The positive and negative experiences of 342 antidepressant users.

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Abstract

Most efficacy and safety studies about medications adopt a quantitative approach, testing specific hypotheses with restricted samples. This online survey provides additional insights by directly asking people open questions. Thematic analysis was used to explore the responses of 342 antidepressant users to "Is there anything else you would like to tell us about your experience of taking medication". 59 (17.3%) made exclusively positive comments, 146 (42.7%) purely negative comments and 137 (40.0%) offered a mixture of positive and negative. Positive themes included: Daily Coping, Life-Changing/Saving and Stepping Stone. Negative themes included: Physical Adverse Effects, Emotional and Cognitive Blunting, and Withdrawal Effects. Many participants also commented on relationships with prescribers. Collaboration was particularly valued. Negative sub-themes included failings in relation to information (especially about adverse effects and withdrawal), support, and alternatives. Clinicians have a duty to inform potential antidepressant users about positive and adverse effects, including withdrawal effects.

Keywords: depression, antidepressants, first person accounts, adverse effects, withdrawal, prescriber-patient relationships,

Introduction

Prescriptions of antidepressants in the U.K. have increased by 170% since 2000. In 2016-17 more than seven million adults (16% of the adult population) were prescribed an antidepressant in England (Department of Health and Social Care, 2018), where individual annual prescriptions now exceed 70

million (OECD, 2018). In the U.S.A. 8% of the population aged over 12 used antidepressants between 1999-2002, increasing to 13% (37 million adults) by 2011-2014 (Pratt et al., 2017). Similarly prescription rates are found elsewhere, most excessively Australia, Iceland, Portugal, Canada, Belgium, Denmark and Sweden (OECD, 2017).

Many trials find antidepressants are not significantly more effective than placebos. Properly blinded and independent studies (not drug industry funded) are particularly unlikely to find any difference to placebo (Khan & Brown, 2015; Khan, Khan, & Brown, 2002; Moncrieff, 2015). A meta-analysis found that "the overall effect of new-generation antidepressant medications is below recommended criteria for clinical significance" (Kirsch et al., 2008), with superiority over placebo only found for "patients at the upper end of the very severely depressed category". A recent meta-analysis (Cipriani et al., 2018) reached more favorable conclusions, but the median duration of treatment in the studies was just eight weeks, whereas typical antidepressant users take them for months or years; and studies were excluded if 20% or more of participants were "treatment-resistant" - meaning that the drugs do not work for them (Timimi et al. 2018). Furthermore Cipriani et al. dichotomised outcomes, reporting either response or non-response, which is known to exaggerate differences between groups. Their meta-analysis also paid no attention to adverse effects. Another recent meta-analysis, of 131 placebo-controlled trials, confirmed that the overall effect size does not reach "clinical significance" and 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).

These harmful effects include many physical effects, such as sexual dysfunction, nausea, headache, dry mouth, insomnia, somnolence, diarrhea, dizziness and constipation (Adkins et al., 2012; Jakobsen et al., 2017). Recent largescale surveys of antidepressant users have also identified high rates of adverse effects in the emotional, psychological and interpersonal domains, including emotional numbing, reduction in positive feeling, caring less about others, and suicidality, (Read et al., 2014; Read et al., 2017; Read and Williams, 2018) as well as high rates of withdrawal effects when trying to reduce or come off the drugs (Davies and Read, 2019; Davies et al., 2018; Read et al., 2014; Read et al., 2018; Read et al., 2019).

Most quantitative studies only indirectly assess the experiences and views of the people who take antidepressants. A review of the few studies of the subjective experiences of antidepressant users (Gibson, Cartwright, & Read, 2014) identified many positive experiences. However, it also found a preponderance of adverse effects in the psychological, emotional and interpersonal domains. These included emotional detachment, a belief that antidepressants prevent natural sadness, harmful effects on relationships, caring less about self and others, fear of addiction, and suicidality (Givens et al., 2006; Goldsmith and Moncrieff, 2011; Liebert and Gavey, 2008; Pestello and Davis-Berman, 2008; Price et al., 2009).

