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How important are informed consent, informed choice, and patient-doctor relationships, when prescribing antipsychotic medication?

Read, John

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Abstract

Background: Antipsychotic medications (APs) are used for people with psychosis diagnoses and, increasingly for other problems and groups.

Aims: This study examines how APs are prescribed, from the perspective of recipients.

Methods: 757 people, from 30 countries, responded to questions about their experiences with APs in an online survey.

Results: Most (70%) were told nothing about adverse effects. Fewer than 2% recall being told about the risks of diabetes, suicidality, sexual dysfunction or reduced life span. None recalled being told about reduced brain volume or withdrawal effects. Only 28% recalled being offered other treatments; with only 14% offered talking therapies. 46% were not told how long to take the APs; and, of those, 48% were told to take them forever. Most respondents (76%) were not told how APs work. Only 19% were satisfied with the prescribing process, and only 25% reported a good, or very good, relationship with the prescriber. Information, satisfaction with the process

and prescriber relationship were all positively related to three self-reported outcomes: reduction of problems the drugs were prescribed for, general helpfulness, and quality of life.

Conclusions: Steps need to be taken to ensure people prescribed antipsychotics are fully informed, especially about adverse effects and alternatives.

Key words: Antipsychotics, Adverse effects, Psychosis, Informed consent, Therapeutic relationship

Introduction

Antipsychotic medications (APs) remain the most common treatment for people diagnosed with 'schizophrenia' spectrum disorders, but are increasingly prescribed for other problems and to older people, adolescents and prisoners (Hutton et al., 2013). A study of 47,724 people prescribed APs in the UK found that only about a half had diagnoses indicative of psychosis, that other common diagnoses included anxiety, depression, dementia and personality and sleep disorders, and that rates were higher for women, older people and people living in deprived areas (Marston et al., 2014).

Governments (NICE, 2015) and professional psychiatry bodies (APA, 2010) strongly recommend APs. Recent studies and reviews suggest, however, that early claims about their efficacy and safety may have been exaggerated (Ceraso et al., 2020; Cooper et al., 2021; Hutton et al., 2013). Some people do find the drugs helpful, particularly in the short term. For example, the online survey on which the current paper is based found that more than a half of respondents (56%) thought the drugs reduced the problems for which they were prescribed (Read & Williams, 2019). About a quarter (27%), however, thought they made the problems worse. Furthermore,

slightly fewer people found the drugs generally 'helpful' (41%) than found them 'unhelpful' (43%); while 35% reported that their 'quality of life' was 'improved' and 54% reported that it was made 'worse' Responses to open-ended questions, in the same survey, about the respondents' overall experience of APs, showed that 14% reported only positive experiences (including that they had saved the participant's life), 28% had mixed experiences, and 58% reported completely negative experiences. The most common 'mixed' theme was 'short-term good, long-term bad' (Read & Sacia, 2020).

A review of 38 trials found that second generation ('atypical') APs failed to meet the 'minimal clinical improvement' threshold (in this case 15 points on the Positive and Negative Syndrome Scale); and that 17% of those taking APs long-term relapsed, compared to 39% of those on placebo, suggesting that only 22% benefitted from the medication (Leucht et al., 2009). A review of 120 studies confirmed that APs are associated with less than 'minimal global improvement' (Lepping et al., 2011). A Cochrane review concluded: 'Data are too limited to assess outcomes from initial antipsychotic medication treatment for individuals with an early episode of schizophrenia' (Bola et al., 2011). A meta-analysis, of 167 double-blind randomized controlled trials, found that 23% of the AP group had a 'good' response, compared to 14% on placebos (and also revealed that independent studies produced significantly worse results than drug company funded studies) (Leucht et al., 2017).

