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Short Communication

Staying on, and coming off, antidepressants: The experiences of 752 UK adults

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HIGHLIGHTS

- 76% had been taking antidepressants for at least a year and 36% for five years or more.
- 26% expected to take them forever.
- 65% had never had a discussion with the prescriber about coming off.
- 45% of those who had stopped the drugs had done so without consulting their doctor.

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ABSTRACT

Introduction: Prescription rates for antidepressants (ADs) are high and continue to increase, despite evidence of significant adverse effects, including withdrawal symptoms, and marginal benefit relative to placebo only for short-term treatment of major depression. Such high rates seem to be explicable more in terms of long term usage and repeat prescribing rather than by increases in depression or new patients.
Method: This paper reports the responses of a convenience sample of 752 people who had taken antidepressants, but no other psychiatric drugs, 'within the last two years' and completed the *Medications for Mental Health Survey* online in the UK.
Results: Most participants had either come off antidepressants (34%) or had tried and failed (36%). Of those still taking them 76% had been doing so for at least a year and 36% for five years or more. 26% expected to take them forever. About half (48%) did not have their drugs reviewed at least every three months. Most (65%) had never had a discussion with the prescriber about coming off. Nearly half (45%) of those who had stopped the drugs had done so without consulting their doctor. However, of those who came off after consulting their doctor, the majority (65%) experienced the doctor to be supportive.
Conclusions: The findings are consistent with the idea that high rates are largely explicable by chronic usage, which in turn is partially explained by withdrawal symptoms. Prescribers should strive to establish collaborative relationships in which patients are fully informed about withdrawal effects and their views, about starting and finishing medication, should be explored and valued.

1. Introduction

Prescription rates for antidepressants (ADs) are very high and ever increasing (Ilyas and Moncrieff, 2012; O.E.C.D., 2016). In 2012 one in eight adults in the USA was prescribed ADs (Kantor et al., 2015). In the U.K. prescriptions have increased 170% since 2000, with 7.1 million adults prescribed ADs in England alone in 2016/17, which is 16.3% (one in six) of the English adult population (NHSBSA, 2018).

These extraordinarily high rates are difficult to justify in terms of efficacy. The differences between antidepressants and placebo are small and of doubtful clinical relevance (Moncrieff and Kirsch, 2016). Although a recent review, of short term studies excluding non-responders, concluded that ADs are slightly better than placebo for severe depression (Cipriani et al., 2018), less than half of all trials have found ADs superior to placebo (Khan et al., 2002). Blinded studies are particularly unlikely to find any difference to placebo (Khan and Brown, 2015; Moncrieff, 2015). Two meta-analyses have found that the effect size does not reach 'clinical significance' (Jakobsen et al., 2017; Kirsch

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et al., 2008). One of these reviews concluded that 'The harmful effects of SSRIs versus placebo for major depressive disorder seem to outweigh any potential small beneficial effects' (Jakobsen et al., 2017, p. 23). These harmful effects are very common, and occur not only in the in the biological domain, but in the psychological and interpersonal domains as well, and include withdrawal symptoms (Read et al., 2014, 2018; Read and Williams, 2018).

The high prescription rates are not accounted for by increased prevalence of depression, or changes in help-seeking (Munoz-Arroyo et al. 2006). Attention has therefore turned to increases in chronic usage. Data on 189,851 GP patients in the UK revealed that a doubling of prescribing over eight years was explained not by increases in new prescriptions but a doubling of the number of prescriptions per patient (Moore et al., 2009). Half of all AD users in England, about 3.5 million people (8% of the adult population), take ADs for longer than two years (Johnson et al., 2012).

In order to improve our understanding of the long term use of ADs, dependency, and efforts to withdraw, the current study reports the experiences of 752 users of ADs in the UK.