The largest study giving participants the opportunity to say anything they wanted analysed how 1,747 New Zealand antidepressant users completed the sentence "In my life antidepressants have been……". Positive experiences included seeing antidepressants as "a necessary treatment for a 'disease', a life saver, a way of meeting social obligations, dealing with difficult circumstances or a stepping stone to further help". Negative themes were "ineffective, having unbearable side effects, undermining emotional authenticity, masking real problems and reducing the experience of control". Mixed experience themes showed how participants "weighed up the unpleasant side effects against the benefits, felt calmer but less like themselves, and felt stuck with continuing on antidepressants when they wished to stop" (Gibson, Cartwright, & Read, 2016).

The current study aimed to add to this small literature giving direct voice to the patient by reporting the responses of 342 antidepressant users in the UK who completed a survey and were then asked "Is there anything else you would like to tell us about your experience of taking medication?"

Method

Instrument and Procedure

The study used the *Medication for Mental Health Survey* (Read et al., 2017; Read et al., 2019), originally designed by *Mind*, Britain's largest mental health NGO. The survey was piloted with people with experience of antidepressants. It asks adult users of psychiatric medication within the preceding two years to answer questions about effectiveness, adverse effects and the process of

starting and ending four types of medication: "Antidepressants", "Antipsychotics", "Mood stabilizers" and "Tranquilizers or sleeping pills'. The participants were also asked to answer the following open question: "Is there anything else you would like to tell us about your experience of taking medication?" The responses of people taking antidepressants but not the other three drug types are the subject of this paper.

The survey, which used Survey Monkey, was advertised on the *Mind* website for four weeks, and wasemailed to all *Mind* members and posted on social media.

Sample Characteristics

A total of 1797 people completed the survey; 342 were taking only antidepressants and answered the question "Is there anything else you would like to tell us about your experience of taking antidepressants". The majority were women (74.7%); 15.0% were 18-24 years old, 28.3% were 25-34, 28.9% were 35-44, 20.2% were 45-54, 6.5% were 55-64, and 1.1% were 65 or over. The majority (87.5%) classified themselves as "White British". 20.7% had been taking antidepressants for less than a year, 14.8% for between one and two years, 26.6% between two and five years, 18.1% between five and ten years, and 19.8% more than ten years. The majority (84.2%) were first prescribed antidepressants by GPs, and the remainder by psychiatrists. Most (86.9%) reported that the drugs were at least "fairly effective" at "helping to manage your mental health problem", with 35.2% responding "very" and 5.3% saying "completely".

Data Analysis

The 342 respondents were coded as positive, mixed or negative by one of the researchers. A randomly selected set of 20 respondents were categorised by a second researcher, blind to the first categorizations. This produced an 85% agreement rate. The three inconsistencies were all in the direction of predominantly negative responses with small positive components being rated by the first researcher as being negative rather than mixed as should have been the case. A final careful checking of all the negative ratings led to six more of the 342 being re-categorized as mixed. Chi-square was used to determine whether gender was related to the categorization of "positive", "mixed" or

"negative". Spearman Rank correlations coefficients were used to assess the relationship of the categorisations with age and length of treatment.

Participants' comments were then coded into themes (and sub themes) using Thematic Analysis. Braun and Clark (2006) define Thematic Analysis as "a method for identifying, analysing, and reporting patterns (themes) within data" (p 83). "A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set". (p 87). To qualify as a theme (or sub theme) at least one in every 25 participants (4%) must have made a relevant comment. Braun and Clarke state that "As this is qualitative analysis, there is no hard-and-fast answer to the question of what proportion of your data set needs to display evidence of the theme for it to be considered a theme" (p. 87). The 4% proportion was arbitrarily selected so as to place a manageable limit on the number of themes generated.

Ethics

The anonymous survey was subject to the NGO's usual management structures. Informed consent was assumed from the participants' decision to complete the survey after reading a description of it on the first page. Secondary analysis was approved by the Ethics Committee of the University of East London's School of Psychology.

Results

Of the 342 respondents 59 (17.3%) made exclusively positive comments, 146 (42.7%) purely negative comments and 137 (40.0%) offered a mixture of positive and negative comments. Overall, 196 made positive remarks and 283 made negative remarks.

