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Using Open Questions to Understand 650 People's Experiences With Antipsychotic Drugs

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Studies of antipsychotic medication, which are increasingly prescribed for a broad range of problems and circumstances, rarely ask the people who take them to describe their experiences with the drugs. In this study, 650 people, from 29 countries, responded, in an online survey, to "Overall in my life antipsychotic medications have been _____?" and "Is there anything else you would like to say, or emphasise, about your experiences with antipsychotic drugs?" Of the total participants, 14.3% were categorized as reporting purely positive experiences, 27.9% had mixed experiences, and 57.7% reported only negative ones. Negative experiences were positively correlated with age. Thematic analysis identified 749 negative, 180 positive, and 53 mixed statements. The 2 positive themes were "symptom reduction" (14) and "sleep" (14), with the majority (153) unspecified. The 4 negative themes (besides "unspecified"—191) were: "adverse effects" (316), "interactions with prescriber" (169), "withdrawal/difficult to get off them" (62), and "ineffective" (11). The adverse effects included: weight gain, emotional numbing, cognitive dysfunction, sedation, akathisia, effects on relationships, and suicidality. "Interactions with prescriber" included lack of information about withdrawal effects, support, or discussion of alternatives. The only mixed theme was "short-term good, long-term bad" (28). Open questions can add to findings from methodologies focused on symptom reduction. Clinicians should pay more attention to the need for respectful and collaborative patient-prescriber relationships. At the point of prescription, this must include providing the full range of information about antipsychotics, including potential benefits and harms, difficulties withdrawing, and information on alternatives treatments such as psychological therapies.

Key words: psychosis/antipsychotics/adverse effects/withdrawal effects/first person accounts/therapeutic relationship

Introduction

Current guidelines[1,2] recommend antipsychotic medication (or "neuroleptics") for adults diagnosed with "schizophrenia" and other diagnoses indicative of psychosis. Antipsychotic drugs are also increasingly used for other mental health problems and with adolescents, older people and prisoners. Recent studies and reviews, however, suggest that claims about their efficacy may have been overstated.[3–8] A recent meta-analysis of 167 RCTs found that 23% in the drug group and 14% on placebos had a "good response."[9] Adverse effects can be severe. They include tardive dyskinesia, cardiovascular effects (eg, cardiac arrhythmia, lengthening of Q-T interval, sudden cardiac death), metabolic effects (eg, glucose intolerance, diabetes, high cholesterol levels, obesity), sexual dysfunction, sedation, dizziness, akathisia, dry mouth, reduced brain volume, and shortened life span.[3,10–14]

Thus far, surveys or interviews about the first-hand experience of people taking these drugs have not played a significant role in evaluating these drugs. Some of these qualitative studies confirm a plethora of commonly experienced and disruptive biological adverse effects (eg, neurological, metabolic, cardiovascular), but have also identified a range of negative effects and functional impairments in the less well researched psychological and interpersonal domains.[15–20] A few studies have focused on the difficulties of withdrawing.[21–24] Others have addressed the prescribing and decision-making processes.[25–27] A recent study of 20 antipsychotic users[26] found opinions divided between "willing acceptance" to taking antipsycotics, "resigned acceptance," and "nonacceptance," 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.[28]

The largest survey to date, of 832 antipsychotic users from 30 countries, found that 64% reported 10 or more adverse effects, including sedation (92%) and suicidality (58%). Equal proportions found the drugs "helpful" (41%) and "unhelpful" (43%). The current article reports the qualitative data, from the same survey, to reveal what it is that people find helpful and unhelpful about antipsychotics.[29]

Methods

The study was approved, in Melbourne, by Swinburne University of Technology's Human Research Ethics Committee.

Instrument

The Experiences of Antidepressant and Antipsychotic Medication Survey,[29,30] an online questionnaire, has quantitative and open questions about: prescribing experience, positive and negative effects of medications, causal beliefs, alternative treatments, and withdrawal. This article reports responses to 2 open questions: "Overall in my life antipsychotic medications have been _____?" and, at the end of the survey, "Is there anything else you would like to say, or emphasise, about your experiences with antipsychotic drugs?"

Participants

Of the 2346 people who responded 668 were recruited by an Australian research company, and 1678 people via advertisements on social media and snowball sampling[30]; 963 met the following 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."[29] Fifty-one matched the Internet Protocol address of another response, indicating the same device was used; 25 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 something other than antipsychotics. Of the remaining 911, 261 did not respond to either question, leaving 650 to be included in the analysis.