Recent studies (Francey et al., 2020; Morrison et al., 2014) and reviews (Calton et al., 2008; Cooper et al., 2020a), have found that psycho-social approaches to psychosis, such as CBT, Need Adapted Therapy and Soteria, have similar or superior outcomes to APs, across a range of measures including symptom reduction, social functioning and cost. Five evaluations of psychosocial treatments combined with AP postponement all found better outcomes for psychosis than immediate AP treatment, in terms of relapse rates, symptoms and social functioning (Bola et

al., 2009). A small study of 48 people diagnosed with schizophrenia spectrum disorders found no difference in symptoms between people taking and not taking APs. 'However, the non-medicated participants had significantly higher levels of general functioning than medicated participants and a longer duration of being non-medicated was significantly associated with a higher level of general functioning (Jung et al., 2016, p. 2179). It has also been found that although reduction/discontinuation of APs during the early stages of remitted psychosis increases relapse in the short-term, it is 3.5 times more likely than maintenance AP treatment to lead to recovery seven years later (Wunderink et al., 2013).

Adverse effects include tardive dyskinesia, cardiovascular effects, metabolic effects, sexual dysfunction, sedation, dizziness, akathisia, dry mouth, reduced brain volume, and shortened life span (Ho et al., 2011; Hutton et al., 2013; Longden & Read, 2016a; Miller et al., 2008; Weinmann et al., 2009, 2010). In the survey on which the current paper is based, the largest 'direct-to-consumer' survey to date, 64% of AP users reported at least ten side effects; including sedation (92%), loss of motivation (86%), slowed thoughts (86%), emotional numbing (85%), weight gain (84%), loss of sex drive (74%) and suicidality (58%) (Read & Williams, 2019).

The adverse effects most frequently reported by 205 people during development of an Australian questionnaire (Ashoorian et al., 2015) were: 'felt tired' (77%) and 'had difficulty waking up' (59%). The recently published *Maudsley Side Effects* measure for APs (Wykes et al., 2017) identifies 53 adverse effects, most frequently 'feel tired' (77%) and 'put weight on' (70%). The most common effects reported by 439 users of an Internet site were sedation, cognitive impairment, emotional flattening and loss of interest (Moncrieff et al., 2019).

The current paper is based on the responses in the previously mentioned large international survey (Read & Williams, 2019), to questions about the process of being prescribed APs, and the prescriber-patient relationship at that time. A similar 'direct-to-consumer' survey, of

antidepressant users, had found that the quality of the patient-prescriber relationship, and the amount of information imparted about the drugs, were predictive of self-reported depression reduction and improved quality of life (Read et al., 2015). In psychotherapy research, therapeutic alliance is well established as a predictor of positive outcome (Ardito, et al., 2011), including in cognitive therapy for psychosis (Goldsmith et al., 2015).

Because information sharing, offering a range of treatments and establishing therapeutic relationships are generally considered good practice, it seemed important to know how often these three things are happening and whether they are related to positive outcomes. Therefore, the current paper reports the extent to which various types of information were given to people when first prescribed APs, what alternative treatments they were offered, and their overall impressions of the prescribing process and of the prescriber-patient relationship. It then investigates whether these variables are related to the three self-reported outcomes: general helpfulness, extent to which the drugs reduced the problems for which they were prescribed, and quality of life.

Methods

The study was approved by Swinburne University of Technology's Human Research Ethics Committee (Melbourne, Australia), where the study design and data collection occurred. Data analysis and manuscript preparation took place at the University of East London, UK.

Instrument

The Experiences of Antidepressant and Antipsychotic Medication Survey, an online questionnaire, has quantitative and open questions about the effects of psychiatric medications (Read, 2020a; Read and Sacia, 2020; Read and Williams, 2018, 2019); beliefs about causes of

depression and psychosis (Read, 2020b; Read et al., 2014) and the prescribing process (Read et al., 2016; Read et al., 2021). This paper reports responses to four specific questions about the prescribing process: 'Did the prescribing doctor tell you how antipsychotic medication works?'; 'Did the doctor inform you of any possible side effects?'; 'Were you offered any other treatment options to consider as alternatives or additions to antipsychotics?'; and 'How long were you told you could expect to take it for?' It also reports responses to two general questions (using 5-point likert scales): 'Overall, how satisfactory was the initial prescribing process for you?'(from 'very satisfactory' to 'very unsatisfactory') and 'How would you describe your relationship with the doctor' ('very good', 'good', 'neutral', 'not good', 'not at all good').

