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RESEARCH ARTICLE

Positive and Negative Effects of Antipsychotic Medication: An International Online Survey of 832 Recipients

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ARTICLE HISTORY

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Abstract: ***Background*:** Antipsychotic medication is currently the treatment of choice for psychosis, but few studies directly survey the first-hand experience of recipients.

***Objective*:** To ascertain the experiences and opinions of an international sample of users of antipsychotic drugs, regarding positive and negative effects.

***Methods*:** An online direct-to-consumer questionnaire was completed by 832 users of antipsychotics, from 30 countries – predominantly USA, UK and Australia. This is the largest such sample to date.

***Results*:** Over half (56%) thought, the drugs reduced the problems they were prescribed for, but 27% thought they made them worse. Slightly less people found the drugs generally 'helpful' (41%) than found them 'unhelpful' (43%). While 35% reported that their 'quality of life' was 'improved', 54% reported that it was made 'worse'. The average number of adverse effects reported was 11, with an average of five at the 'severe' level. Fourteen effects were reported by 57% or more participants, most commonly: 'Drowsiness, feeling tired, sedation' (92%), 'Loss of motivation' (86%), 'Slowed thoughts' (86%), and 'Emotional numbing' (85%). Suicidality was reported to be a side effect by 58%. Older people reported particularly poor outcomes and high levels of adverse effects. Duration of treatment was unrelated to positive outcomes but significantly related to negative outcomes. Most respondents (70%) had tried to stop taking the drugs. The most common reasons people wanted to stop were the side effects (64%) and worries about long-term physical health (52%). Most (70%) did not recall being told anything at all about side effects.

***Conclusion*:** Clinical implications are discussed, with a particular focus on the principles of informed consent, and involving patients in decision making about their own lives.

Keywords: Antipsychotic drugs, psychosis, suicidality, sedation, TAE, second generation, maudsley side effects.

1. INTRODUCTION

Antipsychotic drugs are the cornerstone of treatment for people diagnosed with 'schizophrenia' spectrum disorders, and are increasingly used for other problems and with adolescents, old people and prisoners [1]. Guidelines from governments [2] and psychiatry [3] strongly recommend antipsychotics. Recently, however, studies suggest that claims about their efficacy, and safety, have been exaggerated [4-9].

A review of 38 trials of 'atypical' ('second generation') antipsychotics drugs found that symptom reduction did not meet the threshold for minimal clinical improvement and that 17% of those taking antipsychotics long term relapsed, compared to 39% of those taking placebo, meaning that only 22% benefitted from the medication [4]. Another review, of 120 studies, confirmed that antipsychotics are associated with less than minimal global improvement [5]. A Cochrane review concluded that 'Data are too limited to assess outcomes from initial antipsychotic medication treatment for individuals with an early episode of schizophrenia' [6]. A recent meta-analysis of 167 double-blind randomized controlled trials found that 23% had a 'good' response in the antipsychotic group *vs* 14% on placebos, and that industry-sponsored studies produced significantly more positive results [7].

Five evaluations of psychosocial treatments combined with the postponement of antipsychotics all demonstrated advantages compared to immediate medication treatment [8]. A recent study found no difference in symptom severity between those taking and not taking antipsychotics, and that the non-medicated people had higher level social functioning [9].

1.1. Adverse Effects

Amongst the many adverse effects of the first generation, or 'typical' antipsychotics, the most disturbing was Tardive Dyskinesia, which involves uncontrollable movements of face, hands and feet [2]. The 'atypicals' were marketed, in the 1990s, largely on the claim that they did not cause Tar-

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dive Dyskinesia [10], which was untrue [2, 10, 11]. Moreover, the newer drugs had other adverse effects: cardiovascular effects, metabolic effects, sexual dysfunction, sedation, dizziness, akathisia, dry mouth, reduced brain volume, and shortened life span [2, 12-15]. These effects contribute to findings that about half of antipsychotic recipients do not comply with treatment [16], and about three quarters stop antipsychotics within 18 months [17].

