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What is helpful and unhelpful when people try to withdraw from antipsychotics: an international survey.

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Abstract

Purpose: Antipsychotics remain the first line treatment for psychotic disorders, despite adverse effects which lead many patients to stop their medication. Many stop without the support of the prescriber, who may fear relapse. The objective of this study is to better understand the process of withdrawal from antipsychotics from the perspective of people taking antipsychotics.

Methods: An international online survey elicited quantitative responses about pre-withdrawal planning (560), and qualitative responses about what was helpful and unhelpful when withdrawing from antipsychotics (443). Responses came from users of antipsychotics in 29 countries.

Results: 47% did not consult their psychiatrist before discontinuing. Only 40% made preparations, most commonly making a plan, gathering information and informing family. The most frequently reported helpful factors were focussing on the benefits of getting off the drugs (including ending adverse effects and feeling more alive), information about withdrawal symptoms and how to withdraw safely, withdrawing slowly, and support from psychologists, counsellors and psychotherapists. The most common unhelpful factor was the

psychiatrist/doctor, largely because of their lack of knowledge, refusal to support the patient's wishes and the threat or use of coercion.

Conclusions: Evidence-based, respectful, collaborative responses to patients' concerns about adverse effects and desires to withdraw would probably reduce relapse rates and improve long term outcomes. It would definitely help end pervasive breaching of the principle of informed consent and of human rights legislation.

Key words: Antipsychotics, withdrawal, discontinuation, coercion, relapse, informed consent, tapering, adverse effects, psychiatrists

Introduction

Antipsychotics efficacy and safety

Antipsychotic medications (APs) are the most common treatment for people diagnosed with 'schizophrenia' spectrum disorders. They are also prescribed for other problems and to older people, adolescents and prisoners (Hutton et al.,2013; Larsen-Barr et al., 2018a). A study of 47,7224 people prescribed APs in the UK found that about a half had non-psychosis diagnoses, and that rates were higher for poor people, women, and older people (Marston et al. (2014).

Governments and professional psychiatry bodies strongly recommend APs. Although there is some evidence that they may help some people in the acute stages of psychosis, claims about their efficacy and safety, especially in the long-term, have been exaggerated (Bola et al., 2009, 2011; Harrow et al., 2017; Hutton et al., 2013; Leucht et al., 2017; Moncrieff, 2015; Murray & Di Forti, 2018). The online survey on which the current paper is based found that 56% thought the drugs reduced the problems for which they were prescribed (Read & Williams, 2019), but 27% thought they made the problems worse. While 35% reported that

their ‘quality of life’ was ‘improved’, 54% reported that it was made ‘worse’. Responses to open-ended questions, in the same survey, about the respondents’ overall experience of APs, showed that 14% reported only positive experiences 28% had mixed experiences, and 58% reported purely negative experiences (Read & Sacia, 2020).

A meta-analysis, of 167 double-blind randomized controlled trials, found that 23% of the AP group had a ‘good’ response, compared to 14% on placebos (Leucht et al., 2017). Some studies find that APs are associated with poor long-term outcomes (Jung et al., 2016; Moilanen et al., 2013). For example, reduction/discontinuation of APs during the early stages of remitted psychosis is twice as likely as maintenance AP treatment (40.4% vs 17.6%) to lead to long-term recovery (Wunderink et al., 2013).

Adverse effects include severe weight gain, tardive dyskinesia, cardiovascular effects, metabolic effects, sexual dysfunction, sedation, dizziness, akathisia, dry mouth, reduced brain volume, and shortened life span (Ho et al., 2011; Hutton et al., 2013; Longden & Read, 2016a; Miller et al., 2008; Weinmann et al., 2009; Weinmann & Aderhold, 2010). The most common adverse effects reported by 439 users of an Internet site were sedation, cognitive impairment and emotional flattening (Moncrieff et al., 2009). The largest online survey of AP users to date (which generated the dataset used in the current paper) found an average of 11 adverse effects, most frequently ‘drowsiness, feeling tired, sedation’ (92%), ‘loss of motivation’ (86%), ‘slowed thoughts’ (86%), and ‘emotional numbing’ (85%). Suicidality as a result of the APs was reported by 58% (Read & Williams, 2019).

Discontinuing

These adverse effects are a major factor in the high rates of people attempting to discontinue APs (Cooper et al., 2005; Read & Williams, 2019). People frequently make independent changes to their AP medication regimes to try to minimise the adverse effects

(Bülow et al., 2016). Reviews of 'nonadherence' to APs have found averages of about one in four (Nosé et al., 2003) and about a half (Lacro et al., 2002). About three quarters stop the drugs within 18 months (Lieberman et al., 2005).

Most (70%) of the respondents to the questionnaire used for the current paper had tried to stop taking their APs (Read & Williams, 2019). The most common reason given (64%) was adverse effects.

Withdrawal symptoms

The withdrawal effects of APs tend to be minimised, denied or ignored. Any negative effects of reducing or coming off completely have traditionally been interpreted as a return of the condition for which the drugs were prescribed, leading to reinstatement of the drugs.

A review (Chouinard et al., 2017) found that APs share a range of 'classic symptoms of withdrawal' with all central nervous system drugs, including nausea, tremors, anxiety, agitation, headaches, irritability, aggression, sleep disturbances and decreased concentration. A study of 105 found people who had attempted discontinuation found that 65 (62%) reported withdrawal effects (Larsen-Barr et al., 2018a). A recent review, which could find only five studies, calculated a weighted average of 53% individuals showing withdrawal symptoms after abrupt antipsychotic discontinuation (Brandt et al., 2020). A subsequent study found withdrawal effects after three weeks of use of antipsychotics (Brandt et al., 2022).

The survey on which the current paper is based asked people to describe their overall experience of APs in their own words. One of the main negative experiences of taking APs was difficulty withdrawing from these drugs, with respondents stating, for example: "Withdrawal from the anti-psychotic was torturous and took a very long time. I would never choose to take them again, ever"; "Withdrawal symptoms were always blamed on relapse of

my ‘disease’”; “I suffered hallucinations, and headaches during withdrawal even from stopping a low dosage” (Read & Sacia, 2020).