Efficacy was measured by 5-point likert scales: (i)'How helpful would you say the antipsychotic medication was?' ('very helpful' to 'very unhelpful'); (ii) 'As a result of taking antipsychotic medication, the problems for which they were prescribed were… ('greatly reduced' to 'a lot worse'); and (iii) 'As a result of taking anti-psychotic medication my quality of life was…' ('greatly improved' to 'a lot worse'). Results are published (Read and Williams, 2019b).

Participants

Of the 2,346 people who responded, 668 were recruited by a research company, and 1,678 people via social media. The three inclusion criteria, 'I have been taking or have previously taken antipsychotic medication continuously for at least one month'; 'I am aged 18 or older'; and 'I am not currently compulsorily detained in a psychiatric hospital' were met by 963 people. Fifty-one responses had the same Internet Protocol address as another response, indicating use of the same device; 23 of these were excluded because of identical demographics or similar responses. Of the remaining 938, 27 responded to 'What is the name of your current or most recent antipsychotic

medication?' with a medication that was snot an AP. Of the residual 911, 757 responded to the six questions about the prescribing process listed above, and were included for analysis.

Data analysis

Relationships between categorical variables (gender, having a psychosis diagnosis, being under compulsory treatment, and yes/no questions about the prescribing process) were assessed with chi squares (X^2). Age differences in relation to categorical variables were assessed with two-tailed, independent samples t-tests (t). Relationships between age and the two likert-scales were evaluated with Spearman rank correlation coefficients (rho). Because of the large number of analyses the probability required to indicate significance was reduced from the traditional < .05 level to < .01 to reduce the chances of type 1 (false positive) errors.

Results

Sample characteristics

The majority of participants were women (69.0%). Ages ranged from 18 to 76, averaging 43.0 years (sd 13.3). Participants were from 30 countries, mostly (71.5%) from USA (25.2%), Australia (24.8%) or UK (21.4%). Other countries contributing at least ten were: Canada (4.0%), New Zealand (3.8%), Netherlands (3.1%), Ireland (2.8%), Denmark (2.5%), Germany (2.1%), Norway (1.6%), Switzerland (1.6%) and South Africa (1.3%). Others contributed from one to six participants: Austria, Belgium, Croatia, Estonia, Finland, France, Greece, Iceland, India, Israel, Italy, Lithuania, Poland, Portugal, Romania, Spain, Sweden, Ukraine.

About a quarter (26.5%) had taken APs for 1 to 12 months, 18.6% for one to three years, and 55.0% for more than three years. Among the 663 providing their 'primary

diagnosis', the. DSM-V groupings cited by ten or more participants were: Schizophrenia Spectrum and Other Psychotic Disorders' - 203 (30.6%); 'Bipolar and Related Disorders' - 190 (28.7%); 'Depressive Disorders' - 169 (25.5%); 'Personality Disorders' - 36 (5.4%); and 'Trauma and Stressor-Related Disorders' - 20 (3.0%); Secondary diagnoses included 52 in the schizophrenia spectrum, bringing the total (primary or secondary) for that grouping to 255 (38.5%). A quarter (25.2%) were being compulsorily treated when first prescribed APs.

The survey's outcomes data has been reported before (Read and Williams, 2019). Roughly equal numbers of the 757 in the current sample experienced the drugs as 'helpful' (40.9%) and 'unhelpful' (42.9%). About twice as many found that the drugs 'reduced the problems for which they were prescribed' (55.7%) as thought they made them 'worse' (26.3%). More reported that their 'Quality of Life' was made worse (53.7%) than thought it was 'improved' (35.6%).

TABLE 1 ABOUT HERE

'Did the prescribing doctor tell you how antipsychotic medication works?'

When asked 'Did the prescribing doctor tell you how antipsychotic medication works?', 573 (75.7%) replied 'no' and 184 (24.3%) 'yes'. This was unrelated to gender, age, being under compulsory treatment when prescribed APs, or having a psychosis diagnosis (see Table 1). When the 184 were asked for 'a brief summary of what you were told' 19 could not recall, five just reported being given a leaflet, and 23 either didn't respond or provided irrelevant comments.