1.2. First Person Experiences

Most of these studies, of efficacy and safety, involve quantitative methods, including RCTs, often of short duration [12]. Less attention has been given to the 'real-life' experiences of people who take the drugs. Some of the few studies of self-reports seem less interested in the experiences per se than on predicting 'non-compliance' [18, 19]. A few studies have looked at the process of withdrawing [20-22]. Some small but valuable studies have focussed on adverse effects [23-26]. For example, ten Australian antipsychotic users reported an average of six side effects, with 'a major disruptive impact on their lives' [27]. The most frequent was sedation, described as a 'zombie'-like state. A recent study of 20 British antipsychotic users [28] revealed a range of attitudes to antipsychotics, but 'they commonly experienced their prescribing psychiatrist as not sufficiently acknowledging the negative impacts of medication on life quality and physical health concerns.' Even 69 British people who mostly found antipsychotics helpful, did not feel involved in treatment decisions and had not been warned about side effects or offered alternative treatments [29].

The adverse effects most frequently reported by 205 people used in the development of the Australian *My Medicines and Me* questionnaire [30] were: 'felt tired' (77%) and 'had difficulty waking up' (59%). The recently published *Maudsley Side Effects* measure for antipsychotics included service users in its development [31]. Fifty-three side effects were identified. The mean number of these effects reported by 93 recipients was 21, most frequently 'feel tired' (77%) and 'put weight on' (70%). The most common adverse effects reported by 439 users of an Internet site were sedation, cognitive impairment, emotional flattening and loss of interest [32].

1.3. Aims

The only large scale surveys of psychiatric drug recipients have been for antidepressants [33-36]. The current study replicated these surveys with users of antipsychotics, in order to assess the 'real life' experiences of the largest sample to date.

2. MATERIALS AND METHODS

2.1. Ethical Approval

Approval for the study was granted by the *Swinburne* Human Research *Ethics Committee, at the Swinburne University of Technology in Melbourne, Australia.*

2.2. Instrument

'The Experiences of Antidepressant and Antipsychotic Medication Survey', developed for this study, was based on the New Zealand 'Views on Antidepressants' questionnaire [33, 36]. Questions relating to psychosis and antipsychotics were added, based largely on the research summarized above. The section regarding withdrawal was based on a survey developed by Larsen-Barr and colleagues, also in New Zealand [20]. The current online questionnaire used Qualtrics survey software, and generated quantitative (yes/no and multiple-choice questions) and qualitative data (open-ended questions) about: the prescribing experience, the positive and negative effects of medications, causal beliefs about psychosis/depression, alternative treatments, experiences of withdrawing from the medications, and demographics.

This paper reports the positive and adverse outcomes of the antipsychotics section, and responses to the question (in a Section entitled 'When you were *first* prescribed antipsychotic medication') 'Did the doctor inform you of any possible side effects?' (Yes/No) and 'If Yes, what side effects were mentioned?'.

2.3. Participants

Of the 2,346 people who responded, 1,067 reported that they had taken antipsychotics. However, 104 failed to tick 'Yes' for the item confirming they met three 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'. Among the remaining 963 responses, 51 emanated from the same Internet Protocol (IP) address as another response, indicating use of the same computer. Of these 51, 23 were deemed a repeat response by the same person (based on 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 drug that is not an antipsychotic. Of the remaining 911, 79 completed only the demographics section, leaving 832 for analysis.

Of these 832, 98 (11.8%) were recruited *via* an Australian online research company (GMI Research) and the remaining 734 *via* advertisements on social media and snowball sampling.

2.4. Data Analysis

A Total Adverse Effects (TAE) score was calculated by combining the scores (0-3) of the 16 effects, producing a range of 0 to 48. Spearman Rank Order Correlation Coefficients (*rho*) were used to test for relationships between dimensional variables, *e.g*. age and Likert scale measures of positive and negative effects. Independent sample, two-tailed t-tests were used to explore differences between mean scores in relation to gender and whether or not participants had been informed about adverse effects. The level of significance was set at $p < .05$, except for analyses of the 16 adverse effects for which the $p < .01$ level was used because of the high number of tests and the risk of false positives.

3. RESULTS

3.1. Sample Characteristics

Table **1** summarises the characteristics of the 832 respondents, from 30 countries.

Table 1. Sample characteristics of 832 respondents.