Antipsychotic induced psychosis

APs blockade the dopamine system, and the brain tries to compensate for the blockade (Moncrieff, 2015). The brain’s attempted compensation involves an increase in the number and sensitivity of dopamine receptor cells (Chouinard et al., 2017). When an antipsychotic, and thereby the dopamine blockade, are removed, or reduced, the brain can be overwhelmed with dopamine, partly because of the abnormal drug-induced sensitivity and number of dopamine receptor cells. A reviewer concluded:

> There is evidence to suggest that the process of discontinuation of some antipsychotic drugs may precipitate the new onset or relapse of psychotic symptoms. Whereas psychotic deterioration following withdrawal of antipsychotic drugs has traditionally been taken as evidence of the chronicity of the underlying condition, this evidence suggests that some recurrent episodes of psychosis may be iatrogenic (Moncrieff, 2006)

There have been two recent reviews of the literature on what now tends to be called ‘antipsychotic-induced Dopamine Supersensitivity Psychosis’ or ‘Supersensitivity Psychosis’ (Chouinard et al., 2017; Yin et al., 2017). Other terms are ‘Rebound Psychosis’, or ‘Withdrawal Psychosis’. Estimates of incidence range from 22% to 72% (Read et al., 2019).

What helps and hinders safe withdrawal.

Little is known about the determinants of success or failure when trying to come off or reduce these drugs. Interviews with 12 people in the UK about withdrawing from antipsychotics (Geyt et al., 2017) ‘identified three tasks as important in mediating participants' choices’:

> (a) forming a personal theory of the need for, and acceptability of taking, neuroleptic medication; (b) negotiating the challenges of forming alliances with others; and (c) weaving a safety net to safeguard well-being. . . . Our findings highlight the importance of developing resources for staff to facilitate service user choice.

Interviews with nine people, also in the UK (King et al., 2024), concluded:

> Findings show that antipsychotic withdrawal often involves a lack of information, poor support from services. . . . Results highlight the need for services to consistently
> recognize that antipsychotic users should be given the utmost support regardless of their views on continuation or discontinuation.

Unsurprisingly, it has been found that slower withdrawal increases the chances of successful withdrawal and decreases the probability of relapse (Larsen-Barr et al., 2018b). Among 105 people who had attempted discontinuation, having some form of professional, family, friend, and/or peer support was related to success, but coping strategies were unrelated (Larsen-Barr et al. 2018a). Seven of the women from this study who had successfully withdrawn were interviewed:

> They described managing the process and maintaining their wellbeing afterwards by 'understanding myself and my needs', 'finding what works for me' and 'connecting with support'. (Larsen-Barr & Seymour, 2021)

One attempt to summarise the ‘Barriers to stopping neuroleptic (antipsychotic) treatment in people with schizophrenia, psychosis or bipolar disorder’ (Moncrieff et al., 2020) concluded:

> The major barrier to stopping antipsychotics is an understandable fear of relapse among patients, their families and clinicians. Institutional structures also prioritise short-term stability over possible long-term improvements. The risk of relapse may be mitigated by more gradual reduction of medication, but further research is needed on this. Psychosocial support for patients during the process of reducing medication may also be useful, particularly to enhance coping skills. . . . Many patients want to try

and stop neuroleptic medication for good reasons, and psychiatrists can help to make this a realistic option by supporting people to do it as safely as possible.

Aims of the current study

The current paper is based on the responses in the previously mentioned large international survey (Read & Williams, 2019; Read & Sacia, 2020), to questions about what preparations respondents had made for their withdrawal attempt and what was helpful and unhelpful in the process of trying to withdraw. The aim of this study is to begin to fill a research void by simply documenting the self-reported experiences of a large international sample of people who tried to come off APs.

Methods

Informed consent was obtained from participants at the outset of the survey, following the Participation Information Sheet. The study was approved by the Human Research Ethics Committee of Swinburne University of Technology in Melbourne, from where the data collection took place. The data was analysed, and the paper written, after the author moved to the University of East London.

Instrument

The online questionnaire 'The Experiences of Antidepressant and Antipsychotic Medication Survey' (Read, 2022a; Read & Williams, 2018) was based on the 'Views on Antidepressants' questionnaire (Read et al., 2014). Questions about experiences with antipsychotics were added, based on the relevant research (Read & Sacia, 2020; Read & Williams, 2019). The survey, which used Qualtrics software, produced qualitative (open-ended questions) and quantitative data (yes/no and multiple-choice questions), about the prescribing process (Read, 2022a), the positive and negative effects of antipsychotics (Read & Williams, 2019; Read & Sacia, 2020), causal beliefs about psychosis (Read, 2020),

alternative treatments and, the subject of the current paper, experiences of withdrawing from antipsychotics (Read, 2022b).

This paper reports responses to the two questions: 'Did you consult with a doctor before stopping your medication regime?' and 'What, if any, preparations did you make for your attempt to stop taking anti-psychotic medication?'; with respondents being invited to endorse as many of 15 listed types of preparation (see Table 1) that applied to them. They were also invited to identify 'other' types of preparation. They were then asked two open-ended questions: 'What did you find most [helpful/unhelpful] in your attempt to stop taking anti-psychotic medication and why'?

Participants

Of the 2,346 people who responded, 12% were recruited via an online research company and the remaining 78% via advertisements on social media and snowball sampling. 832 met criteria for being users of antipsychotic medications (Read & Williams, 2019; Read & Sacia, 2020). Of these respondents, 585 had tried to stop taking their antipsychotics at least once and were therefore eligible for inclusion in the current analyses.

Sample characteristics

Of the 585, 71.0% were women. Ages ranged from 18 to 76, averaging 42.8 years (SD 13.1). Respondents were from 29 countries, primarily the USA (26%), Australia (24%) and the UK (21%). Other countries contributing more than 2% were: New Zealand, Canada, Netherlands, Germany, Ireland and Denmark. The most frequently self-reported ethnicities were 'white'/'Caucasian' (48%), 'Australian' (10%) and 'European' (7%). 26% had taken antipsychotics for 1-12 months, 18% for 1-3 years, and 56% for more than three years. 23 drugs were cited, most frequently quetiapine (35%), olanzapine (17%), aripiprazole (12%)

and risperidone (12%). Most (91%) reported a second generation ('atypical') drug (91%), and that the drug was taken in pill form (96%) rather than by injection.