The other 137 provided one or more specific mechanisms (Table 2), most commonly 'corrects chemical imbalance' (51), 'improves sleep' (20), and 'tranquillises/calms/sedates' (19) (Table 1).

TABLE 2 ABOUT HERE

Age was unrelated to the explanations about how APs work. Two groups were more likely than other people to be told that the drugs work by correcting a chemical imbalance; those with a psychosis diagnosis (61.3% vs 17.4%; $X^2 = 26.7$, $p < .001$) and those being compulsorily treated (62.1% vs 28.7%; $X^2 = 10.9$; $p = .001$).

'Did the doctor inform you of any possible side effects?'

The responses to this question have been reported previously, in a paper reporting the actual adverse effects experienced (Read and Williams, 2019). In the current sample of 757, 534 (70.5%) replied 'no' and 223 (29.5%) 'yes'.

Those responding 'yes' were younger (X = 40.2 years) than those not informed (44.2 years) ($t = 3.73$, $df = 750$, $p < .0001$). Only 15.5% of those over 60 were told anything about side effects. There were no differences in relation to gender, diagnosis (psychosis vs other), or compulsory treatment.

The side effects that participants were most frequently told about were weight gain (127; 16.8% of the 757) and drowsiness/sedation/tiredness (74; 9.8%). All other effects were mentioned by fewer than 3% of respondents, including: tardive dyskinesia - 18 (2.4%); diabetes - 9 (1.2%); suicidality - 8 (1.1%); sexual dysfunction - 6 (0.8%); neuroleptic malignant syndrome - 3 (0.4%); and reduced life span/death - 1 (0.1%). None of the 757 recall being told about withdrawal effects or reduced brain volume.

'Were you offered any other treatment options to consider as alternatives or additions to antipsychotics?'

About two thirds (64.4%) were offered no other treatments to consider; 27.8% were offered one or more, and 5.7% could not remember. More women (33.2%) than men (23.0%) were offered alternatives ($X^2 = 7.3$, p = .007). Age, diagnosis and compulsory treatment were unrelated to being offered other treatments.

Of the 197 who went on to say what alternatives were offered for consideration, 105 (13.9% of the 757) were offered some form of talking therapy, most commonly cognitive behaviour therapy (23), followed by group therapy (6), dialectical behaviour therapy (5), and counselling (5). Only two were offered family therapy. Being offered talking therapy was unrelated to age, gender, compulsory treatment or diagnosis.

Other psychiatric drugs as alternative treatments were mentioned by 76 (10.0%), most commonly anti-depressants (37), benzodiazepines (29) and lithium (15). In the sub sample of 197, those with a non-psychosis diagnosis were more likely than those with a psychosis diagnosis to be offered other drugs (45.3% vs 26.0%; $X^2 = 7.1$, p = .008). Women were far more likely than men to be offered other drugs (43.9% vs 15.0%; $X^2 = 11.3$, p = .001). Age and compulsory treatment were unrelated.

Electroconvulsive therapy (ECT) was cited by 29 participants (3.8%). Among the subsample of 197, men were more likely to be offered ECT than women (27.5% vs 10.9%; $X^2 = 7.2$, p = .007). Those offered ECT were older (X = 51.7) than other participants (X = 41.4) (t = 3.9, df = 201, p < .0001). Diagnosis and compulsory treatment were unrelated.

Other alternative approaches offered to two or more participants were: hospitalisation (6), occupational therapy/employment assistance (6), exercise/yoga (5), art/music therapy (5),

meditation (3), peer support (2), transcranial magnetic stimulation (2), financial support/advice (2), employment assistance/advice (2).

'When you were first prescribed antipsychotic medication, how long were you told you could expect to take it for?'

