et al.* Anti-depressants in primary care: analysis of treatment discontinuations. *Pharmacoepidemiol Drug Saf* 2000;9:521–8.
- Maddox J, Levi M, Thompson C. The compliance with antidepressants in general practice. *J Psychopharmacol (Oxford)* 1994;8:48–53.
- Meijer WEE, Heerdink ER, Leufkens HMG, *et al.* Incidence and determinants of long-term use of antidepressants. *Eur J Clin Pharmacol* 2004;60:57–61.
- van Geffen EC, van Hulten R, Bouvy ML, et al. Characteristics and reasons associated with non acceptance of SSRI treatment. Ann Pharmacother 2008;42:218–25.
- Elliott R, Boyd M, Waring J, et al. Understanding and appraising the new medicines service in the NHS in England. http://www. nottingham.ac.uk/~pazmjb/nms/downloads/report/files/assets/ basic-html/index.html#1
- Stevenson FA, Barry CA, Britten N, *et al.* Doctor-patient communication about drugs: the evidence for shared decision making. *Soc Sci Med* 2000;50:829–40.
- 34. Greenhalgh T, Howick J, Maskrey N. Evidence based medicine: a movement in crisis? *BMJ* 2014;348:g3725.
- Garfield S, Francis SA, Smith FJ. Building concordant relationships with patients starting antidepressant medication. *Patient Educ Couns* 2004;55:241–6.

- Fullagar S, O'Brien W. Immobility, battles and the journey of feeling alive: women's metaphors of self-transformation through depression and recovery. *Qual Health Res* 2012;2:1063–72.
- 37. Dummit J. The depsychiatrisation of mental illness. *J Public Ment Health* 2005;4:8–13.
- Givens JL, Datto CJ, Ruckdeschel K, *et al.* Older patients' aversion to antidepressants. A qualitative study. *J Gen Intern Med* 2006;21:146–51.
- Johnston BJ. The role of patient experience and its influence on adherence to antidepressant treatment. J Psychosoc Nurs Ment Health Serv 2013;51:29–37.
- Swanson KA, Bastani R, Rubenstein LV, et al. Effect of mental health care and shared decision making on patient satisfaction in a community sample of patients with depression. Med Care Res Rev 2007;64:416–30.
- Charles C, Gafni A, Whelan T. Decision-making in the physicianpatient encounter: revisiting the shared treatment decision making model. *Soc Sci Med* 1999;49:651–61.
- Fosgerau CF, Davidsen A. Patients' perspectives on antidepressant treatment in consultations with physicians. *Qual Heal Res* 2014;24:641–53.
- Johnston O, Kumar S, Kendall K, *et al.* Qualitative study of depression management in primary care: GP and patient goals, and the value of listening. *Br J Gen Pract* 2007;57:872–9.
- 44. Sansone RA, Sansone LA. Antidepressant adherence are patients taking their medications? *Innov Clin Neurosci* 2012;9: 41–6.