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

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Abstract

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 anti-psychotic drugs?' 14.3% of participants were categorised 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 two positive themes were 'symptom reduction' (14) and 'sleep' (14), with the majority (153) unspecified. The four 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, withdrawal effects, effects on relationships, and suicidality. 'Interactions with prescribers' included lack of information, 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 focussed 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, the difficulty in 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 for people 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 (e.g.cardiac arrythmia, lengthening of Q-T interval, sudden cardiac death), metabolic effects (e.g. 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 (e.g. 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 focussed 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 'non-acceptance', 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 ten or more adverse effects; including sedation (92%) and suicidality (58%). Equal proportions found the drugs 'helpful' (41%) and 'unhelpful' (43%). The current paper 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 paper reports responses to two 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 anti-psychotic drugs?'.

Participants

Of the 2,346 people who responded 668 were recruited by an Australian research company, and 1,678 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; 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 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 two 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 were analysed with spearman rank correlation coefficients (*rho*), and with gender using a two-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 sub-themes, by one of the researchers. The other researcher independently assigned 44 units of analysis to the 22 sub themes generated by the main coder, blind to their original coding (one each of the 22 subthemes and an additional random 22). Inter-rater reliability was 86.4% (38/44), which is a kappa of 0.857. The six 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.

Table One About Here

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 USA (25.1%), Australia (24.5%) or the UK (22.6%). Other countries contributing more than 1% were: New Zealand (4.5%), Canada (3.8%), 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 contributed from one to five participants: Austria, Belgium, Croatia, Estonia, Finland, France, Greece, India, Israel, Italy, Lithuania, Poland, Portugal, Romania, Spain, Sweden, 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 to 12 months, 18.1% for one to three years, and 57.2% for more than three years.

Of the 650 participants, 579 provided their 'primary diagnosis'. DSM-V groupings cited by five 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 Disorder's - 5 (0.9%). Secondary diagnoses included 49 in the schizophrenia spectrum, bringing the total (primary of 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 categorised as more negative than positive, with 34.9% being 'extremely negative'. Nearly a quarter of participants' responses (22.1%) were categorised as more positive than negative, with 5.7% 'extremely positive'. Mixed responses comprised over a quarter of participants' responses (27.9%), with 10.9% categorised 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* = .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 categorised 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, most commonly statements about short versus long term experiences. Positive quotes were categorised into three themes (see Table 2 for examples from each of the three themes). Mixed quotes were categorised into two themes (Table 3). Negative quotes were categorised into five themes, two of which were further divided into subthemes (Tables 4 and 5).

Tables 2 - 5 About Here

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 focussing 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 categorised as more positive than negative on the OAR scale (scale points 5-7). 5.7% were scored as 'extremely

positive', with several people characterising 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 randomised 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 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 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, on dissatisfaction with interactions with the prescriber, or with mental health services in

general. Despite neither of the questions asking about the topic, 169 comments were about 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 two questions analysed 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 import of relationships with prescribers.[25-28,38]

The 21 participants who reported 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.[3,12,17,44-47] Reviews show that alternatives to antipsychotic medications may have equally good, or better, outcomes.[3, 47-49] Examples of moves towards alternatives are the 'Open Dialogue' approach,[50] the Hearing Voices Network,[51] and the government-mandated creation of drug-free treatment options in Norway.[52]

Many of the problems that need addressing here were captured by a 40 year old woman in the UK 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, towards 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 was 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 the researchers. 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 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.

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

Scale point	**Criteria**	**Examples**	
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 re-connected 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%)

Table 2: Positive Experiences (n= 180)

UNSPECIFIED POSITIVE EXPERIENCES (n=152)	age, gender, country
Helpful	32 M India
It's helpful. I don't want to stop taking my medication	48 M Netherlands
Having the medication makes it possible to thrive instead of just surviving on a day to day basis	33 F USA
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 NZ
I don't know how I would survive without them	31 F USA
I cannot over-estimate their helpfulness. My life is hell without them	58 F UK
SLEEP (n=14)	
If forgotten to take sleep is impossible	35 F UK
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 NZ

Table 3: Mixed Experiences (n = 53)

UNSPECIFIED MIXED EXPEREINCES (n=25)	age, gender, couintry
Necessary, but not without heavy price	33 F USA
Beneficial but problematic	45 F UK
Is a necessary evil	31 M UK
SHORT TERM GOOD, LONG TERM BAD (n=28)	
Useful in the short term, a curse in long term use	49 M NZ
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 USA