Data Analysis

Responses to the 2 questions were combined for each participant. A Likert scale, from 1—"extremely positive" to 7–"extremely negative" (table 1), provided an Overall Antipsychotic Rating (OAR) score. Reliability was assessed by one of the researchers independently scoring 20 random items, blind to the scores of the main scorer. Inter-rater reliability was 95% (19/20). This translates to a kappa, which allows for expected agreement by chance, of 0.94. Kappa scores above 0.75 are considered "excellent."[31] The relationship of OAR scores with age and treatment duration was analyzed with Spearman rank correlation coefficients (*rho*), and with gender using a 2-tailed *t*-test.

Thematic analysis[32] was used to identify themes. Units of analysis (participants' written answers, or parts thereof) were first classified as positive, negative, or mixed and then into themes and subthemes, by one of the researchers. The other researcher independently assigned 44 units of analysis to the 22 subthemes generated by the main coder, blind to their original coding (one each of the

Table 1. Seven-Point Likert Scale Point Definitions for Overall Antipsychotic Rating (OAR)

Scale Point	Criteria	Examples	n (%)
1	Extremely negative: Superlatives ("very" or "extremely") OR strong or extremely negative descriptor	"torturous," "disastrous," "poison," "extreme pain"	227 (34.9%)
2	Negative: All negative but without extremes	"frustrating," "unhelpful," "ineffective"	148 (22.8%)
3	Mixed, mostly negative: More negative than positive issues identified	"felt disconnected, gained weight and felt like an emotional zombie, but they did help me sleep"	60 (9.2%)
4	Equally balanced: Equal number of positive and negative issues OR one extreme that balances out several minor issues	"beneficial but problematic," "mixed blessing" "helpful short-term, unhelpful long-term" "a saviour and a curse both"	71 (10.9%)
5	Mixed, mostly positive: More positive than negative issues identified	"reduced hallucinations, delusions and reconnected me with people but experienced weight gain"	51 (7.8%)
6	Positive: All positive but without extremes	"helpful," "effective"	56 (8.6%)
7	Extremely positive: Superlatives ("very" or "extremely") OR strong or extremely positive descriptor	"lifesaving," "wonderful," "very helpful"	37 (5.7%)

22 subthemes and an additional random 22). Inter-rater reliability was 86.4% (38/44), which is a kappa of 0.857. The 6 discrepancies included overlapping subthemes. For example, "withdrawal" and "difficult to get off them" were initially separate categories, but it was agreed they were too similar and were combined into one category.

Results

Sample Characteristics

The majority of the sample (71.6%) were women. Ages ranged from 18 to 76, with an average of 43.0 (SD 13.07). Participants were from 29 countries, but the majority (72.2%) were from the United States (25.1%), Australia (24.5%), or the United Kingdom (22.6%). Other countries contributing more than 1% were: New Zealand (4.5%), Canada (3.8%), the Netherlands (3.1%), Denmark (2.5%), Ireland (2.5%), Germany (2.2%), Norway (1.8%), South Africa (1.4%), and Switzerland 1.2%. The following countries contributed from 1 to 5 participants: Austria, Belgium, Croatia, Estonia, Finland, France, Greece, India, Israel, Italy, Lithuania, Poland, Portugal, Romania, Spain, Sweden, and Ukraine. The most frequently reported ethnicities (self-definition) were "white"/"Caucasian" 319 (49.1%), "Australian" 73 (11.2%), and "European" 36 (6.0%). A quarter (24.6%) had taken antipsychotics for 1–12 months, 18.1% for 1–3 years, and 57.2% for more than 3 years.

Of the 650 participants, 579 provided their "primary diagnosis." DSM-V groupings cited by 5 or more participants were represented as follows: "Schizophrenia Spectrum and Other Psychotic Disorders"–200 (34.5%); "Bipolar and Related Disorders"—140 (21.5%); "Depressive Disorders"—137 (21.1%); "Personality Disorders"—42 (7.3%); "Trauma and Stressor-Related Disorders"—19 (3.3%); "Obsessive-Compulsive and Related Disorders"—8 (1.4%); "Anxiety Disorders"—8 (1.4%); "Dissociative Disorders"—6 (1.0%); and "Neurodevelopmental Disorders"—5 (0.9%). Secondary diagnoses included 49 in the schizophrenia spectrum, bringing the total (primary or secondary) for that grouping to 249 (43.0%).