Gender	**Male (28.0%)**	**Female (72.0%)**	**-**	**-**	**-**
Age	mean = 43.1 (sd= 13.1)	-	-	-	-
Employment	Employed 45.7%	Unemployed 23.4%	Student 9.0%	Disabled 7.1%	Retired 7.1%
Ethnicity (self-defined)	white/caucasian 54.9%	Australian 13.7%	European 10.0%	British 6.3%	-
Country*	USA 25.1%	Australia 24.8%	UK 21.6%	Canada 4.2%	New Zealand 3.6%
-	Netherlands 3.2%	Ireland 2.9%	Denmark 2.5%	Germany 2.0%	Norway 1.9%
-	Switzerland 1.4%	South Africa 1.2%	-	-	-
Time on antipsychotics	< 3 months 7.2%	3-12 months 19.2%	1-3 years 18.7%	>3 years 54.9%	-
Current status	Still taking 43.6%	Stopped taking 56.4%	-	-	-
Medication type	Only Antipsychotics 19.4%	Antipsychotics + Antide-pressants 80.6%	-	-	-
Most common Diagnoses	Schizophrenia spectrum 28.0%	Bipolar Disorder 24.9%	Depression 24.3%.	-	-

*Countries with less than 1%: Austria, Belgium, Croatia, Estonia, Finland, France, Greece, Iceland, India, Italy, Israel, Lithuania, Poland, Portugal, Romania, Spain, Sweden, Ukraine.

Table 2. Perceived efficacy of antipsychotic medication.

How Helpful was the AP Medication?	**Very Helpful**	**Somewhat Helpful**	**Unsure**	**Somewhat Unhelpful**	**Very Unhelpful**	**Negative Out-come Related to.**
(n = 758)	16.1%	24.8%	16.4%	7.7%	35.1%	Age*
'The problems for which the AP was pre-scribed were…' (n = 755)	Greatly reduced 23.8%	Slightly reduced 32.1%	Unchanged 17.6%	Slightly worse 6.2%	A lot worse 20.3%	-
'As a result of AP my quality of life was…' (n = 759)	Greatly improved 14.9%	Slightly improved 20.6%	Unchanged 10.8%	Slightly worse 12.1%	A lot worse 41.6%	Age **

*= $p < .05$; ** = $p < .01$.

3.2. Efficacy

Table **2** summarises the self-reported efficacy of the antipsychotics, in response to three questions. There was no difference, on any of these efficacy variables, between those who had only taken antipsychotics and those who had also taken antidepressants. Gender was unrelated to the three variables. Older age was correlated with negative outcomes for two of the three: Helpful - rho = .08 ($p < .05$); and Quality of Life – *rho* = .10 ($p < .01$). Length of time taking antipsychotics was unrelated to Reduction of problems or Quality of Life, but was related to being less Helpful (*rho* = .10, $p < .001$).

3.3. Adverse Effects

The mean number of adverse effects was 11.2 (sd = 3.5), with an average of 5.0 (sd = 4.0) reported as 'severe'. Nearly two-thirds of respondents (64.3%) reported ten or more effects. Table **3** shows that 14 of the 16 effects were reported by the majority of respondents, most commonly: 'Drowsiness, feeling tired, sedation' (92.5%) and 'Loss of motivation' (85.8%). Nine of the effects were reported as 'severe' by over a third of participants, most commonly: 'Drowsiness, feeling tired, sedation' (49.1%) and 'Weight gain' (45.3%).

The mean Total Adverse Effects (TAE) score was 24.8 (sd = 10.7). There were no differences in TAE score, or any of the 16 adverse effects, between those who had only taken antipsychotics and those who had also taken antidepressants.

Gender was unrelated to TAE. There was only one specific difference; men produced a higher mean for High blood pressure (0.9) than women (0.5) ($t = 4.05$, df 332.3, $p < .001$). Nearly half the men (46.6%) reported high blood pressure, compared to 30.0% of the women.

Age was positively correlated with TAE (*rho* = .13, $p < .01$), and with six specific effects ($p < .01$ level or beyond; Table **3**), most strongly ($p < .001$) with Loss of sex drive, Dry mouth, Weight gain and Emotional numbing.

Length of time taking antipsychotics was positively correlated with TAE (*rho* = .18, $p < .001$). Duration was also significantly correlated with seven specific effects ($p < .01$ level or beyond: Table **3**), most strongly ($p < .001$) Weight gain, Increased Appetite, Withdrawal symptoms and Loss of sex drive.