Table 4. Negative Themes and Subthemes I: Adverse Effects

	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 UK
	Awful side effects I never had before being put forced to take injections depot	66 F UK
	I don't feel like the benefits of the anti-psychotic have been worth the negative side effects for me	28 F NZ
	Virtually every anti-psychotic I tried gave me very serious side effects	31 F USA
2 Physical (n = 117)		
(2a) Weight gain (n=58)	My body is still scarred with stretch marks from the uncontrollable weight gain	24 M USA
	The fight against weight gain is a nightmare	73 F UK
	I think they made me gain like 10kg and that bummed me out as a teens/20s girl	26 F UK
	I put on 27 kgs and developed diabetes	67 F Austr.
(2b) Sedation (n=19)	I refuse to call these medications anti-psychotics. They are major tranquilisers	40 M Austr.
	Severe sedation made it impossible to continue	46 F Austr.
(2c) Unspecified (n=16)	Very damaging to my mental and physical health	59 F USA
	It contributed to the deterioration in my physical health	50 F Austr.
(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 UK
	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 Austr.
	Created an at times unbearable internal restlessness that drove me to suicidal thoughts	51 F NZ
(2e) Tardive Dyskinesia (n=9)	Due to the rather large doses I have long-term TD and seizures	35 M Austr.
	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	55 F UK

	rest and feels it does not belong in your mouth. I wish they had killed me instead	
3 Psychological (n = 80)		
(3a) Emotional numbing (n=42)	I was very emotionally numb when on antipsychotics	20 F USA
	If the point of antipsychotics is to make you an emotional and spiritual zombie, they succeeded	27 F USA
	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 UK
	Terrible side effects. Zombified and unable to collect thoughts	58 F UK
	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 NZ
	I was frightened about my loss of mental acuity	63 F USA
	These are difficult drugs to take. Having cotton wool for a brain was not easy	27 F UK
(3c) Caused or exacerbated psychosis (n=10)	20mg of olanzapine gave me the worst hallucinations I have ever experienced	48 F NZ
	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 Austr.
4 Long Term (n=31)	It has now been over 4 years and I am still suffering severe side effects	45 M NZ
	I have long term physical issues as a result of their use, including tremors and an auto-immune response associated with taking long term pharmaceuticals	50 F USA
	2+ years after stopping still have sleep issues as withdrawal symptoms	72 F Austr.
	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 USA

	Loss of concentration meant I couldn't keep up friendships etc.	74 F Austr.
	I could not relate to my partner and 4 children	58 F Austr.
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 UK
	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 UK
	When I am not on psychiatric medication I am not suicidal. I want professionals and medication users to acknowledge suicidality can happen	27 F USA
	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 UK
	Antipsychotics made me suicidal, and I tried to kill myself when under CTO. I've never been suicidal when not on antipsychotics	42 F ?

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

		age, gender, country
	UNSPECIFIED NEGATIVE EXPERIENCES (n = 191)	
	Taking them was a very frightening experience. I would never want to repeat it	43 F USA
	A disaster. Anti-psychotics took away the best years of my life	42 F USA
	Basically makes life unliveable, pointless and increases suffering	23 M Estonia
	These medications are disabling. They are dehumanising	40 M Austr.
	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 UK
	My suffering continues and I have NO SUPPORT from the medical profession	22 M NZ
	I am now being refused support because I am deemed as "non compliant"	26 F UK
	Why did no one listen to me?	46 F UK
	… through the hell of withdrawal with zero support from the medical community	34 F NZ
	lack of professional and personal support	58 F Norway
2 Lack of Informed Consent (n = 56)	If I had known about the risks of this medications I would have never have taken them	30 M UK
	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 UK
	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 USA

	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 UK
	The info from the doctors is very slanted and does not fully warn you of long-term effects	50 F NZ
	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 USA
	Other avenues should definitely be explored before resorting to prescribing anti-psychotics. I literally just met this doctor for the first time, had a half an hour long conversation and BOOM	25 F UK
	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 UK
	They never talk about withdrawal or secondary withdrawals	41 F USA
	Most doctors do not have a clue. They turn their backs on suffering patients, denying the existence of withdrawal damage	M 22 NZ
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 Austr.
	'Akathisia was misdiagnosed as 'agitated depression' and 'converted from depression to bipolar', requiring MORE meds	46 M UK
	WITHDRAWAL/DIFFICULT TO GET OFF (n = 62)	
	I wish I never started. Now i am slowly quitting, but withdrawel is terrible	38 F Nether.
	It was not worth it and it took a full darned year to finish withdrawals and even begin to feel normal	65 F USA

	I suffered hallucinations, and headaches during withdrawal even from stopping a low dosage	32 F UK
	The withdrawls process has runied 4 years of my life so far and counting	52 M USA
	The withdrawal process was horrible and caused very distressing physical, mental and emotional changes	35 F USA
	The withdrawal process was almost worse than the illness itself	41 F USA
	Withdrawal from the anti-psychotic was torturous and took a very long time. I would never choose to take them again, ever	34 F Austr.
	Withdrawal symptoms were always blamed on relapse of my "disease"	34 F USA
	INEFFECTIVE (n = 11)	
	They do not work	58 F UK