2. Method

The *Medication for Mental Health Survey* was designed by *Mind*, a national mental health charity England and Wales (www.mind.org.uk), to inform an article by *The Times* newspaper about the side effects of psychiatric drugs. The online survey asked a convenience sample of adult British users of psychiatric medications a range of questions, with yes/no or multiple choice responses, about their experiences with four types of psychiatric medication. The survey was advertised on the *Mind* website for four weeks, and was emailed to all *Mind* members, and posted on social media. The findings regarding the high levels of interpersonal adverse effects, with and without also taking antipsychotics, have been published elsewhere (Read et al., 2017). This paper reports the responses of the 752 who had taken ADs but no other psychiatric drugs, in relation to the process of trying to withdraw from ADs.

2.1. Sample characteristics

Most (76.1%) were women, and 97.1% self-defined as White. 12.1% were aged 18–25; 62.5% were 26–44; 24.8% were 45–64, and 0.6% were 65 or more.

83.8% had first been prescribed ADs by a GP and 16.2% by a psychiatrist. Almost all of the 495 (98.0%) were being prescribed to by a GP when completing the survey

In response to 'How effective do you feel your current medication is in helping to manage your mental health problem?' 4.1% ticked 'completely', 30.5% 'very', 49.7% 'fairly', 12.6% 'not very' effective, and 3.1% 'not at all'.

3. Results

3.1. Participants still taking ADs

Of the total sample of 752, about two thirds (495; 65.8%) were still taking an AD. The number responding to the items in this section ranged from 455 to 495.

3.1.1. Length of time on ADs – actual and predicted

75.6% had been taking ADs for at least a year, 60.4% for at least two years, 35.6% for at least five years and 19.8% for at least ten years.

In response to 'How long do you think you will continue to take your medication?' 28.5% said less than a year, 12.9% between one and two years, and 5.9% said between two and five years. About one in four (25.8%) expected to be on the drugs 'for the rest of my life'; and a similar number (26.9%) ticked 'I don't know'. Thus less than half (44.9%) expected to stop taking the drugs within the next five years.

3.1.2. Attempting, or thinking about, stopping

In response to 'Would you like to stop taking your medication?' 37.0% said 'Yes, 33.8% 'No', and 29.2% didn't know. In response to 'Have you ever tried to stop taking your medication?' 60.2% had tried in the past, 6.8% were trying to stop at the time of the survey, and 33.0% had never tried.

3.1.3. Information about adverse effects and withdrawal

In response to 'Do you feel you were given enough information about the medication, including side effects and withdrawal?' 48.1% said 'Yes', 39.6% said 'No' and 12.3% ticked 'Can't remember/don't know'.

3.1.4. Medication reviews

Responses to 'On average how often is your treatment reviewed or monitored?' 51.6% ticked 'at least every three months'; 23.6% endorsed 'every six months', 8.5% 'every year', 7.6% 'less often than every year', and 8.7% said it had never been reviewed.

3.1.5. Some of the participants' comments follow

- See my GP every month and we discuss the best course of action.
- I have faith that I am being monitored and it is also up to me to keep GPs informed.
- Initially every 2–4 weeks, then 6 weeks and now 8 weeks. I have a wonderful GP
- I have no idea when it will be reviewed.
- I have reviews between six months to a year but they are not very thorough and I often feel as if I am just handed a repeat prescription and told to go away.
- Initially it was reviewed after 3 weeks, then again after 6 weeks. But now I just get repeat prescriptions and haven't been told to go back to GP.
- I have a repeat prescription that I renew on line. The doctor could not care less. I feel very alone with this.
- I continually ask for review but receive no support with this.
- Reviewed at first then left for 4 years.
- After 1 month then never since.
- I quite often get lost in services where they don't communicate to each other, so no review.
- GP is supposed to review every 3mths but I've not seen anyone in the last year.
- Only when I suggest it.

3.1.6. Discussions with prescriber

Only 33.3% had had any discussion with their GP or Psychiatrist about 'plans to come off your medication'. Most (63.8%) had never had such a discussion. (2.9% didn't know).

3.2. Participants who had stopped taking ADs

Of the total sample of 752, about a third (257; 34.2%) were no longer taking an AD. The number responding to the items that follow ranged from 237 to 257.