Correlates of Positive/Negative Experience

Whether people's experiences were categorized as "positive", "mixed", or "negative" was not significantly related to gender ($X^2 = 4.63$, p = .10), age (rho = 0.06, p = .25), or length of treatment (rho = .01, p = .86).

Positive Experiences

The 196 participants who reported positive experiences consisted of the 59 participants who reported purely positive experiences and the 137 reporting mixed experiences.

Table 1

Frequency of positive themes

Themes	**Frequency**	**% (of 342)**
Prescriber Relationship	35	10.2%
Stepping Stone	26	7.6%
Daily Coping	21	6.1%
Life-Changing/Saving	15	4.4%
Overcoming Skepticism	15	4.4%

Table 1 summarizes the themes emerging from the thematic analysis that involved more than 4% of the people making positive comments.

Stepping Stone

This theme (26; 7.6% of the total sample of 342) involved experiencing medication as a valuable temporary treatment on a path toward alternative treatments. Some examples of this theme follow:

"It has been very helpful to me to manage the worse of my depression and allow me the strength and perspective to try additional therapies such as counseling/ self -help."

"It helped me to get to a place where I was well enough to undergo CBT and address underlying issues. Eventually, I will come off it with the support of my CBT therapist."

"They calmed me enough to allow the CBT to work. I feel CBT wouldn't have been as effective or it would have been a longer process had I not taking tablets to stabilize my mood."

"I think it alleviated the symptoms enough to help me use other means to deal with the causes of my illness and get my life back on track."

Daily Coping

Twenty one participants (6.1%) viewed medication as an effective way to cope with daily activities.

> "If I don't take my medication I can't even go through the day with normal activities such as cleaning the house or shopping for food."
>
> "My medication enables me to cope with life's up and downs"
>
> "On medication I am able to work fulltime and live my life without being restricted and disabled by the symptoms of OCD and depression."
>
> "My medication allows me to function and continue to work."

Life Changing/Saving

Fifteen (4.4%) saw medication as life-changing or even life-saving.

> "I thought my medication to be the only thing that had any effect on my depression. It has completely changed my life."
>
> "I feel like it saved my life because I was desperate for help and I did not feel there were any other options. … It would have taken months to organize therapy. … Therapy and lifestyle changes can be as effective as medication but when you are desperate you need something quick or you risk becoming suicidal."
>
> "My depression is endogenous and without the medication I would have a miserable, unstable existence."
>
> "Venlafaxine saved me for the second time in my life, along with a complete change in lifestyle."
>
> "Citalopram changed my life. I left long–term hospital, stopped hurting and trying to kill myself, moved house, was discharged from Community Mental Health Team and now work full time and I'm pregnant."

Overcoming Skepticism

Fifteen participants with positive views (4.4%) reported that they started out with negative views about antidepressants.

"I was very skeptical about medication for years but I am glad I finally opted for medication as a short time help because my symptoms were unmanageable without it. I wish I had taken them sooner."

"I was a total cynic about antidepressant before taking them, could not work out how a pill could affect my mind. However, having suffered from nightmares all my life, I now rarely get them - for me this is sufficient enough proof of an effect."

"I thought medication would mask my emotions and I wouldn't know if I was making positive progress or whether it was because of the tablets. However, I no longer have the prolonged 'dark periods' and feel more balanced."

"I tried many options before hand and was very sceptical about the medication, but it has made me almost completely better."

Prescriber Relationship

Thirty five participants (10.2% of all 342) identified positive aspects of the relationship with the prescriber, with a particular focus on collaboration and flexibility.

"My GP was very supportive."

"My GP was great because she didn't force me to take medication but went through the options with me. She was very supportive of me managing my mental health condition and suggested practical things as well as medication."

"I was anti medication but my GP opened up a dialogue where I felt very included in my treatment."

"The decision to put me on medication wasn't taken lightly and they talked me through everything thoroughly to ensure I was happy."

"My GP makes me feel empowered and is supporting me to come off the medication in the coming months."