Table 4 lists the responses to this question. The two most common, by far, were 'I wasn't told/this wasn't discussed' (46.9%) and 'the rest of your life' (25.6%). Only 67 (8.9%) were told they would be on the drugs for a year or less. Whether or not people were told how long they would be on the drugs was unrelated to age, gender or diagnosis. However, those being compulsorily treated were more likely (65.4%) than others (49.0%) to be told how long they would be on the drugs ($X^2 = 15.0$, $p < .0001$), and more likely to be told they would be on them for life (34.0% vs 22.8%; $X^2 = 9.1$, $p = .003$). Those with a psychosis diagnosis were also more likely to be told they would be on the drugs for life (33.1% vs 23.0%; $X^2 = 8.4$, $p = .004$). Those people told 'rest of your life' also had a significantly higher average age (45.7 years) than others (42.1) ($t = 326$, $df = 750$, $p = .001$). Gender was unrelated to being told one should be on the drugs for life.

TABLE 4 ABOUT HERE

'How would you describe your relationship with the doctor?'

12.2% described their relationship with the prescriber as 'very good', and, at the other extreme of the five-point scale, 21.7% endorsed 'not at all good' (see Table 1). Those with a psychosis diagnosis reported worse relationships ($X^2 = 36.1$, $df = 4$, $p < .0001$), as did those under compulsory treatment ($X^2 = 28.4$, $df = 4$, $p < .0001$). Gender and age were unrelated.

'Overall, how satisfactory was the initial prescribing process for you?'

Table 1 shows that 5.2% found the prescribing process 'very satisfactory' and 41.2% ticked 'not at all satisfactory'. Satisfaction was negatively related to compulsory treatment (X^2 = 27.5, df = 4, p < .0001), a psychosis diagnosis (X^2 = 25.0, df = 4, p < .0001), and age (rho = .12, n = 752, p = .001) (i.e. younger people were more satisfied). Gender was unrelated.

Relationships of prescribing process variables with self-reported efficacy of antipsychotics

Three of the four specific prescribing variables were strongly, positively related to all three outcome measures, as was overall satisfaction with the prescribing process and quality of relationship with prescriber (see Table 4). Being told how long to take APs was significantly related only to the 'reduced problems for which APs were prescribed' outcome measure. For example, 24.7% of those who were told how the drugs work experienced the drugs as 'very helpful', compared to 13.5% of those who were not told. Similarly, 24.4% of those who were told about adverse effects reported the drugs to be 'very helpful' compared to 12.8% of those not informed. The difference for those offered at least one alternative treatment and those offered none, was 22.0% vs 11.5%.

Both the overall satisfaction with the prescribing process and the quality of relationship with prescriber were even more strongly related to the three measures of efficacy (all at the < .0001 level) than were the specific variables (Table 4).

Of those who experienced the process as 'very satisfactory' 61.5% reported that Quality of Life was 'greatly improved' by the APs and only 7.7% said it was made 'a lot worse'; whereas the corresponding figures for those who found the process 'not at all satisfactory' were 2.9% 'greatly improved' and 71.5% 'a lot worse'. Similarly, 66.7% of those reporting the whole process as 'very satisfactory' said the APs were 'very helpful' and 2.6% said 'very unhelpful; but

the figures for those describing the process as ‘not at all satisfactory’ were 2.6% ‘very helpful’ and 62.7% ‘very unhelpful’. Likewise, 71.8% of the ‘very satisfactory’ group reported that APs had ‘greatly reduced’ the problems for which they had been prescribed and none said it made them ‘a lot worse’; whereas in the ‘not at all satisfactory, group the figures were 11.9% ‘greatly reduced’ and 38.6% ‘a lot worse’.

Similarly, of those who described the quality of the relationship with the prescriber as ‘very satisfactory’ 41.8% reported that their Quality of Life was ‘greatly improved’ by the APs and 14.3% said it was made ‘a lot worse’; whereas the corresponding figures for those who found the relationship ‘not at all good’ were 1.2% ‘greatly improved’ and 76.8 ‘a lot worse’. Whereas 47.3% of those reporting the relationship as ‘very good’ said the APs were ‘very helpful’ and 9.9% ‘very unhelpful’, the figures for those describing the relationship as ‘not at all good’ were 1.8% ‘very helpful’ and 67.5% ‘very unhelpful’. Finally, 51.68% of the ‘very good’ group reported that the APs had ‘greatly reduced’ the problems for which they had been prescribed and 6.6% said it made them ‘a lot worse’; whereas in the ‘not at all good’ group the figures were 8.0% ‘greatly reduced’ and 46.9% ‘a lot worse’.