DSM-V groupings cited as 'primary diagnosis' by 3% or more of participants were: 'Schizophrenia Spectrum and Other Psychotic Disorders' – 37%; 'Bipolar and Related Disorders' - 21%; 'Depressive Disorders' - 21%; 'Personality Disorders' - 7%; and 'Trauma and Stressor-Related Disorders' - 3%.

72% reported some degree of withdrawal effects. Of these, 19% described the effects as 'mild (29% as 'moderate', and 52% as 'severe' (Read & Williams, 2019). The most commonly reported were insomnia, anxiety, and extreme/labile feelings. Those who reported withdrawal symptoms were significantly older than those who did not. Duration of treatment was significantly related to withdrawal symptoms. Withdrawal effects were unrelated to gender, education or income (Read, 2022). A minority (18%) reported a return of, or increase in, psychosis (Read, 2022).

40% had only tried to stop once, 34% had tried two or three times, 19% had tried four to nine times, and 6% had tried 10 times or more (Read, 2022). Of the 268 who responded to 'Approximately how long did it take you to reduce to no medication?' 41% said 0-7 days, 35% took between one week and 12 months, and 24% took a year or more. Length of withdrawal was positively correlated with duration of treatment.

Data analysis

Responses to the quantitative questions about consulting with the doctor and making preparations were analysed in relation to age (two-tailed independent t-tests) and gender (chi-squares). Because of the high number of analyses the level of significance was set at $p < .01$, rather than the traditional $p < .05$, to reduce the likelihood of type one (false positive) errors.

Answers to the two questions about preparation are reported as frequencies. Responses to the two open-ended questions about what was helpful and unhelpful were subjected to 'conventional' content analysis (Hsieh & Cannon, 2005) to develop categories directly from the data. Only categories with ten or more examples in the data set were reported.

Results

Consultation and Preparation

Of the 538 who responded to 'Did you consult with a doctor before stopping your medication regime?' 286 (53.2%) said 'yes' and 252 (46.8%) 'no'.

Of the 560 who responded to 'Did you make any preparations for your attempt to stop taking anti-psychotics?' most (329; 58.8%) said 'no' (223 (39.8%) said 'yes, and 8 (1.4%) could not remember. Table 1 shows how many participants endorsed the types of preparations which the survey listed, along with 'other' preparations made by three or more participants. The most commonly endorsed were making a plan, gathering information and informing family. Neither consultation nor preparation (in general or types) were related to age or gender.

What was helpful and unhelpful?

Table 2 presents the categories derived from the responses of the 443 people who answered 'What did you find most helpful in your attempt to stop taking anti-psychotic medication and why?' The most common responses were: the expectation of improved wellbeing as a result of getting off the drugs, information about withdrawal symptoms and the process of coming off, withdrawing slowly, counsellors/psychotherapists and determination.

Table 3 lists the categories developed from the answers of the 429 participants who answered ‘What did you find most unhelpful in your attempt to stop taking anti-psychotic medication and why?’ By far the most common unhelpful factor was the medical professional involved, identified equally as ‘psychiatrist’ or ‘doctor’, followed by lack of support in general, and stresses from family or friends.

Table 1

Types of preparation for withdrawal from antipsychotics endorsed from a checklist

Type of Preparation	N	% [out of 560]
none	329	58.8%
any	223	39.8%
made a plan for gradual withdrawal	143	25.5%
gathered information about coming off anti-psychotic medication	138	24.6%
informed my family, partner or spouse about my intentions and how I wanted them to support me	117	20.9%
informed friends of my plans and what to expect	76	13.6%
reduced the stress in my environment	74	13.2%
made sure I had a steady, regular routine	72	12.9%
started seeing a psychologist, counsellor or psychotherapist to help me manage my experiences during withdrawal	63	11.2%
got into a regular sleeping pattern	55	9.8%
learned meditation	54	9.6%
stopped or reduced taking drugs	50	8.9%
created an advanced directive with a plan for how I wanted to handle relapse if it happened	45	8.0%
arranged a safe, quiet place to go in case the need arose	44	7.9%
took time off work or away from study	44	7.9%
joined a support group	40	7.1%
stopped or reducing drinking alcohol	34	6.1%
‘Other’, including:	69	12.3%
improved diet/nutrition/vitamins	11	

started/increased exercise	6	
alerted/made plan with doctor	6	
started tranquiller/sleeping pills	5	
started/increased marijuana	3	

Table 2

Responses of 443 people to 'What did you find most helpful in your attempt to stop taking anti-psychotic medication and why?'

Helpful factor and n	Examples	Age, Gender, Country
Positive outcomes – current or anticipated 52	I suddenly had feelings I had not felt for years. I was able to cry for the first time in years. The distance I felt from myself and others disappeared. I started to lose the weight I had gained. I was more excited about my life.	60, F, UK
	just the thought of feeling normal again.	52, F Canada
	the feeling of taking my life back	30, M, UK
	The thought of being in control of my life again	25, M Denmark
	Being off them was relief enough. Even in distress, I had better clarity of thought being off them.	56, F, NZ
	knowing that my body will feel better without the medication	39, F Switz-erland
	being aware that stop taking medications could be tough, but would lead to something better in the end	39, F Norway
	I believed that I would feel better without it	38, F Sweden
	The growing conviction that I was right to stop. This was borne out more day by day as I was then able to hold down a job and get a life	66, F, UK
	The knowledge that I was going to get off a drug that had caused me many problems, that I would be healthier and that eventually the withdrawal effects would subside	33, F Australia
	I felt so much better, more myself and more alert	58, F, UK
	Getting my life back, antipsychotics had berieved me of my life	42, F, UK