3.2.1. Length of time on ADs

Of those who were no longer taking ADs, 60.7% had taken them for at least a year before stopping, 33.9% for at least two years, 14.0% for at least five years, and 4.3% for ten years or more.

3.2.2. Reasons for stopping

Table 1 shows that the main reasons for stopping were: not needing the ADs any more (34.2%), the side effects (32.3%), and not wanting to be on medication for a long time (31.5%). Only 9.3% reported that they

Table 1
'What was the main reason you stopped taking your medication'?

	N[a]	% (of 257)
I suggested it because I didn't feel I needed it anymore	88	34.2%
I suggested it because I didn't like the side effects	83	32.3%
I suggested it because I didn't like the thought of being on medication for a long time	81	31.5%
I suggested it because I didn't think it was working	55	21.4%
I suggested it because I decided to try talking treatments or alternative therapies instead	29	11.3%
My GP or psychiatrist suggested it because they felt I was ready to come off	24	9.3%
I wanted to start a family/became pregnant, and didn't want to risk harming my baby	14	5.4%
I was only on them for a set period to cope with a difficult time	12	4.7%

[a] Some participants gave more than one reason despite being asked to tick just one 'main' reason.

came off at the initiative of their GP or psychiatrist.

3.2.3. Discussions with the prescriber

In response to 'Did you discuss coming off your medication with your GP/psychiatrist?' 54.9% said Yes, and 45.1% No. Of the 138 who had discussed it with their doctor, the majority (64.7%) found the doctor to be either 'very supportive' (34.5%) or 'supportive' (30.2%). About a quarter (23.7%) endorsed 'neither supportive nor unsupportive'. 'Quite unsupportive was endorsed by 7.2% and 'very unsupportive' by 4.3% (see Table 2).

The most common reasons for not discussing it with the doctor were: a belief that they could come off without the doctor's help (52.6%); a belief that the doctor would not support their decision to come off (29.8%) and a feeling that their doctor does not listen (27.2%).

3.2.4. Coming off

Most (68.0) took less than three months to come off their ADs, but 20.6% took between three and six months; 6.1% took between six and 12 months; and 5.3% took more than a year. 20.0% found it 'very easy' to come off, 50.6% 'fairly easy'; and 29.4% 'Not easy at all'.

Table 2
Discussions with GP or psychiatrist before coming off? If so, how supportive was the doctor? If not, why not?

Discussion or not? $n = 253$		
Discussion 139 (54.9%)		% (out of 139)
Very supportive	48	34.5%
Supportive	42	30.2%
Neither	33	23.7%
Quite unsupportive	10	7.2%
Very unsupportive	6	4.3%
No discussion 114 (45.1%)		% (out of 114)[a]
I felt I could do it myself without their help	60	52.6%
I didn't feel they would support my decision to come off them	34	29.8%
I don't feel my doctor listens to me	31	27.2%
I don't feel able to raise issues like this with my doctor	16	14.0%
I had tried to discuss coming off and they said I should stay on them	10	8.8%
I was worried I might be detained under the Mental Health Act (sectioned) or otherwise forced to take my medication	3	2.6%

[a] Participants could endorse more than one reason for not discussing.

4. Discussion

4.1. Chronic usage

Of those who were still taking ADs 36% had done so for at least five years. These, and similar findings in New Zealand (Read et al., 2018), USA (Mojtabai and Olfson, 2014), England (Johnson et al., 2012) and in an international sample (Read and Williams, 2018), are of concern, because of the adverse effects associated with long term use, and because withdrawal effects are more likely the longer one is on the ADs (Read et al., 2014, 2017; Read and Williams, 2018). They are consistent with findings that prescriptions per patient have increased over time (Mojtabi & Olfson, 2014; Moore et al., 2009). The finding that 26% thought they would never stop taking them, is particularly alarming.