Discussion

Informed consent

The failure to provide adequate information about possible adverse effects to most of the people responding to this survey has been reported, and discussed, before (Read & Sacia, 2020; Read & Williams, 2019). Even allowing for some forgetting by the respondents of what they were told, it seems the majority of prescribers are breaching the basic ethical principle of informed consent. The fact that hardly any of 757 people were told about diabetes, sexual dysfunction, suicidality, potential shortened life span, neuroleptic malignant syndrome (which is a life-threatening

reaction to APs involving rapid onset fever and muscle rigidity), and none were told about withdrawal effects or reduced brain volume, might reasonably be described as negligent.

There has been little research, with small samples, into this important ethical issue. A study of 20 British AP users, with diverse attitudes about the drugs, 'commonly experienced their prescribing psychiatrist as not sufficiently acknowledging the negative impacts of medication on life quality and physical health concerns' (Morant et al., 2017). Most of 69 British people who found APs helpful reported, nevertheless, not being warned about side effects (Gray et al., 2015).

Prescribers may fear that informing people about the adverse effects of APs would decrease the chances of their taking the medication, thereby negatively influencing outcomes. This is a reasonable explanation given that few people would take something if told it might cause diabetes, reduced brain size and shortened life span; but it is not an excuse for unethical practice. Psychiatrists may be reassured to learn that participants who *were* informed of adverse effects reported *better* outcomes.

Psychiatrists may also fear that informing people about adverse effects will lead to greater reporting of those effects and attributing them, wrongly or rightly, to the drugs. A previous analysis of respondents to the current survey, however, found that those informed about adverse effects reported significantly *fewer* adverse effects (Read & Williams, 2019).

Failure to inform patients about withdrawal is understandable because the withdrawal effects of APs, like those of anti-depressants (Davies & Read, 2019; Read et al., 2019a), have long been minimised, denied or confused with relapse (Cooper et al., 2020b; Moncrieff, 2013; Read, 2021; Read et al., 2019b).

Older people being less likely to recall being told about adverse effects might be explained by clinical practice improving over time, or by older people being less likely to recall what they

were told, or by an ageist assumption that negative effects matter less in older people; or some combination of these three possibilities.

Withholding information about how APs work is also unhelpful. Sharing information about this was positively related to all three outcome measures (helpfulness, quality of life, problem reduction). There is little research on this topic. The most common explanation offered in the current study is that the drugs correct a chemical imbalance, which is a disputed theory with little robust evidence for the imbalance, or the correction thereof (Moncrieff, 2013; Read, 2013). Accurate or not, this explanation clearly locates the problem within the person's brain rather than in their developmental history or social circumstances (Longden & Read, 2016b; Read, 2019; Read & Dillon, 2013).

The findings that about half were told nothing about how long to take APs, and that about one in four were told to take them forever, are problematic. Some psychiatrists believe that it is necessary to keep patients on antipsychotics for years, or forever. In practice, many people do remain on these drugs for their entire (albeit perhaps shortened) lifespans. Given the severity and frequency of the drugs' adverse effects summarised earlier, including potential shortening of life span, duration of treatment should be kept as short as possible (Moncrieff, 2015; Weinmann et al., 2009).