Negative Experiences

Of the 342 who provided comments 283 (82.7%) made negative comments. These 283 comprised of 146 who only made negative comments and 137 who also made positive comments. The themes involving more than 4% of all respondents are listed in Table2.

Table 2

Frequency of negative themes

Theme (and sub themes)	**Frequency**	**% (of 342)**
Prescriber Relationship	109	31.9%
(Information)	(45)	(13.2%)
(Alternative Treatments)	(33)	(9.6%)
(Support)	(31)	(9.1%)
Physical Adverse Effects	79	23.1%
Withdrawal Effects	48	14.0%
Emotional and Cognitive Blunting	20	5.8%

Physical Adverse Effects

Seventy nine participants (23.1% of the total sample) reported a wide range of physical effects of drug therapy. The most common were: dry mouth, insomnia, frequent urination, sweating, diarrhea, tiredness, loss of libido and anorgasmia, dizziness, headaches, weight gain, insomnia, alcohol dependency, teeth grinding. For some, the adverse effects were severe and affected their abilities to perform daily activities.

"I suffered from every type of effects – dry mouth, rashes, frequently needing to urinate, hallucinations, sweats, total loss of libido and more."

"The side effects are awful and there was no positive effect. I got all the side effects and was left feeling really ill."

"I couldn't sleep, had headaches most days, palpitations, night sweats and if I did sleep I had disturbing dreams. I was permanently tired, which affected my mood."

"Side effects such as frequent yawning, severe fatigue and diarrhea made my experience quite hard."

"Problems getting to sleep and then sleeping for over 12 hours when asleep, constant tiredness, sluggishness, lack of motivation and energy and orgasm problems."

"After about 6 weeks I developed a chronic clenched jaw, which was painful and annoying, and feeling like I was on recreational drugs, immense difficulty in sleeping."

Some participants reported loss of libido and anorgasmia.

"It affected my sexual relationship with my partner as I had no desire to have sex and we are still feeling the effects of this now as he is nervous to ask."

"All the antidepressants I have taken always have a significant negative effect on sex drive and a reduced ability to reach orgasm."

"I hate the side effects - I sweat constantly and have very poor libido which depresses me even more."

Withdrawal Effects

Forty eight (14.0%) reported withdrawal effects when trying to stop or reduce antidepressants. The most common were headaches, nausea, and dizziness, but there was an extensive range, some of which were severe and/or long lasting. For example:

"I did try to withdraw from them completely but I spent a week in bed with severe withdrawal effects."

"The side effects were horrific when I last tried; vertigo, nausea, painful paresthesia-like electric shock down my arms and hands, and terrifying nightmares every night where I would wake drenched in sweat and weak with terror."

"The horrendous withdrawal effects, combined with my underlying health problems, were overwhelming and debilitating. I have been hospitalized. I am still in the process of completely quitting medication, and would not wish this experience to anyone."

"I had to take time off sick from work as withdrawal made me ill."

"I was taking SSRIs, and took 10 years to come off them. Each time I tried I experienced severe withdrawal symptoms and had to start taking them again."

"I suffer withdrawal symptoms even if I just forget a tablet one day, and when I tried to gradually come off them completely it was too difficult."

"They read the Pharmaceutical guide which states to slowly withdraw for 2-4 weeks. I THINK IT SHOULD READ 2-4 YEARS!! It is criminal what these drugs do to people."

"It was sheer hell! The shakes, dizziness, light headedness, insomnia was almost unbearable."

"The withdrawal landed me in hospital."

"The withdrawal symptoms were worse than the depression itself."

"If I accidentally miss a tablet, even for one day, the side effects are practically instant and quite severe, resulting in me been fairly incapable of doing anything for about 3 days. Once, it was so severe, I thought I was having a nervous breakdown; I was hearing and seeing things, until I realised I'd forgotten my tablet!"

"Had I been forewarned of the possible issues with withdrawal from this drug, I would probably not have chosen to take it".

Emotional and Cognitive Blunting

Twenty participants (5.8%) reported that their feelings were blunted by the medication, using terms like "flattened" or "numbed", while others found it difficult to concentrate and reported that their thoughts slowed.

"It "blunts" me – no extreme laughter or tears. … I don't feel fully myself."