In the survey's quantitative section,[29] roughly equal numbers of the 650 in the current sample reported that the drugs were "helpful" (40.1%) and "unhelpful" (44.5). More found that the drugs had "reduced the problems for which they were prescribed" (55.4%) than thought they had been made "worse" (27.6%). More reported that their "Quality of Life" had been made worse (56.0%) than thought it had been "improved" (34.9%).

Rating Scores

Table 1 shows that two-thirds (66.9%) of the participants were categorized as more negative than positive,

Table 2. Positive Experiences (n = 180)

Themes	Age, Gender, Country
Unspecified positive experiences (n = 152)	
Helpful	32, M, India
It's helpful. I don't want to stop taking my medication	48, M, The Netherlands
Having the medication makes it possible to thrive instead of just surviving on a day to day basis	33, F, United States
It was the right choice of treatment. I benefitted greatly from using it	37, F, South Africa
I consider being prescribed antipsychotic medication to have allowed me to start living a life and have a future that I had never even imagined as a teenager as I didn't think I would be alive	30, F, New Zealand
I don't know how I would survive without them	31, F, United States
I cannot over-estimate their helpfulness. My life is hell without them	58, F, United Kingdom
Sleep (n = 14)	
If forgotten to take sleep is impossible	35, F, United Kingdom
They are not "antipsychotic" they just helped me sleep	53, M, Canada
Symptom reduction (n = 14)	
They stopped the voices, and bought me back to reality	39, F, Ireland
They have taken away delusions and paranoia	40, F, Ireland
I had an alternative to suicide/self-harm and stopping my distressing thoughts and extreme emotions	30, F, New Zealand

Table 3. Mixed Experiences (n = 53)

Themes	Age, Gender, Country
Unspecified mixed experiences (n = 25)	
Necessary, but not without heavy price	33, F, United States
Beneficial but problematic	45, F, United Kingdom
Is a necessary evil	31, M, United Kingdom
Short-term good, long-term bad (n = 28)	
Useful in the short term, a curse in long term use	49, M, New Zealand
Maybe helpful for a short time, but likely not worth it in the end they clouded my perceptions and sense of self very badly	34, M, ?
Good short (very short term) but hurting my feeling competent person if insisted to use life-long	61, F, Lithuania
There are times they are necessary in certain doses and temporarily, but it is not the solution to the problem long term	39, F, Spain
Helpful until they were harmful. At this point it's hard to know what's caused by the drug or helped by it!	24, F, United States