	I was disgusted at the physical changes, weight gain, muscle loss & sexual orgasm issues & was wanting a decent life back	65, F, USA
	I was glad the symptoms of dyskenesia gradually went away, other people were starting to notice them.	55,M,USA
	I was no longer experiencing really bad side effects. I did not feel drugged down.	29, F, USA
	The desire to live life came back, that was a huge motivation. Walking on the beach and suddenly I could feel the sand between my toes, things like that	56, F Denmark
	The experience of getting my life back, being able to make descisions. These things gave me hope. Laugh and cry	56, F Denmark
	I knew that I could get well and live a normal life without the need to constantly be medicated and feel shit all the time	40, F, UK
	The thought I would lose weight and I will get back to a normal level of cholesterol	32, F, Romania
	My belief that withdrawal would be temporary, that I would be healthier and possibly live longer, that I could learn how to feel my feelings and not be afraid of them	35, F Canada
Information (e.g. about withdrawal effects and/or how to come off) 38	Knowledge & information on how to withdraw slowly	42, F Australia
	As much information as I could get my hands on about the specific drugs I was coming off of	50, F, USA
	Information about what to expect	34, F, USA
	Knowing bad side effects of withdrawal.	41, F, USA
	didn't know then about gradual withdrawal and withdrawal symptoms caused by these medications. Now I know.	33, M France
	The knowledge, that these are withdrawal effects and not symptoms of my illness	35, F Austria
	The single most important thing in helping me detox was reminding myself that I was sane and that the symptoms I was experiencing were from the detox, not a sign that I was mentally ill	37, F, USA
Withdrawing/ tapering/ reducing slowly 37	Doing it very, very slowly	70, F Australia
	going slowly, the drug is very powerful	24, F, USA
	Go very slowly: helps your brain to adapt.	31, F

	Reducing the dosage much more slower than recommended	Belgium 34, M
	tapering off slowly making a plan and keeping a diary	Germany 48, F, UK
Counsellor, psychologist, psychotherapist 35	The psychologist I was seeing who recommended the book Your Drug May be Your Problem and also because she helped me start to understand my difficulties in a different way	47, F, UK
	when one has a good counsellor, its about problem solving, acknowledging feelings, taking stock of where you are with medication and what is going on in ones life from time to time, it has offered me checks and balances and helps me make informed decisions that are ultimately mine	46, M Ireland
	with my meditation and the work I am doing with therapist and if reduce very gradually I should be okay (hopefully)	39, F Ireland
	Psychotherapy. It allowed me to be	28, M India
	Validation of how I was feeling and looking at the positive things I was experiencing with my psychologist was extremely helpful	36, F Australia
	Professional people (social workers and psychologists) believed I could do it	65, M, USA
Nothing 35	Nothing	23. M Estonia
	Huh? I just focused on surviving, nothing was helpful.... you're in 24/7 hell	??, F, USA
	nothing - I had no support	58, F, USA
	Nothing helped me	35, M, UK
	Nothing specific	44, M India
	Nothing needed	41, F, UK
Determination/ perseverance /strong will 32	My commitment My determination My strength My willingness to stay alive, endure and fight, to have a better life no matter what	50, F Australia
	Determination to succeed	67, M, UK
	Determination. Disgust at what it did to me	51, F, USA
	Perseverance	58, F, USA
	Just my strong will	67, M Australia
	My newly-found guts because they helped me stand up to my doctor and parents	18, F, USA
	I told myself I am a strong person	36, F

		S. Africa
	Reminding myself that I had the ability within myself to cope with life without numbing agents like anti-psychotics, and repeating to myself the reasons I wanted to live medication-free	37, F, USA
Internet (information and/or support, from websites and/or online support groups) 25	Reputable sources of information on the internet about withdrawal	40, M, NZ
	All the resources on the internet on reducing medication helped	34, M, UK
	information I got from the internet.	55, M, UK
	The support from the friends I made on the internet	47, M Canada
	Websites that describe the problematic effects of psych meds, withdrawal from antipsychotics, etc..	33, F, USA
	making friends on facebook with people who have made it through withdrawal	45, F Switz-erland
	online support groups because these things gave me hope that I could get through it	48, F, USA
Family 23	Support of family	25, F Australia
	Mum	54, F Australia
	To have my husband who understand and helped the best he could	53, F Canada
	Parents / family not getting too worried, trusting it will turn out ok	34, F Belgium
	having the emotional support of my loved ones	31, M Switzer-land
	Partner - became my carer & keeps me safe from myself, fully supportive of goal to be medication free	33, F Australia
Supportive doctors 23	Having a doctor who was at least willing to let me try	27, F, USA
	She [doctor] let me control what I put into my body and trusted my experience. This made me feel empowered and capable at healing myself.	27, F Canada
	It worked when I withdrew slowly under doctor's supervision	45, F, USA
	My doctor listening when I said medication was making me sicker	24, M, USA
	Close contact with my Psychiatrist/Psych Ward so my fears, side effects, and concerns were handled as quickly as possible	36, F Australia
	My psychiatrists support and belief in my ability to live medication-free	30, F, USA
	finally having a psychiatrist that supported my choice to be off meds	43, F, NZ

Peer support/ reading about others' experiences 21	Others who had been through it. Sharing with people both locally and online who understood	59, F, USA
	Knowledge from those who have gone through the process has been extremely powerful. The re-framing of language used around mental health by peer supporters and advocates also gave me hope	34, F, USA
	Peer support - the most trust-worthy help from someone that had "been there, done that"	48, F Norway
	Peer support, because it was honest, knowledgeable and had faith in me while not claiming to have all the answers	43, F Australia
	The support of others who were going through this and others who have recovered, gave me the hope and the answers that my doctors did not	59, F, USA
	Researching all of the truth through testimonials out there. Because once you learn the truth (that anti psychotics aren't all they're cracked up to be- and in fact perhaps make many if not most people sicker) you can't help but want to stop poisoning yourself	27, F, USA
	reading about other people with a schizophrenia diagnosis' success in living off meds and finding ways to endure altered states and still function and contribute to society, knowing if others can do it I can do it too gave me hope	33, F, NZ
	reading the stories of others who got free, built lives, used and use a range of coping tools, and shared their insights with others	61, F, USA
	To hear the experience from other people who had succeded coming off meds. and that gave me hope that i could do it as well.	46, M Denmark
	The self-help group of Hearing Voices Greece in which I participate because it accepts me	46, M Greece
Accepting/ believing in self 20	My own trust in myself and my ability to heal myself	40, F, UK
	Accepting myself for who I am	23, F Australia
	trusting in myself that I was doing the right thing	32, F, UK
	believing i could do it	33, F, USA
	Trusting my instincts and intuition	59, F, USA
Rejecting 'medical model'/ psychiatry/ diagnosis 17	I learned to love myself and leave the unscientific 'diagnoses' behind	69, M Ireland
	the strong belief that i would get thru it and that i did not have a 'mental illness' which required them	51, F, NZ
	self-care, and deprogramming from medical model psychiatry	29, F, UK

