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Short Communication

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

John Read^{a,*}, Aimee Gee^b, Jacob Diggle^b, Helen Butler^b^a School of Psychology, University of East London, Water Lane, London E15 4LZ, UK^b Mind, Stratford, London, UK

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

* Corresponding author.

E-mail address: john@uel.ac.uk (J. Read).

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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 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 anti-psychotics, 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

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