Table 4. Negative Themes and Subthemes I: Adverse Effects

	Themes	
	Adverse Effects (n = 316)	Age, Gender, Country
1. Unspecified Side Effects (n = 55)	The side effects were bad enough that I considered stopping the treatment	23, F, United Kingdom
	Awful side effects I never had before being put forced to take injections depot	66, F, United Kingdom
	I don't feel like the benefits of the antipsychotic have been worth the negative side effects for me	28, F, New Zealand
	Virtually every antipsychotic I tried gave me very serious side effects	31, F, United States
2 Physical (n = 117)		
(2a) Weight gain (n = 58)	My body is still scarred with stretch marks from the uncontrollable weight gain	24, M, United States
	The fight against weight gain is a nightmare	73, F, United Kingdom
	I think they made me gain like 10 kg and that bummed me out as a teens/20s girl	26, F, United Kingdom
	I put on 27 kg and developed diabetes	67, F, Australia
(2b) Sedation (n = 19)	I refuse to call these medications antipsychotics. They are major tranquilizers	40, M, Australia
	Severe sedation made it impossible to continue	46, F, Australia
(2c) Unspecified (n = 16)	Very damaging to my mental and physical health	59, F, United States
	It contributed to the deterioration in my physical health	50, F, Australia
(2d) Akathisia (n = 15)	I developed severe akathisia within a week of the first dose of Depixol. It lasted over 3 months and ended in a hospital admission	26, F, United Kingdom
	The inner restlessness was probably one of the worst side effects I have ever experienced. Developed muscle spasms, jerking limbs, twitching, inner agitation, restless legs, and could no longer function	34, F, Australia
	Created an at times unbearable internal restlessness that drove me to suicidal thoughts	51, F, New Zealand
(2e) Tardive Dyskinesia (n = 9)	Due to the rather large doses I have long-term TD and seizures	35, M, Australia
	The big movements are ugly; the small ones make you look stupid; your mouth is never comfortable again; there are always sores from teeth clamping down; and tongue has no place to rest and feels it does not belong in your mouth. I wish they had killed me instead	55, F, United Kingdom
3 Psychological (n = 80)		
(3a) Emotional numbing (n = 42)	I was very emotionally numb when on antipsychotics	20, F, United States
	If the point of antipsychotics is to make you an emotional and spiritual zombie, they succeeded	27 F, United States
	They dumb me down & numb me up, I have no happiness or joy	44, M, Ireland
	They made me feel less than human, dead inside	39, F, United Kingdom
	Terrible side effects. Zombified and unable to collect thoughts	58, F, United Kingdom
	It also shut down the good/happy things and the lively energy. … just emptied the whole world from meaning and shut me down completely	30, F, Israel
(3b) Cognitive dysfunction (n = 28)	They took away the one thing I had previously been able to rely on: my mind, and rendered it useless	51, F, New Zealand
	I was frightened about my loss of mental acuity	63, F, United States
	These are difficult drugs to take. Having cotton wool for a brain was not easy	27, F, United Kingdom
(3c) Caused or exacerbated psychosis (n = 10)	20 mg of olanzapine gave me the worst hallucinations I have ever experienced	48, F, New Zealand
	They caused psychosis, something I hadn't experienced before	70, F, Norway
	It did not make the voices go away; it increased the amount of voices and how often I heard them	50, F, Australia
4. Long Term (n = 31)	It has now been over 4 years and I am still suffering severe side effects	45, M, New Zealand
	I have long-term physical issues as a result of their use, including tremors and an autoimmune response associated with taking long-term pharmaceuticals	50, F, United States
	2+ years after stopping still have sleep issues as withdrawal symptoms	72, F, Australia
	I believe my health has been permanently damaged and my life shortened by unnecessary psychiatric drugging	54, F, Canada
5. Relationships (n = 17)	Antipsychotics were life shattering. Imagine not being able to connect with partners anymore	28 F Canada
	I lost 10 years of my life. I withdrew from my sons, my siblings, and my friends	70, F, United States
	Loss of concentration meant I couldn't keep up friendships etc.	74, F, Australia
	I could not relate to my partner and 4 children	58, F, Australia

Table 4. Continued

	Themes	Age, Gender, Country
	Adverse Effects (n = 316)	
6. Suicidality (*n* = 16)	Worst experience of my life. I had such severe akathisia (a side effect from antipsychotics) I felt like killing myself	41, F, United Kingdom
	My first and only suicide attempt was because of the restlessness of akathisia. No one would believe how much pain I was in	26, F, United Kingdom
	When I am not on psychiatric medication I am not suicidal. I want professionals and medication users to acknowledge suicidality can happen	27, F, United States
	The flattening of my emotional, sexual, and social state was unbearable. This lack of pleasure in my life drove me to suicidal ideation. No attempt was made, but it got to a plan	55, F, United Kingdom
	Antipsychotics made me suicidal, and I tried to kill myself when under a Community Treatment Order. I've never been suicidal when not on antipsychotics	42, F,?

with 34.9% being "extremely negative." Nearly a quarter of participants' responses (22.1%) were categorized as more positive than negative, with 5.7% "extremely positive." Mixed responses comprised over a quarter of participants' responses (27.9%), with 10.9% categorized as equally balanced.

The mean score on the OAR scale (1–7) was 2.83 (SD 1.93), well to the negative side of the midpoint of 4. OAR was not related to gender or duration of treatment. Older age was related to lower, more negative, scores (*rho* = 0.13, *P* = .001). The 249 respondents with a primary or secondary diagnosis in the schizophrenic spectrum had a significantly more negative mean OAR score (2.53) than those without such a diagnosis (2.99) (*t* = 2.90, *df* = 577, *P* = .004). Nevertheless, the majority of both groups were categorized as more negative than positive (schizophrenia—72.7%; other—63.3%).

Thematic Analysis

Most of the 982 individual statements (units of analysis) were clearly either positive (180, 18.3%) or negative (749, 76.3%). There were 53 instances (5.4%) where the positive and negative components of a mixed statement could not be separated into smaller units of assessment without losing meaning. These were most commonly statements about short- vs long-term experiences. Positive quotes were categorized into 3 themes (see table 2 for examples from each of the 3 themes). Mixed quotes were categorized into 2 themes (table 3). Negative quotes were categorized into 5 themes, 2 of which were further divided into subthemes (tables 4 and 5).

Discussion

This is the largest survey directly addressing people's experiences with antipsychotics. In this sample, of 650 people from 29 countries, open questions led to negative experiences far outweighing positive ones, with many participants reporting mixed accounts. This suggests that studies focusing on symptom reduction, including RCTs, may be missing the broader impact of drugs on people's lives.