	being angry about a life sidelined by a hoax (psychiatry) was empowering	67, F, USA
	Learning about mental Illness in more holistic sense	33, F Germany
	I also did a lot of reading about alternatives to the medical model of mental illness	47, F, UK
Social support – unspecified 17	Support network as they know you and are more approachable than professionals	25, M Spain
	A support system is important when coming off antipsychotic medications	47, M, USA
	support from other people	24, M, UK
Friends/ boyfriends/ girl friends 14	Support from friends and family	39, F Norway
	My boyfriend and friends	30, F Denmark
	The support from the friends I made on the internet	47, M Canada
Exercise 14	Diet, exercise and friends	62, M, UK
	excercising and keeping myself busy	36, F, USA
	positive attitude, exercise, healthy food	52, F, USA
Purpose in life/ helping others/ children 12	a paid job & responsibilities	43, F Australia
	a loving purpose in my life, a need to care for my young children	52, F, USA
	I had a dog which was really helpful because even though I was feeling aweful I would still have to care for her.	29, F, NZ
	Doing volunteering etc. I need a dayly dose of feeling that what I do matters/who I am matters to someone.	39, F Belgium
Healthy diet 12	Good diet. I felt better by eating proper food	34, M Norway
	I learned about the foods, herbs and supplements which were helpful	68, F Ireland
	Nutrition and diet are key and since many psyciatrists are unwilling to help, we are most often left to do it without their help	57, F, USA
Being left alone /staying home/ avoiding stressors/ getting away 12	being alone	40, F Australia
	being away from work and stresses.	44, M, UK
	I learnt to manage my triggers, and to keep away from situations or people that ae not good for me.	36, F S. Africa
Sleeping well 11	regular sleep	49, M, NZ
	I think sleep is just so important, so i've been allowing myself to go slower than I want while I learn how to sleep without meds	37, F Australia

	Passion flower to aid with sleep increased sleeping meds. I NEED my sleep or I am a wreck	44, M, UK 57, F Australia
Cannabis 11	marijuana for anxiety Medical cannabis helped get me through the most painful parts of the neuropathy, anxiety, headaches, and depression Marijuana. I think it can be helpful for some and not for others. It helped stabilise my mood, helped me sleep and stop having nightmares and it helped stop psychotic episodes.	46, F, USA 34, F, USA 20, F S. Africa
God/prayer 10	Belief in myself and my God Keeping busy with my church groups . Faith in God praying and go to church	73, M, USA 61, F, USA 36, F, Nether-lands
Relaxing/ Resting 10	relaxing music Resting relaxation techniques I learned how to relax because the lobotomizing effects of the drugs were decreasing	32, F, UK 58, F Australia 44, M, UK 68, F Ireland
Keeping busy/ Distractions 10	keeping myself busy Having a job which passionates me Keeping a stable and busy routine was important, because I tend to have more symptoms when I'm not active Distraction	36, F, USA 31, F Belgium 27, F, USA 22, M Ukraine

Table 3

Responses of 429 people to 'What did you find most unhelpful in your attempt to stop taking anti-psychotic medication and why?'

Unhelpful factor and n	Examples	Age, Gender, Country
Professionals 131		
(doctors/ medical professionals -	Doctors not understanding the symptoms of withdrawal and claiming that it was highly unusual	34, F Australia

unspecified) (59)	Doctors weren't helpful and would not advise on properly getting off of the medications.	31, F, USA
	Doctors who do not know what they are doing.	59, F, USA
	lack of support from my doctors	40, F, UK
	My doctor telling me that I have to take them without actually really listening to the counter arguments.	40, M, Finland
	the doctors do not know much about the side effects of withdrawing	35, F Germany
	The doctors trying to stop me and puting me in pressure to resume but no support	45, F Australia
	Drs telling me that it couldn't be the medication and was part of my mental illness	35, M Australia
	Doctors. Wish they knew of the better ways out there of dealing with mental illness. I found them myself though	27, F, NZ
	The lack of knowledge from my prescribing doctor about withdrawal symptoms. His arrogance and ignorance stunned me, and I knew I had to turn to elsewhere for real help.	34, F, USA
(psychiatrists) (57)	psychiatrists belittling me & denying my free will/pathologising my behaviour	30, M, UK
	Being met with utter disbelief and dismissal from my psychiatrist(s).	26, F, UK
	Belligerent and narcissistic attitude of the psychiatrist. I was being uncooperative. My life experience and trauma history were not taken into account. If a psychiatrist cannot relate to the experience of the patient - if the psychiatrist thinks they are the ultimate authority and all knowing, it's not going to be a pleasant experience.	52, F, USA
	Lack of support from psychiatrist	49, F, UK
	Mental Health Unit & psychiatrists pushing more drugs upon me	43, F Australia
	My psychiatrist. He refused to support even a reduction in dosage	45, F, UK
	My psychiatrist... Did not listen to me	47, F, USA
	My psychiatrists and my psychologist try continuously to persuade me not to reduce my dose and that's unethical I think.	46, M Greece
	Psychiatrist - didn't support or agree with what I was doing	61, F, UK
	Psychiatrist - offered no advice or help in coping with any side effects	51, F, UK
	Psychiatrist saying I couldn't do it and I would relapse when stressed	37, F