3.3.1. Suicidality

'Suicidality' was reported to be 'a side effect of taking antipsychotic medication' by 58.3% of participants, with 21.1% ticking 'severe'. Suicidality was not significantly related to gender or age. It was negatively correlated with all three efficacy measures (at the $p < .001$ level). The specific adverse effects most strongly correlated with Suicidality (all $p < .001$) were: Feeling not like self (*rho* = .46), Loss of motivation (.43), Difficulty concentrating (.40); Withdrawal effects (.40); Emotional numbing (.37) and Loss of sex drive (.35).

3.3.2. Withdrawal Effects

'Withdrawal effects' were reported to be a side-effect by 65.2% of respondents, with 33.2% reporting these to be 'severe'. 'Withdrawal effects' was correlated with length of time taking the medication (*rho* = .19; $p < .001$). For example, 19.0% of those on the drugs for three to six months reported severe withdrawal effects, compared to 42.9% of those who had been taking them for more than three years.

3.3.3. 'Other' Adverse Effects

Besides the responses to the 16 listed effects, 331 people wrote in the 'other' box. Table **4** lists the side effects reported by five or more people.

Of the 19 who reported new or increased psychotic symptoms, 13 reported symptoms other than those reported in response to 'What experiences were you having that led you to being prescribed antipsychotic medication?', indicating the creation of psychosis by the antipsychotics. Examples of writings in the 'other' side effects box follow:

A feeling of being utterly stripped of any sense of myself.

They killed my creativity, my brain felt wrapped in cotton matting; I was living a half-life.

I could not feel my spirit/personality.

Increased saliva, depression, anxiety, increased loss of feeling a connection with other people, loss of creativity to speak or write.

Creativity gone, humor gone, memory gone, sexual drive gone, happiness and pleasure in life gone.

3.4. Reasons for Stopping Antipsychotics

Of the 613 who responded 'yes' to 'Have you ever thought about stopping your antipsychotic medication', the most frequently endorsed of the 'reasons for wanting to stop' were 'Medication caused unpleasant side effects' - 395 (64.4%) (Table **5**).

3.5. Medication Types

The 652 who named their 'current or most recent antipsychotic medication' cited 24 antipsychotics, most frequently quetiapine (232 - 35.6%), followed by: olanzapine (101 - 15.5%); aripiprazole (181 - 12.4%); risperidone (75 - 11.5%) and haloperidol (22 - 3.4%). Comparisons were made only on the four with 75 or more cases. The majority (596; 91.4%) were second generation 'atypical' antipsychotics and 56 (8.6%) were first generation 'typical' antipsychotics.

3.5.1. Efficacy

There was no significant difference between the four antipsychotics in terms of their effects on the problems for which they had been prescribed. Olanzapine was, however, less 'helpful', on average ($X = 3.49$), than quetiapine ($X = 2.97$); $t = 2.88$, df 330, $p < .01$. Olanzapine also had a more negative effect on Quality of Life ($X = 3.80$), than both quetiapine ($X = 3.27$; $t = 3.006$, df 211.6, $p < .01$) and aripiprazole ($X = 3.25$; $t = 2.47$, df 158.2, $p < .05$). There were no differences between first and second generation drugs on the three efficacy variables.

3.5.2. Adverse Effects

The only difference between the four drugs in terms of TAE was that olanzapine ($X = 27.25$) scored higher than quetiapine ($X = 23.30$); $t = 3.07$, df 301, $p < .01$.

Table 3. Responses to 'What were the side effects of taking antipsychotic medication for you?' and related variables.

Symptoms	Any	Mild	Moderate	Severe	Mean[a]	Related to.
Drowsiness, tiredness, sedation	92.5%	14.0%	29.4%	49.1%	2.20	-
Loss of motivation	85.8%	19.4%	22.8%	43.6%	1.96	age** duration*** aripiprazole[b] ** olanzapine[b]**
Slowed thoughts	85.5%	20.3%	28.7%	36.5%	1.87	olanzapine[b] ***
Difficulty concentrating	84.9%	18.3%	27.2%	39.4%	1.91	
Emotional numbing	84.8%	16.2%	26.4%	42.2%	1.96	age*** olanzapine[b] ***
Weight gain	83.5%	14.7%	23.5%	45.3%	1.98	age*** duration*** aripiprazole[b] *** olanzapine[b] ***
Feeling not like myself	82.7%	15.3%	22.9%	44.5%	1.95	age** olanzapine[b] **
Increased appetite	79.5%	16.6%	26.2%	36.6%	1.79	duration*** aripiprazole[b] ** olanzapine[b] **
Loss of sex drive	74.0%	13.6%	23.8%	36.6%	1.71	age*** duration***
Dry mouth	72.5%	16.8%	26.2%	26.5%	1.52	age*** duration***
Withdrawal effects	65.2%	13.9%	18.1%	33.2%	1.50	duration***
Dizziness	65.4%	27.5%	23.0%	14.9%	1.18	-
Suicidality	58.3%	15.6%	21.6%	21.1%	1.22	-
Tremors	57.6%	20.1%	19.6%	17.9%	1.13	duration**
High blood pressure	34.7%	14.6%	13.9%	6.2%	0.61	men*** atypicals[c] ***
Diabetes	18.1%	6.1%	8.0%	4.0%	0.34	atypicals[c] ***