Positive Experiences

Nearly a quarter of participants' responses (22.1%) were categorized as more positive than negative on the OAR scale (scale points 5–7); 5.7% were scored as "extremely positive," with several people characterizing the drugs as life-changing or even life-saving. In the thematic analysis, 18.3% of the units of analysis were positive with a further 5.4% mixed. These findings are similar to the meta-analysis of 167 double-blind randomized controlled trials which found that an average of 23% had a "good" response.[9] In the current study, relatively few people who experienced the drugs positively were able to articulate specifically why or how. Only 14 people said that the drugs reduced psychotic symptoms. Of the 180 units coded as positive, 153 (85.0%) were "unspecified" but this was the case for only 25.5% of the negative units (191/749).

Negative Experiences

The broad range, and high frequencies of the adverse effects reported, such as emotional numbing/sedation, weight gain, and cognitive dysfunction, are broadly consistent with previous studies, both qualitative[15–18,33] and quantitative.[3,4,11] Further research and clinical attention are urgently needed to address the incidence and severity of withdrawal effects and suicidality. In the current sample, these were reported by 65% and 58%, respectively when asked directly in another section of the survey.[29] The recent schizophrenia guidelines published by the German Association for Psychiatry, Psychotherapy and Psychosomatics[34] is, to our knowledge, the first

Table 5. Negative Themes and Subthemes II: Unspecified, Interactions with Prescriber, Withdrawal and Ineffective

	Themes	
	Unspecified Negative Experiences (n = 191)	Age, Gender, Country
	Taking them was a very frightening experience. I would never want to repeat it	43, F, United States
	A disaster. Antipsychotics took away the best years of my life	42, F, United States
	Basically makes life unliveable, pointless, and increases suffering	23, M, Estonia
	These medications are disabling. They are dehumanizing	40, M, Australia
	Antipsychotics are poisons	48, M, Canada
	Interactions With Prescriber (n = 169)	
1. Lack of Support ($n = 64$)	My psychiatrist would not support any sort of medication reduction so I did it myself by going cold turkey— not something I would recommend!	45, F, United Kingdom
	My suffering continues and I have NO SUPPORT from the medical profession	22, M, New Zealand
	I am now being refused support because I am deemed as "non-compliant"	26, F, United Kingdom
	Why did no one listen to me?	46, F, United Kingdom
	… through the hell of withdrawal with zero support from the medical community	34, F, New Zealand
	Lack of professional and personal support	58, F, Norway
e2. Lack of Informed Consent ($n = 56$)	If I had known about the risks of these medications, I would have never have taken them	30, M, United Kingdom
	I don't think the potential side effects are explained well enough or the impact they have on your life taken seriously enough	36, F, United Kingdom
	I think, given the significant side effects, it is important to clearly communicate to the patient the real risks involved, the purpose of it, what the plan is for its use (short or long term). This didn't happen for me	42, F, United States
	I was not warned about permanent/semi-permanent effects of antipsychotics which I got	22, F, Ukraine
	I was told NOTHING about them	59, F, United Kingdom
	The info from the doctors is very slanted and does not fully warn you of long-term effects	50, F, New Zealand
	I think I would have gained better results earlier, with more information from the beginning	46, F, Norway
3. Lack of Alternative Approaches Offered ($n = 21$)	Being presented with medications as the only possibility to feel relief from overwhelming distress turns the decision into: "feel this afraid and miserable forever or take these medications"	30, F, Canada
	Why wasn't I told about alternative mental health help/methods?	36, F, United States
	Other avenues should definitely be explored before resorting to prescribing antipsychotics. I literally just met this doctor for the first time, had a half an hour-long conversation and BOOM	25, F, United Kingdom
	I wish there was alternative treatment available like psychotherapy when I needed help	28, M, India
4. Lack of Information Regarding Withdrawal Effects ($n = 17$)	If I had known the seriousness of withdrawing from my medication, I would have not relapsed	35, F, United Kingdom
	They never talk about withdrawal or secondary withdrawals	41, F, United States
	Most doctors do not have a clue. They turn their backs on suffering patients, denying the existence of withdrawal damage	M, 22, New Zealand
5. Misdiagnosis ($n = 11$).	I had never expected I would be prescribed antipsychotics given my symptoms and diagnosis are entirely consistent with anxiety. I have zero psychotic symptoms	31 F Australia
	"Akathisia" was misdiagnosed as "agitated depression" and "converted from depression to bipolar," requiring MORE meds	46 M United Kingdom
	Withdrawal/Difficult to Get Off ($n = 62$)	

national guidelines to properly address withdrawal from antipsychotics.