		Canada
	Psychiatrist told me that I needed to reduce my expectations of what 'normal' was. I was told that I could not return to the life I had prior to my illness. He would not support reducing my medication and did not believe I could function without it. Very upsetting and unhelpful, especially given my success and standard of living I now have.	27, F, UK
	Psychiatrists. Because they think those drugs are the answer to everything	28, F Denmark
(professionals – unspecified) (15)	I could not find any professionals willing to partner with me	50, F, USA
	Professional advice. It was all, primarily, drug, drug, drug	63, M, USA
	Lack of professional support	46, M Spain
	No real professional help or experience, so no advice from the people who should know.	44, M, UK
Lack of support 44	Doing it alone	49, F Ireland
	I had zero support about stopping my medication	29, F, USA
	Lack of support from friends	26, F, NZ
	lack of support from my doctors	40, F, UK
	Lack of support from psychiatrist	49, F, UK
	Having no support from my doctors, family and friends	61, F, USA
	There was NO support system other than the internet available. Zero services to assist in my education and process of learning how to navigate the withdrawals	62, F, USA
Family/friends 40	Excess stress particularly family feuds	49, M, NZ
	Family members questioning my decision	28, M, USA
	Family's fears	54, F Ireland
	Fear from spouse	64, F, NZ
	I cannot talk to most of my friends or family about my experience because they are all on medications too, and my feeling is they are waiting for me to fail	54, F Australia
	My family was very scared when I started reducing my medication	30, F, USA
	I couldn't enlist the support of my family who are medical model stalwarts	70, F Australia
	I could not confide in close family, my family had been brainwashed by the biomedical sick brain model	46 M Ireland

	My ex boyfriend had been monitoring my medication use when i was on risperidone and i had to avoid him	45, F, UK
	Pressure from parents to accept the biological model of mental illness and to take drugs.	30, M, USA
	Parents and friends being against the idea as they were concerned I would become extremely unwell again	36, F Australia
	Husband was unable to cope with my withdrawal symptoms and he left me in 4th month	65, F, USA
Nothing 39	Nothing	18, F Netherlands
	Nothing	40, M Finland
Being told to stay on / go back on 32	My doctors thought I should take them longterm	36, F Germany
	Medical profession "it's dangerous to go off your drugs"	54, F Australia
	Doctors trying to persuade me to stay on it.	27, F, NZ
	There was NO SUGGESTIONS as to how to go about it from the psychiatric services. They said I should stay on medication for as long as I live	59, F Norway
	'Don't ever stop' 'You need them to help keep you well.' 'You tried before and you couldn't cope' (referring to my earlier attempt to come off all at once, but not explaining to me that abrupt withdrawal was the wrong method)	66, F, UK
	doctors demonized voice hearing as some terrible problem that would keep me on Abilify forever without acknowledging how physically and emotionally damaging this drug is	34, F, USA
	Hearing that you will be on them for life	53, F, USA
	Medical professionals had no advice on how to get off the meds but just kept saying "you need to be on these for the rest of your life."	34, F, USA
	That the psychiatrist and nurses kept saying that I would need some meds for the rest of my life (boy, did I prove them wrong!)	48, F Netherlands
	The indoctrination and fears instilled by psychiatry. I was terrified because I had been told I had to take these things the rest of my life	62, F, USA
	insisting I had a life-long bio-chemical imbalance that I would need to take medications as a diabetic needs to take insulin	52, F Australia

	No help, no understanding. Everybody too afraid to take responsibility and help me through my crisis. Instead wanting a quick solution by keeping me on drugs	35, F Austria
Insufficient/ incorrect information 22	Lack of information	35, gender-queer, NZ
	The lack of knowledge from my prescribing doctors about withdrawal	34, F, USA
	Not knowing what was happening to me and having to find that information out for myself	26, F, UK
	I had to go through the internet for any information to learn about withdrawal from the medication	48, F, UK
	lack of guidance, information and advice	30, M, UK
	My primary care physician had very little knowledge of psych med withdrawal	48, F, USA
	No-one explained anything. I learned most of what I did from the internet or medical text books	51, F, UK
Withdrawal denied/ minimised/ misinterpreted as relapse of original condition 21	Drs telling my that it couldn't be the medication and was part of my mental illness	35, M Australia
	Doctors who immediately attributed any withdrawal effects to an underlying condition	27, F, USA
	The lie that it will be a mild withdrawal	32, M, USA
	My psychiatrist, She did not believe there are any negative side-effects or withdrawal effects that last longer than maybe a few weeks.	35, F Estonia
	not having my withdrawal symptoms recognized as withdrawal symptoms - I ended up in the hospital three times because of withdrawal symptoms	58, F, USA
	That the psychiatrist said I was getting worse without knowing that it was symptoms from withdrawing. So i thought I was getting completely insane	25, M Denmark
	Doctors who immediately attributed any withdrawal effects to an underlying condition	27, F, USA
Withdrawing too fast 19	Abrupt cessation is not the way to go !	30, M Ireland
	I probably tapered a little too quickly	37, F, USA
	pressure from myself to get off them quickly	37, F Australia
	Being told to cold turkey!	61, F Australia
	Its bad to take it off abruptly	28, M

	Being forced to stop extremely abruptly	India 26, F Australia
Coercion 18	The terror of knowing I could at any time be forcibly drugged	30, M Australia
	Being told that refusing further medication would make me ineligible for further support	26, F, UK
	I was locked up and put on forced invega sustenna	32, F Sweden
	Forced treatment seclusion and restraint Threats & fear	44, F Australia
	The fear of being sent to forced treatment and forced to take meds	28, F Norway
	the persistent threats of involuntary commitment to a psychiatric hospital	44, M, UK
	I contacted mainstream health system (I wanted someone to talk with), which ended up in the even worse antipsychotic nightmare with forced injections	42, F, UK
Sleep difficulties 18	Withdrawal symptoms caused increased anxiety and sleeplessness.	57, F, USA
	Felt sick and couldn't sleep	69, F, USA
	I only stopped for a day and went back on because I was worried I wouldn't get enough sleep	31, F Australia
	I couldn’t sleep without it	32, F Netherlands
	I felt I couldn't continue, as the insomnia/restlessness returned	33, M, USA
Psychiatry’s medical model 17	Biases from people who had totally bought into the concepts of biological psychiatry	65, M, USA
	My doctor's and parents' desire that I have a brain defect instead of being a free agent who can take care of myself	18, F, USA
	Psychiatry and the "chemical imbalance myth" that they have almost everyone believing because it prevented family and friends from supporting my decision.	52, F Canada
	That I couldn't enlist the support of my family who are medical model stalwarts	70, F Australia
	been frowned upon and not supported by family, due to the brainwashing of the public into the biomedical model	45, F Ireland
	the biomedical model of mental illness that views everything as a return of symptoms	44, F Australia
	People telling me that I had a lifelong biochemical illness and that going off medications would harm my brain and cause "a severe	24, gender-queer, USA