"The drugs make me totally disconnected from everything and lifeless."

"The medication did nothing apart from turn my emotions off which for some can be beneficial but for me was not. I could not feel anything and was dead inside, worse than the darkest days I had problems with. I realized it to be a problem when I narrowly avoided a car accident on the motorway where upon nearly colliding with a lorry but felt completely at ease and calm."

"The medication made me become a zombie. I felt no emotion even when I was told someone very close to me has died. I had no perception of danger around me and I often had near misses with cars and in the kitchen (e.g. with cutting food and switching off appliances). … It was after the death of someone, I made a conscious decision to come off meds slowly and I did it and I will never let anyone put me on them again."

Prescriber Relationship

One hundred and nine participants (31.9%) commented negatively on their interactions or relationship with prescribers. These comments were further categorised into three subthemes: "information", "alternative treatments" and "support."

*Information. F*orty five participants (13.2%) reported that their prescriber did not provide sufficient information, particularly about side effects or withdrawal effects.

"He just wrote me out a prescription for a standard antidepressant without giving me more information."

"More education in regards to what might happen coming off the meds. I was initially told by my doctor that I "might have one or two side effects, but probably not. I really was not prepared for what happened to me!"

"The side effects were not explained well by the GP. … The addictive part of the medication was not explained until I had already started on the medication and that was only after I researched further myself and asked about it."

"The first GP I went to actually told me in all seriousness that there were no known side effects! I'm not retarded. A quick read through the leaflet put his misinformation straight."

"Really not enough information about withdrawal effects or side effects."

"I wasn't told about the side effects. In fact, when I researched myself and then told my doctor, she hadn't got a clue it could affect you in the way it affected me."

Alternative treatments. Thirty three (9.6%) felt they had not been offered other types of treatment.

"GP never offered me any other help or support."

"I wasn't offered any counselling or other forms of therapy and although the medication is helping somewhat, I feel a talking therapy would be useful."

"I was palmed off with drugs and not offered therapies or any alternatives."

"GPs do not have nearly enough access to or knowledge of alternative treatments in order to suggest these in combination with medicines."

"I very much felt that they gave me the drugs and stopped caring. I had no psychological help."

"I am really quite cross that my own health was compromised by an easy reliance on drugs rather than other therapeutic support!"

Support. Thirty one (9.1%) commented on having insufficient support during their treatment, or when trying to come off the drugs.

"I wanted support with my feelings of anxiety and reassurance that I was coping well with my first child (as I was). Instead I was given no choice but to take the medication which led me to having a total breakdown and being placed in an in-patient mother and baby unit for 12 weeks."

"I have found there to be very little support. I struggle with OCD and depression and my doctors surgery is next to useless!"

"I had little to no review or monitoring from GP and tried to stop taking medication by myself, this led me to a suicide attempt."

"Coming off I've received no support from my GP. So, I went through it all myself having researched online the best way to manage it."

"I am currently trying to taper my meds VERY slowly but have little support from my GP who thinks I should continue to take them."

Discussion

It is impossible to generalize about the ratio of positive to negative experiences as the sample was not randomized or representative of all antidepressant users. The percentages of each type of experience (positive and negative) are almost definitely underestimates as the pertinent question was asking about "anything else" and there had already been many questions about positive and negative outcomes. The types of experiences *within* the positive and negative categories, and the *relative* frequency of those types is more informative.

Positive Effects of the Medication

While there have been a few studies reporting first-hand accounts of the negative effects of antidepressants (Gibson et al., 2014), it is rare to read about what it is like to benefit from the drugs, particularly to hear what "effectiveness" means to recipients. In total 10.5% of participants described positive effects, ranging from improving ability to cope with daily tasks to being life-changing or life-saving. The fact that antidepressants are no more effective than placebo for the majority of recipients (Jakobsen et al., 2017; Kirsch et al., 2008) cannot detract from the fact that for some people the medications are experienced as helpful or even life-saving, and therefore *are* helpful or life-saving. In the largest direct to consumer survey, self-reported efficacy of antidepressants was strongly predicted by the quality of the relationship with the prescriber (Read et al., 2015).