N ranged from 679 to 692.
a: 'did not experience' = 0; 'mild' = 1; 'moderate' = 2; 'severe' = 3.
b: higher mean score than quetiapine.
c: higher mean than typicals combined.
** = $p < .01$; *** = $p < .001$.

Table 4. Other side effects reported by five or more participants.

Side Effects	No. of Participants	Side Effects	No. of Participants
Akasthesia/Restlessness	40	Memory Dysfunction	10
New/Increased Psychosis	19	Increased Anxiety	10
Tardive Dyskinesia	19	Tachycardia/Palpitations	9
Lactation (in women)	17	Reduced Coordination	8
Sleep Problems	16	Reduced Creativity	7
Aggression/Agitation	16	Seizures/Epilepsy	6
Dystonia/Muscle spasms	16	Excessive Sweating	5
Eyesight problems	14	Feeling Like 'Zombie'	5

Table 5. Reasons for wanting to stop, of the 613 who had thought about stopping.

Reasons	Percentage
Medication caused unpleasant side effects	395 (64.4%)
I worried about the long-term effect on my physical health	318 (51.9%)
I wanted to solve the problem without medication	268 (42.4%)
The medication was not helping	249 (40.6%)
I felt better and thought I didn't need the medication	195 (31.8%)
I was afraid I would get dependent on the medication	105 (17.1%)
I was worried about stigma associated with medication use	79 (12.9%)
I don't remember	28 (4.6%)

Table 6. How many of 814 people were told about specific side effects.

Side Effects	No. of Patients	Side Effects	No. of Patients
Weight gain	130	Diabetes	6
Drowsiness/Sedation/Tiredness	77	Increased appetite	6
Dry mouth	21	Sexual dysfunction	6
Tardive Dyskinesia	19	Reduced concentration	6
Dizziness	13	Constipation	6
Muscle tightness/spasms	10	High cholesterol	5
Tremors	8	Low blood pressure	5
Rash	8	Slowed thoughts	5
Unusual movements	8	Nausea	5
Akathesia/restlessness	7	Increased anxiety	5
Suicidality	7	Extrapyramidal symptoms	5

Table **3** shows that this was also the case for six specific effects and that aripiprazole scored worse than quetiapine on three effects.

First and second generation drugs did not differ on TAE. The atypicals produced a higher mean than the typicals for Diabetes and High Blood Pressure.

3.6. Information About Adverse Effects

Of the 787 who answered 'Did the doctor inform you of any possible side effects?' 239 (30.4%) replied 'Yes' and 548 (69.6%) 'No'. Those who reported being informed were younger (X = 40.1 years) than those who were not told (44.1 years); t = 3.98, df 780, $p < .001$. There was no gender difference.

Those who were not informed scored significantly higher on the TAE scale (X = 25.98) than those who were informed (X = 22.15) (t = 4.35; df 680; $p < .001$). Those who were not informed reported significantly worse outcomes on each of the three efficacy measures, all at the $p < .001$ level. For example, 51.1% of those who were told about side effects found antipsychotics 'helpful', compared to 36.6% of those who were not told ($X^2 = 23.9$, $p < .001$).

The side effects that at least five people report being informed about are listed in Table **6**, most frequently Weight gain (130; 16.0%) and Drowsiness/sedation/tiredness (77; 9.5%). Less than 3% of respondents recall being told about any of the other effects.

Examples of what people remember being told include:

All the side effects across the board were attributed to my "illness" called "schizophrenia" and I believed them.

I only remember being told that any side effects would be temporary. I was discouraged from showing any concern for side effects.