4.2. Withdrawal effects and addiction

Chronic usage in such high numbers raises the issue of whether this is partly because people experience withdrawal symptoms when they try to stop. A British survey found that of 817 people who had stopped taking ADs, 63% experienced withdrawal symptoms (Royal College of Psychiatrists, 2012). The large New Zealand survey found that 55% experienced withdrawal symptoms (Read et al., 2014, 2018). An international survey found that 59% reported withdrawal (Read and Williams, 2018). The first ever review of the incidence, severity and duration of AD withdrawal reactions found that over half of people who try to come off experience withdrawal effects, that about half of these effects are described as 'severe', and that it is not uncommon for these effects to last weeks or months (Davies and Read, 2018).

Such findings raise the issue of whether ADs are addictive. Unlike benzodiazepines, ADs are not associated with drug seeking behavior, or dose escalation. Nevertheless, a review by the Nordic Cochrane Centre concluded that withdrawal reactions to antidepressants are similar to those for benzodiazepines (Nielsen et al., 2012). 27% of AD users reported 'addiction' in the New Zealand survey (Read et al., 2014, 2018) and 40% in the international survey (Read and Williams, 2018). Many smaller studies find that many AD users believe that ADs are addictive (Bogner et al., 2009; Gibson et al., 2014; Hoencamp et al., 2002; Kessing et al., 2005).

Another possible contributor to high rates of unnecessarily long term usage is that some prescribers may not be sufficiently supportive, of either the decision to come off or during the process of doing so. In the current study only 9% stopped ADs at the suggestion of their doctor. Furthermore, a third (35%) of those who discussed coming off with their doctor did not describe the doctor as 'supportive'; and 27% of those who did not discuss it didn't feel their doctor listened to them and 30% did not believe the doctor would support a decision to come off. A previous study found that only one in four made reductions after a review of their AD (Johnson et al., 2012).

There are practical problems that doctors and patients must solve, not least the fact that currently only a very limited number of registered standard doses are (or can be) provided by pharmacists. Tapering strips appear to provide an urgently needed solution. In a recent Dutch study 71% of 895 people who wished to stop their ADs succeeded in tapering their antidepressant medication completely, using a median of two strips over a median of eight weeks (Groot and van Os, 2018).

4.3. Conclusions/clinical implications

The findings lend further support to the idea that the recent extraordinarily high prescription rates are largely explicable by chronic usage, which in turn is partially explained by difficulty coming off these drugs because of withdrawal symptoms.

4.3.1. When prescribing

All prescribers must warn people about the high probability of

withdrawal effects. Not to do so breaches the ethical principle of 'informed choice' (Read et al., 2018; Read and Williams, 2018). Doing so increases the changes that some people will make an informed and reasonable choice not to start ADs, and that people who do start them will be able to withdraw carefully, safely and successfully when they decide to do so.

A few studies have found that prescribers tend to adopt a rather narrow medical framework and to focus on medication adherence (Bull et al., 2002; Linden and Westram, 2011; Young et al., 2006: Sun et al., 2010). A more collaborative approach seems essential.

4.3.2. After prescribing

Frequent reviews need to be held, and should involve discussion about how much longer the person should continue on ADs. Differences of opinion between prescriber and patient should be respectfully explored. AD users who wish to come off their medication need to be supported.

Responsible guidelines suggest that flexibility in the amount of time taken (including temporary levelings off, and even increases), and support from other people, are key factors in successful withdrawal (Groot and van Os, 2018; Hall, 2012; Inner Compass, 2018; I.I.P.D.W., 2018; Mind, 2017).

4.4. Limitations

This is a self-selected, convenience sample. Ethnic minority groups, for example, are underrepresented. People who have had negative experiences with ADs may be more motivated to complete online surveys on the topic. However, the fact that 84% found their ADs at least 'fairly effective' suggest that this may not have been the case.

Some of the questions, like the one concerning information about adverse effects, relied on recall of events that occurred several years ago.

The sample may under-represent people who take ADs for a short term and then stop them without experiencing any problems; but the proportion of long term users in the current study is comparable to previous studies (Johnson et al., 2012; Mojtabai and Olfson, 2014; Read et al., 2018; Read and Williams, 2018).

Conflicts of interest

None.

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