Informed choice

Another ethical principle guiding all medical and mental health professionals, is that patients should, where appropriate, be informed about, and offered, a range of treatments, rather than be persuaded (or forced) to take the professional's preferred option. This applies equally to psychiatrists and non-medical mental health professionals such as clinical psychologists. The findings that two thirds were offered no alternatives and only one in seven was offered some

form of talking therapy clearly breach this principle. There are numerous evidence-based non-medical approaches to treating or supporting people who experience psychosis, all of which have fewer adverse effects than APs, including, for example, CBT for psychosis, Open Dialogue, and Soteria, (Calton et al., 2008; Cooke, 2017; Cooper et al., 2020a; Hurley et al., 2021; Morrison et al., 2018; Nelson, et al., 2020; Read, 2019; Read & Dillon, 2013; Read et al., 2020; Ridenour et al., 2019; Steele et al., 2020). Although the evidence base is still being developed, peer-led Hearing Voices Groups also seem promising (Hornstein et al., 2020; Longden et al., 2018). In a recent report promoting 'person-centred and rights-based approaches' to mental health services, the World Health Organisation described 22 interantional examples of alternatives to traditional medication oriented services (W.H.O., 2021).

People have a right to be informed about these alternatives, including their positive and negative effects, *and* to be offered them. People diagnosed with 'schizophrenia' and other diagnoses indicative of psychosis consistently attribute their difficulties more to psycho-social issues than bio-genetic factors (Read et al., 2013), including those responding to the current survey (Read, 2020b). The help they are offered should therefore include approaches addressing the adversities and traumas they report (Bentall et al., 2014; Cooke, 2017; Read, 2019; Read & Dillon, 2013; Read et al., 2020; Ridenour et al., 2019; Shevlin et al., 2011; Steele et al., 2020). The study of 69 British patients who experienced APs as helpful found that most had not been offered alternative treatments (Gray et al., 2015).

A related, but rarely discussed, issue is the need for information about how to successfully withdraw from these medications (Cooper at al., 2020b; Guy et al., 2019; Horowitz et al., 2021; Larsen-Barr, 2018; Larsen-Barr & Seymour, 2021; Moncrieff et al., 2020).

The impact of information sharing, collaborative decision making and relationship building on outcome

In the current study all aspects of the prescribing process were strongly related to positive outcomes. This is consistent with a similar, large direct-to-consumer survey of antidepressant users, which found that the patient–prescriber relationship and the amount of information imparted about the antidepressants predicted self-reported depression reduction and improved quality of life (Read et al., 2015). A British study of 228 people meeting DSM-IV criteria for schizophrenia or schizoaffective disorder found that a poor relationship with the prescriber of APs and experience of coercion during admission predicted a negative attitude toward treatment (Day et al., 2005).

Informed consent and informed choice are not only fundamental patient rights, they are also essential ingredients of successful treatment. As all AP trials demonstrate, a significant component of any positive outcome is to be found in the non-specific, placebo effects, which may include the process of prescribing drugs (Bola et al., 2009, 2011; Hutton et al., 2013; Lepping et al., 2011; Leucht et al., 2009, 2017). Non-specific and placebo effects are important components of all interventions, biological and psychological (Kirsch, 2019; Priebe et al., 2019). The current study suggests these may include honesty about negative as well as positive drug effects, and offering alternatives to the drugs.

Clinical implications

The findings of this study confirm that clinicians should always strive to adhere to the ethical principles of informed choice and informed consent. Prescribers of APs should fully inform

patients of all the potential benefits and risks (without fear of worse outcomes) and always offer a range of alternative, safer, treatments.

Forcing people to take APs drugs against their will breaches these two principles, and can also damage or destroy the therapeutic relationship, which is so often essential in the healing process (Day et al., 2005; Prytherch et al., 2021; Shattock et al. 2018).

Non-medical mental health staff should play their part in ensuring that mental health services adhere to these ethical principles in relation to psychiatric medication (Guy et al., 2019).

Limitations

An obvious potential limitation of this study is that respondents were a non-randomised, convenience sample. People responding to an online invitation about psychiatric drugs might be more likely than other users of those drugs to have strong opinions, a story to tell or an 'axe to grind'. It seems unlikely, however, that the sample disproportionately included people with negative attitudes towards APs, because more than half (56%) reported that their APs had 'reduced the problems for which they were prescribed', which is far higher than the 23% found to have a 'good' response in a recent meta-analysis of drug trials (Leucht et al., 2017).