A similar proportion (7.6%) focused on effectiveness as a "stepping stone", helping them to engage with other treatments that would facilitate necessary changes in their lives. These other treatments were primarily psychological therapies, such as CBT or counselling. This experience of antidepressants as a stepping stone to other treatments was also a theme in the largest similar study to date (Gibson et al., 2016).

Negative Effects of the Medication

The finding that the most frequent type of negative experiences (23.1%) were physical is consistent with previous studies reporting a very broad range of commonly experienced biological side effects (Adkins et al., 2012; Jakobsen et al., 2017; Read et al., 2014; Read and Williams, 2018), which are recognised by N.I.C.E. (2009). For example, in the two largest direct to consumer surveys to date, drowsiness, dry mouth, weight gain, headaches, insomnia and dizziness were reported by between 45% and 60% of participants (Read et al., 2014; Read and Williams, 2018). Sexual difficulties were reported by more than 60% in both surveys. Among the current sample "sex life" was the most affected (44%) of six life domains (Read et al., 2017). These biological effects can be particularly distressing when one is already depressed and may even increase the depression. These frequencies are concerning but they do not fully capture the extreme nature of some of the experiences, as described by people themselves: "awful", "feeing really ill", "severe fatigue and diarrhea", "really unpleasant", "constant tiredness", "chronic clenched jaw, which was painful", "I sweat constantly and have very poor libido", "I felt really ill, sick, aches and pains, horrible dreams", or "I hate the side effects - which depresses me even more."

Far fewer people (5.8%) reported emotional or cognitive flattening. The two largest surveys, using lists of possible adverse effects, have found rates of "emotional numbing" of 66% (John Read & Williams, 2018) and 60% (Read et al., 2014). Perhaps adverse effects other than those in the physical domain are harder to spontaneously recognize and report than the more traditional sort of "side effects" typically associated with medications. Alternatively (or additionally) the biological effects may be more concerning than those in the emotional and psychological domains and are therefore more likely to be spontaneously reported in response to a broad, open question.

Withdrawal effects were mentioned by 14.0%. As was the case for other types of experiences (positive and negative) this is an underestimate of the actual number who had experienced withdrawal effects because the question was about "anything else" and there had already been questions about withdrawal. These questions - reported elsewhere for all the antidepressant recipients, including those who had not responded to the "anything else" question (Read et al., 2019) - found that of the 138 (out of the current sample of 342) who were no longer taking antidepressants,

28 (20.3%) had found it "very easy" to come off, 59 (42.8%) "fairly easy" and 50 (36.2%) "not easy at all". 48 (34.8%) had taken more than three months to come off, with 20 (14.5%) taking more than six months. A further 152 of the 342 (44.4%) had tried to come off but had not yet succeeded. This quite startling finding has been discussed in the paper analyzing all the antidepressant recipients, including those who had not responded to the "anything else" question (Read et al., 2019). A recent review found that the withdrawal incidence rates from 14 studies ranged from 27% to 86% with a weighted average of 56% (Davies and Read, 2019). Furthermore, four large studies of severity produced a weighted average of 46% of those experiencing antidepressant withdrawal effects endorsing the most extreme severity rating on offer. Seven of the ten studies providing data on duration contradict the UK and USA withdrawal Guidelines (American Psychiatric Association, 2010; National Institute for Health and Care Excellence, 2009) in that they found that a significant proportion of people who experience withdrawal do so for more than two weeks, and that it is not uncommon for people to experience withdrawal for several months, as in the current study. The experience of these effects could be alarming: "a week in bed with severe withdrawal effects", "horrific", "terrifying nightmares every night where I would wake drenched in sweat", "horrendous", "overwhelming and debilitating", "hospitalized", "sheer hell", "unbearable".

In September, 2019 Public Health England published its report (Taylor et al.) on "*Dependence and withdrawal associated with some prescribed medicines: an evidence review"* .On the basis of a comprehensive review of the literature about a range of drugs, including antidepressants, the report made important recommendations in five areas:

1. Increasing the availability and use of data on the prescribing of medicines that can cause dependence or withdrawal to support greater transparency and accountability and help ensure practice is consistent and in line with guidance.