Another area in need of greater focus is the long-term adverse effects, which some participants reported continued even after coming off the drugs.

Another major finding emanating from use of open questions rather than closed questions on topics chosen by researchers is that the negative opinions were not just based on the adverse effects of the drugs prescribed, but also, in large numbers, based on dissatisfaction with interactions with the prescriber, or with mental health services in general. Despite neither of our questions asking about the topic, 169 comments were about the lack of information or support. Failure to fully inform people of adverse effects breaches the fundamental ethical principle of informed consent. Yet, in the quantitative section of the survey, only 30.2% replied "yes" to "Did the doctor inform you of any possible side effects?", identical to the larger sample[29] (which included those who did not respond to the 2 questions analyzed here). This is comparable to the extent to which people are told about the adverse effects of antidepressants.[30,35–37] Other qualitative studies of users of antipsychotics have highlighted the importance of relationships with prescribers.[25–28,38]

The 21 participants who reported that they were not given an alternative to antipsychotic medication align with a recent study that found practitioners were often reluctant to consider reduction or to propose alternative approaches to antipsychotics.[39] This is inconsistent with the recommendation that decision-making should be shared.[2]

The finding that older age is correlated with more negative OAR scores is matched by quantitative data from the same survey,[29] and by other studies finding particularly high rates of adverse effects in older people.[40–42] This is of particular concern given the increasing inappropriate, "off-label" use of antipsychotics with older people, especially those in care.[42,43]

The findings from this study regarding short-term benefit/long-term negatives, and functional impairment, are consistent with previous studies demonstrating greater long-term functional impairment in those staying on antipsychotics for several years.[3,5,6,12,17,44,45]

Reviews show that alternatives to antipsychotic medications may have equally good, or better, outcomes.[3,5,46,47] Examples of moves toward alternatives are the "Open Dialogue" approach,[48] the Hearing Voices Network,[49] and the government-mandated creation of drug-free treatment options in Norway.[50]

Many of the problems that need addressing here were captured by a 40-year-old woman in the United Kingdom who answered the first question with "Necessary evil" and added, in response to the second question, "Should have been told about side effects, shouldn't have been brushed off when I raised concerns about side effects, shouldn't have been left to take them long term, should have been able to discuss other options."

Limitations

A limitation of this study is that it uses a convenience sample, not a randomly selected one. It is possible that people who were dissatisfied with their antipsychotics were more likely to participate. More than half, however, had reported that the drugs had to some extent reduced the problems for which they had been prescribed, a figure far higher than most drug trials report.[9] Even if the sample were biased, toward either those with positive or negative experiences, the study still provides important insights into what the largest sample to date find helpful and unhelpful about taking antipsychotic drugs.

The fact that it was an online survey may mean that the economically disadvantaged may be underrepresented because of lack of internet access. People from "developing" countries and ethnic minorities were certainly underrepresented.

Another limitation is that the data were self-reported. Some of the adverse effects may not have been related to the antipsychotics. It is also possible that some of the positive outcomes may have resulted from life changes, spontaneous remission, or placebo effects.

Conclusions

Asking open-ended questions about first-hand experiences allows deeper insight than asking participants to respond to specific questions predetermined by researchers. The most recent and thorough review, of 35 qualitative studies of people's experiences of taking antipsychotics (or "neuroleptics"), suggests that "The rich nature of qualitative data means these studies can highlight the complex alterations to conscious experience, mental functions and behavior that neuroleptics produce, arguably more successfully than quantitative approaches (e.g. use of side effect scales)'. The reviewers found that 'Users of neuroleptics consistently described a consistent experience, characterised by sedation, cognitive impairment, emotional blunting and reduced motivation, which was associated with a variety of physical effects, including neurological effects, weight gain and sexual dysfunction".[51]

The 650 people who gave their time to share their experiences, positive and painful, seem to be telling us that the important things for clinicians (and researchers) to pay attention to include: establishing a collaborative, respectful relationship with potential users of antipsychotics, which requires the provision of full information about all possible adverse effects, including sedation, suicidality and withdrawal effects, and about alternative treatment pathways; and responding respectfully and therapeutically when patients voice the sorts of concerns raised in this study and the 35 previous qualitative studies.[51]

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