The study used a cross-sectional, rather than a longitudinal, design and therefore possible cause and effect relationships cannot be established with a high degree of certainty.

Poor people may have been less likely to participate for lack of internet access. People from low and middle income countries, and ethnic minorities, were clearly underrepresented.

It is possible that reducing the probability required to indicate significance, from $< .05$ to $< .01$, was insufficient to eliminate all type 1(false-postive) errors.

Conclusion

People are often not informed about the risks of APs and not offered alternatives. The reasons for this need to be studied further. Rapid remedial steps need to be taken to ensure people prescribed antipsychotics drugs are informed of the way these drugs work, potential adverse effects and alternative treatments. By adhering to the principles of informed consent and informed choice, prescribers will improve their relationships with, and outcomes for, their patients.

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Table 1

Summary of responses to survey.

	Yes	No				Related variables
Told how APs work	24.3%	75.7%				
Told about side effects	29.5%	70.5%				Younger + CTO* -
Told how long to take APs	53.1%	46.9%				CTO +
Offered other treatments	30.2%	69.8%				Women +
Satisfaction with prescribing process	Very satisfactory 5.2%	Satisfactory 14.1%	Neutral 22.5%	Not satisfactory 17.0%	Not at all satisfactory 41.2%	CTO - Younger + Psychosis -
Relationship with prescriber	Very good 12.2%	Good 23.1%	Neutral 25.1%	Not good 17.9%	Not at all good 21.7%	CTO - Psychosis -

\+ positively related

\- negatively related

* CTO = compulsory treatment order when prescribed APs

Table 2

When prescribing doctors did say how antipsychotics work, what did they say?

	n	% of 137 who reported what they were told	% of 757, whole sample
BIOLOGICAL	56	40.9%	7.4%
Corrects chemical imbalance	51	37.2%	6.7%
Other/unspecified brain process	6	4.4%	0.8%
EMOTIONAL	36	26.3%	4.8%
Tranquillises/calms/sedates	19	13.9%	2.5%
Controls mood swings/mania/'bipolar'	15	10.9%	2.0%
Reduces depression	3	2.2%	0.4%
IMPROVES SLEEP	20	14.6%	2.6%
IMPROVES THINKING	14	10.2%	1.8%
REDUCES PSYCHOTIC SYMPTOMS	8	5.8%	1.1%
ENHANCES/ENABLES OTHER TREATMENTS	6	4.4%	0.8%
Antidepressants	4	3.0%	0.5%
Psychological treatments	2	1.5%	0.3%

Table 3

'When you were first prescribed antipsychotic medication, how long were you told you could expect to take it for?'

Response	n	% of 757
I wasn't told / this wasn't discussed	355	46.9%
The rest of your life	194	25.6%
Until you felt better	54	7.1%
About a month	11	1.5%
1 - 3 months	23	3.0%
4 - 6 months	14	1.8%
7 - 12 months	19	2.5%
More than a year	48	6.3%
Other	39	5.2%

Table 4

Relationship between prescribing processes and three self-report measures of efficacy of antipsychotics.

	'Reduced problems for which APs prescribed'	'Helpful'	'Improved Quality of Life'
Told how APs work (n = 751)	X^2 = 17.0 *	X^2 = 16.8 *	X^2 = 14.5 *
Told about side effects (n = 751)	X^2 = 19.0 **	X^2 = 24.0 ***	X^2 = 19.2 **
Told how long to take APs (n = 755)	X^2 = 17.3 *	X^2 = 7.2 ns	X^2 = 7.0 ns
Offered other treatments (n = 711)	X^2 = 15.5 *	X^2 = 17.6 *	X^2 = 27.1 ***
Overall satisfaction with prescribing process (n = 755)	rho = .49 ***	rho = .60 ***	rho = .60 ***
Good relationship with prescriber (n = 754)	rho = .43***	rho = .50 ***	rho = .50 ***

X^2 = chi square; rho = Spearman rank correlation coefficient

*< .01, **<.001, ***< .0001; ns = not statistically significant