What I do remember is many psychiatrists saying that I would need to accept whatever side-effects arose, because my mental health should supersede any physical complaints.

Doctors have actually actively attempted to keep me from getting this info but nurses will go behind them and do it.

4. DISCUSSION

4.1. Efficacy

It is notable that on two measures (Helpfulness and Quality of life) more people reported negative than positive outcomes. These rather general measures may be influenced by adverse effects and are therefore not pure measures of efficacy in the traditional sense. The question that focussed exclusively on symptom reduction produced a better result. The majority (55.9%) reported that the drugs reduced the specific

problems for which they were prescribed. This figure is higher than that produced by most traditional drug trials. In the review of 38 clinical trials [5], only 41% of the AP recipients were classified as 'responders'.

Nevertheless, it is important to note that 26.9% reported that the problems for which the drugs were prescribed were made worse. A two to one ratio between effective and no difference might be acceptable. A two to one ratio between being made better and being made worse represents an unsatisfactory cost-benefit ratio.

4.2. Adverse Effects

The high frequency of 14 adverse effects (reported by 57% or more), and the fact that nine were described as 'severe' by at least one in three people, is of concern.

4.2.1. Sedation

The five most commonly reported effects could all be characterised as the slowing, or closing down, of emotion and cognition, namely 'Drowsiness, feeling tired, sedation' 'Loss of motivation', 'Slowed thoughts', 'Emotional numbing' and 'Difficulty concentrating'. These five effects were reported by between 85% and 92% of respondents and were described as 'severe' by between 36% and 49%. In previous studies sedation, reduced concentration, and emotional flattening have consistently been among the most reported effects [27, 37, 38]. For example, the most frequently reported effect in the large website study was: 'Sedative effects (increased sleep, daytime drowsiness, fatigue, lethargy, difficulty waking)' [32]. A smaller survey found that 78% reported Tiredness and 66% had Concentration problems [24]. Feeling tired was the most frequently reported effect (77%) in the recently developed *Maudsley Side Effects* measure [31]. Sedation was reported by the same percentage (77%) in the development of the *My Medicines and Me* questionnaire [30].

The original descriptor of 'major tranquillisers' used in the early years of AP prescribing, might be a more accurate name than 'antipsychotics'. It has been suggested [32, 39] that the sedating, tranquillising, closing down, or 'psychic indifference' [40] accounts, at least partly, for perceived therapeutic effects, *via* reduced *responsiveness* to symptoms (and to adverse life events) rather than an actual reduction in symptoms as traditionally claimed.

4.2.2. Suicidality

It is typically assumed that the very high rates of suicide among people diagnosed with 'schizophrenia', spectrum, disorders are due to their mental health problems. Although suicide as a result of taking antidepressants has recently been established [33, 41], little attention has been paid to antipsychotics in this regard. People diagnosed with 'schizophrenia' live between ten and twenty years less than other people, and the negative medical/biological effects of antipsychotics contribute [14, 15]. Although the very high suicide rate clearly also contributes to the reduced life span, it is not known how much of that suicidality is caused, directly or indirectly, by the antipsychotics, because suicide is never included as a side effect in traditional studies [12].

To our knowledge, no checklists or measures of adverse effects for antipsychotics ask about suicidality. The 2009 website analysis [32] found that 3% of the comments *spontaneously* reported antipsychotic-induced suicidal thoughts (rising to 14% among those experiencing the side effect akathisia). In the current study, the largest first-person survey to date, and the first questionnaire to directly ask about suicidality, 58% reported suicidality as a result of taking antipsychotics. One in five (21%) reported 'severe' suicidality.

The proportion reporting suicidality goes up to 74% amongst those who thought the drugs had made no difference or had made their problems worse. Perhaps whatever degree of suicidality is generated by the adverse effects of antipsychotics, the discovery that the drugs do not work, or even make things worse, could further increase depression, hopelessness and suicidality. These results suggest that all future studies and checklists should include suicidality as a potential side effect.

4.2.3. Withdrawal

The withdrawal effects experienced when stopping or reducing of antipsychotics has not received the attention it warrants. The finding that 65% of the current sample reported 'withdrawal effects' (self-defined) is similar to a recent finding that 65 of 105 (62%) people trying to come off antipsychotics experienced withdrawal effects [20]. Withdrawal effects can, and should, be distinguished from a relapse of the pre-existing psychosis symptoms [42] so that people can receive the acknowledgement and support they need to gradually come off if they wish to do so [20-22, 42].