	episode" that would require hospitalization, people pathologizing every mood and emotion I had when I was coming off the meds	
	The unrelenting message of bio psychiatry in all its manifestations	46, M Ireland
	Biochemical explanations of distress, paternalistic health professionals	42, F, UK
	In short, the medical model. The notion that my weird and whacky experiences were 'a problem' to be 'fixed'. Instead of inspiring hope, they tell you your brain is fucked. Instead of encouraging you to creatively problem solve, they tell you to lower your horizons. This is not a recipe for personal growth	32, M, NZ
Stressors 15	Assignments at University caused me stress	45, F, UK
	Being in a stressful situation	33, F, NZ
	I took on too many activities and started getting very stressed	42, F, UK
Having to keep it secret 12	It may be better to keep your doctor thinking that you're still following his orders other than telling him and risking that s/he might do something that could make things more difficult	57, F, USA
	Fear of psychiatrist...and the fact i need to hide it from him	38, F Croatia
	Psychiatrists want you to take it so have to do secretly	58, F, UK
	having no support to do so, you are afraid to tell anyone because they might commit you .	39, F Ireland
	The fact that I could not share my experiences with doctors for fear of being put back on medication	68, M, UK

Discussion

Limitations

Although this was the largest sample ever surveyed, respondents constituted a non-randomised, convenience sample, and therefore may not be representative of everyone who has tried to withdraw from APs. Poor people may have been less likely to participate for lack of internet access. Men (29%) were underrepresented, as were people from low- and middle-income countries.

People responding to an online invitation about psychiatric drugs might be particularly likely to have strong opinions on the matter. It is unlikely, however, that the sample was biased towards people with negative attitudes about APs, because more than half (56%)

reported that their APs had ‘reduced the problems for which they were prescribed’, more than double the 23% with a ‘good’ response in a meta-analysis of drug trials (Leucht et al., 2017).

Analysis of open-ended questions is inevitably subjective. Another researcher may have developed different categories or merged some of the categories. For example, the two ‘helpful’ categories ‘Determination/perseverance/strong will’ and ‘Accepting/believing in self’ are similar and might have been merged. Providing numerous examples of each category allows the reader to assess whether the categories are meaningful.

Previous research

Some of the responses to the question about what was helpful confirmed previous findings that withdrawing slowly, receiving some kind of personal or professional support, and professionals being less coercive and more respectful of patients’ choices and rights, are all important factors (Geyt et al., 2017; King et al., 2024; Larsen-Barr et al. 2018a, Larsen-Barr & Seymour, 2021; Moncrieff et al. 2020).

Professionals

Perhaps the most important *new* finding is that many patients find their psychiatrists, and other doctors, unhelpful. Some were described as uniformed; others as actively obstructive, trying to persuade, or compel, patients to stay on the medication. The failure to be informed, and to inform, may be understandable if psychiatrists are relying on inaccurate guidelines, drug company information or cultural norms within psychiatry. Ignorance about withdrawal effects could lead to telling patients withdrawal symptoms do not exist, and/or misdiagnosing them as a relapse of the condition for which the drugs were prescribed. This has been found to often be the case for antidepressant users (Read et al., 2023 a,b). It is important to note,

too, that discarding a biomedical model of their difficulties helped some patients to come off their medication. This dominant model often creates a barrier to reducing or stopping.

Clinical psychologists, psychotherapists and counsellors, too, could make a greater contribution. (Aston et al., 2021). Many non-medical mental health professionals have, for decades, tended to see the medication related issues of their clients as 'none of their business' and have therefore remained rather uninformed and unhelpful. In 2019, the All Party Parliamentary Group for Prescribed Drug Dependence, in conjunction with the British Psychological Society, several counselling and psychotherapy associations and the International Institute for Psychiatric Drug Withdrawal. published '*Guidance for psychological therapists: Enabling conversations with clients taking or withdrawing from prescribed psychiatric drugs'* (Guy et al., 2019). It includes important information for psychologists and others about the effects of anti-psychotics in general (Moncrieff & Stockman, 2019), about withdrawal from antipsychotics (Read et al., 2019) and about 'The role of the therapist in assisting withdrawal from psychiatric drugs: What do we know about what is helpful? (Guy et al., 2019b).

Compulsion

Antipsychotics are frequently given against the will of the recipient, under mental health legislation, sometimes by forcible, long-acting injections. Physicians who are so convinced that the drugs concerned are vitally necessary that they are willing to force them upon unwilling patients may, perhaps with good intentions, be relatively unlikely to listen to a patient's complaints about adverse effects or to their request for support to come off the drugs. The fear of being forcibly incarcerated and or medicated if the psychiatrist finds out, leads some to try to withdraw secretly, with no professional support. Fear of one's doctor is unfortunate and not conducive to a therapeutic relationship (Prytherch et al., 2021), without

which the chances of recovery are reduced (Ardito & Rabellino, 2011; Goldsmith et al., 2015; Shattock et al., 2018). This fear of compulsory treatment may partially explain why nearly half (46.8%) did not consult with their doctor before starting to come off.