2. Enhancing clinical guidance and the likelihood it will be followed.

3. Improving information for patients and carers on prescribed medicines and other treatments, and increasing informed choice and shared decision making between clinicians and patients.

4. Improving the support available from the healthcare system for patients experiencing dependence on, or withdrawal from, prescribed medicines.

5. Further research on the prevention and treatment of dependence on, and withdrawal from, prescribed medicines. (p. 120).

Relationship with Prescribers: Positive and Negative

A total of 144 people (42.1%) commented on aspects of their relationship with the GP or psychiatrist who first prescribed the antidepressants. It seems this is at least as important to antidepressant users as the drugs themselves. indeed, we have already noted that the quality of the relationship with the prescriber predicts self-reported efficacy of antidepressants (J. Read et al., 2015).

It is important to note that the participants were particularly appreciative of prescribers who worked collaboratively. Collaborative processes in psychotherapy are consistently associated with therapeutic change (Corrêa, Ribeiro, Pinto, & Teixeira, 2016).

However, the majority of the comments about prescribers were negative. Reports that the prescriber was unsupportive, disinterested or disempowering further confirm the importance of the relationship per se, separate from the drugs or information about the drugs.

Nevertheless, the inadequate provision of information, notably about adverse effects - including withdrawal symptoms, was mentioned by 45 of the 109 who commented on prescriber relationships (41.2%) (see Table 2). When asked, earlier in the survey, "Do you feel you were given enough information about the medication, including side effects and withdrawal?" only 48% had said "Yes" (John Read et al., 2019). Of 107 patients prescribed antidepressants by GPs in Britain, 41% could not recall any discussion about adverse effects (Byng, Bury, & Weaver, 2007). In the largest survey to date, in New Zealand, 64% responded "Yes" to "Did the doctor inform you about possible side effects?". The specific side effects they were informed about were biological, such as nausea and weight gain. Very few were told about psychological or interpersonal effects, and only 1% were told anything about withdrawal effects (Read et al., 2014; Read et al., 2018). The second largest, international, survey found that only 34% of antidepressant users replied "Yes" to "Did the doctor inform you of any possible side effects?" (John Read & Williams, 2018), mostly, again, biological. Less than 1% were told about withdrawal.

Not being offered alternatives to antidepressants was remarked on by 33 participants (30.3% of those with negative comments about prescribers). The data does not indicate how many were offered alternatives but does suggest that those who were not found it problematic. In New Zealand most antidepressant users (82%) received at least one alternative recommendation, most commonly "Counsellor/Psychologist/Psychotherapist" (74%) and Exercise Schedule (43%) (John Read, Gibson, & Cartwright, 2016).

Limitations

This is a self-selected, convenience sample and is not, therefore representative of antidepressant users in general. Black and ethnic minority groups, for example, are underrepresented. It is also possible that people 'with an axe to grind' are differentially attracted to online surveys. However, the fact that 86.9% found their antidepressants at least "fairly effective" suggest that this was not the case. Some of the participants' comments involve remembering events from several years ago, and may, therefore, be less than completely accurate.

Conclusion

This study confirms that simply reporting research participants' responses, to a completely open question, produces data that can 'bring to life' pre-existing quantitative findings, rendering them more meaningful and powerful. It can also, however, generate less expected results. In the current study, for instance, antidepressant users were just as keen to talk about the importance of their interactions with the prescriber as about the effects of the drugs.

Apart from highlighting the importance of therapeutic relationships, our findings also confirm the importance of the related professional, ethical principle of informed choice. Prescribers and other mental health professionals all have a duty to inform potential antidepressant users about their adverse effects, and about the difficulties that so many have when they try to come off or reduce. It seems that, too often, this is not happening. All mental health professionals should play their part in ensuring that the principle of informed choice is strictly adhered to. Clinicians, including non-medical mental health professionals (Guy et al. 2019), also have a responsibility to ensure that people receive

appropriate professional support when they choose to reduce or withdraw from antidepressants. Perhaps the use of verbatim quotations, positive and negative, of the kind generated by this study might render information sheets more meaningful and accessible to readers.

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