4.3. Age

Older people found the drugs less helpful and reported an even worse effect on their quality of Life than younger people. They also reported more adverse effects, including Loss of sex drive and emotional numbing. Other studies have found particularly high rates of adverse effects in older people [43]. Paradoxically, older people were particularly unlikely to be told about adverse effects. These findings should be considered in the context of steadily increasing use of antipsychotics with older people, with or without psychosis, in recent years.

4.4. Information

The finding that less than one in three (30%) recall being told anything about adverse effects suggests that most prescribers of antipsychotics may be breaching the ethical principle of informed consent. The largest survey of AD users to date found that 64% recalled being told something about their side effects [33]. This is not the first study to find that clinicians are particularly reluctant to inform patients about the effects of antipsychotics [24, 28, 29]. This may be for fear that a fully informed patient might wrongly attribute unrelated symptoms to the drugs. Prescribers may also fear that an informed patient may be less likely to take the medication and that this would negatively influence outcomes. Psychiatrists may be reassured to learn that participants who were informed of adverse effects reported fewer adverse effects and better outcomes.

4.5. Limitations

A limitation of this study is that it uses a convenience sample, not a randomised one. Therefore the poor outcomes and high rates of adverse effects may be the result of people who were dissatisfied with their antipsychotics being more likely to participate. The rates of many of the adverse effects are indeed higher than in other studies. For example, previous surveys found rates for Weight gain of 40% [32], 50% [24], 53%, [30] and 70% [31], compared to 84% in the current study. We have already seen, however, that if there was a bias in our sample it was towards participants with relatively *positive* views about efficacy, because more participants reported a positive effect on their symptoms than in drug trials. Furthermore, even among participants who felt the drugs had reduced their symptoms, rates of adverse events remained high, *e.g*. 'Drowsiness, tiredness, sedation' - 91%; Slowed thoughts - 83%. Nevertheless, large scale randomised surveys are desirable.

The fact that it was an online survey may mean that very poor people may be underrepresented because of lack of internet access. Particularly disturbed people may also be underrepresented, because of difficulty using, or lack of interest in the internet.

Another potential limitation is that the data was self-reported. It has been established, however, that people can reliably report the adverse effects of antipsychotics [19, 44-47]. It has also been shown that self-reported adverse effects are not related to severity of psychosis [31].

Some of the adverse effects may not have been related to the antipsychotics. One study, however, found that patients frequently fail to attribute adverse drug effects to antipsychotics [24]. It is also possible that some of the positive outcomes may have resulted from life changes, or spontaneous remission.

CONCLUSION

This study confirms many previous findings, using various methodologies, that although some people benefit from antipsychotics, many, perhaps most, do not [5-9]. The study also found that many people (27% - 54%) report that the drugs make them worse. Meanwhile, the majority experience a range of adverse effects, some of which are physically dangerous and emotionally numbing or depressing. These drugs should, therefore, be used with caution, probably only after safer and more effective approaches [8, 46, 47] have been tried. Furthermore, doctors must adhere to the principle of *informed* consent.

Screening for adverse effects in psychiatric services usually relies on general questioning and observation, leading to underestimation [48, 49]. The checklists that are sometimes used include a limited range of effects [12]. The 53 item *Maudsley Side Effects* measure [31], generated in consultation with antipsychotic recipients, and demonstrated to have sound psychometric properties, could be a way forward.

The experiences of our 832 respondents reinforce a *British Journal of Psychiatry* Editorial, entitled 'Antipsychotics: Is it time to introduce patient choice?'.

"In the context of emerging evidence regarding the overestimation of the effectiveness of antipsychotics and the underestimation of their toxicity, as well as emerging data regarding the possibility of alternative treatments, it may be time to reconsider the prevailing opinion that all service users with psychosis require antipsychotic medication in order to recover [50]".

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study is approved by Swinburne Human Research Ethics Committee, at the Swinburne University of Technology in Melbourne, Australia (Approval no. 2015/274).

HUMAN AND ANIMAL RIGHTS

Not applicable.

CONSENT FOR PUBLICATION

Not applicable.

AVAILABILITY OF DATA AND MATERIALS

The data are not publicly available due to restrictions *e.g.* their containing information that could compromise the privacy of research participants.

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CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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