The following excerpt from a recent joint publication from the World Health Organization and the United Nations offers some hope for the future in this regard:

> From a human rights perspective, coercive practices in mental health care contradict international human rights law, including the Convention on the Rights of Persons with Disabilities. They conflict with the right to equal recognition before the law, and protection under the law, through the denial of the individual's legal capacity. Coercive practices violate a person's right to liberty and security, which is a fundamental human right. They also contradict the right to free and informed consent and, more generally, the right to health. . . . There is an immediate international obligation to end these practices. (W.H.O. & U.N., p. 15)

Focussing on the benefits of withdrawing

Another important finding was that the most frequently cited helpful factor was focussing on the benefits of getting off the drugs. This took the form of thinking about the reduced adverse effects or about a return of feelings and feeling more alive again, sometimes after long periods of feeling numbed by the drugs. This is consistent with responses to the question 'What were the effects of withdrawing from the medication?', reported previously; 26% reported at least one positive outcome, most commonly more energy, more alive, clearer thinking, reduced side effects, and 'more like myself again'.

Interviews with 26 participants in the RADAR study comparing antipsychotic dose reduction and discontinuation with maintenance treatment (Moncrieff et al., 2023), found that:

> Most participants reported reduced adverse effects of antipsychotics with dose reductions, primarily in mental clouding, emotional blunting and sedation, and some

> positive impacts on social functioning and sense of self. . . . There are relapse risks and challenges, but some people experience medication reduction done with clinical guidance as empowering. (Morant et al., 2023)

Once prescribers have educated themselves about withdrawal effects and the need to support their patients to come off gradually and safely, helping them stay focussed on the benefits of getting will be important. This contrasts with frightening patients with an exclusive focus on potential negative consequences.

Family and friends

Some respondents received helpful support from loved ones, in and beyond the family, which is consistent with previous findings (Larsen-Barr et al. 2018a,b; Larsen-Barr & Seymour, 2021). The current study revealed, however, that loved ones can sometimes be unhelpful, often because of their understandable fear, generated by negative messages and predictions from prescribers and the 'medical model' more generally. Family sessions, focused on balanced, evidence-based information about benefits and risks, and discussions of what sort of support is needed would be ideal, and would contrast with recruiting families to try to get the patient to be compliant out of fear. The non-withdrawing individuals may also need support themselves, especially those living with the person withdrawing.

Internet and peer-support

Numerous respondents cited the internet as a valuable source of information and support, often from people who have been through the process of withdrawing themselves. This is consistent with surveys of people withdrawing from antidepressants (Read et al., 2023a,b; White et al. (2021). It seems that for both groups of people the void left by the failure of professionals to provide information and support is being filled by self-help, on a large scale.

Research and training implications

Extensive research is urgently needed into the withdrawal symptoms of APs, including incidence, duration, severity, and specificity to different APs. It should be a cause for collective shame that until very recently there had been little or no research into how to get off these drugs safely. This crucial gap in our knowledge must be filled, quickly. Among the recent contributions is a Taiwanese study which found that showing that if you taper gradually and hyperbolically there is no excess relapse compared to maintenance, that many people can reduce, and that doing so slightly improves their social functioning (Liu et al., 2023). Another recent study included an understanding of the neurobiology involved in the withdrawal process (Horowitz et al., 2024).

In the meantime, and in the absence, yet, of any official guidelines, leading withdrawal expert, Dr Mark Horowitz, and various British psychiatrists, have proposed strategies based on the little we do know (Horowitz and Taylor, 2019; Horowitz et al., 2021). For example:

> The process of stopping antipsychotics may be causally related to relapse, potentially linked to neuroadaptations that persist after cessation, including dopaminergic hypersensitivity. Therefore, the risk of relapse on cessation of antipsychotics may be minimized by more gradual tapering. . . . We, therefore, suggest that when antipsychotics are reduced, it should be done gradually (over months or years) and in a hyperbolic manner (to reduce D2 blockade "evenly"): ie, reducing by one quarter (or one half) of the most recent dose of antipsychotic, equivalent approximately to a reduction of 5 (or 10) percentage points of its D2 blockade, sequentially (so that reductions become smaller and smaller in size as total dose decreases), at intervals of 3–6 months, titrated to individual tolerance. Some patients may prefer to taper at 10% or less of their most recent dose each month. This process might allow underlying adaptations time to resolve, possibly reducing the risk of relapse on discontinuation. Final doses before complete cessation may need to be as small as 1/40th a therapeutic dose to prevent a large decrease in D2 blockade when stopped. This proposal should be tested in randomized controlled trials. (Horowtiz et al., 2021, p. 1116)

This is the sort of information that urgently needs to reach prescribers, via national training programmes throughout the world. Co-author, Professor Robin Murray, perhaps the UK's leading schizophrenia researcher, commented:

> Some psychiatrists are reluctant to discuss reducing antipsychotics with their patients. Unfortunately, the consequence is that patients suddenly stop the medication by themselves with the result that they relapse. Much better that psychiatrists become expert in when and how to advise their patients to slowly reduce their antipsychotic. (Murray, 2021)

A study using focus groups of British psychiatrists concluded that:

> Concerns about risk and other barriers means that clinicians are often reluctant to implement reduction or discontinuation of antipsychotic medication. In order to increase the treatment options available to service users, more research and guidance on how to minimise the risks of antipsychotic reduction and discontinuation is required to enable clinicians to engage more constructively with service users' requests, offering people more choice and control in managing their mental health condition. (Cooper et al., 2019)

Informed consent

A previous paper (Read, 2020,b),based on the same survey on which the current paper is based, reported that none of the 585 who had tried to come off APs (and none of the larger sample of 832) recall being told, when first prescribed the drugs, anything at all about withdrawal effects, dependence, withdrawal psychosis, or the need to reduce gradually. This breach of the fundamental ethical principle of informed consent extends beyond whether to take psychiatric drugs in the first place, to when and how to come off them. The previously mentioned World Health Organisation and United Nations joint report states:

> Countries should adopt a higher standard for the free and informed consent to psychotropic drugs given their potential risks of harm . . . . Legislation can require medical staff to inform service users about their right to discontinue treatment and to

receive support in this. Support should be provided to help people safely withdraw from treatment with drugs.' (W.H.O. & U.N., 2023)

Conclusion

Many psychiatrists would argue that long-term medication is appropriate for most people and discontinuation should generally be discouraged. New guidelines (Cooper et al., 2022) and training programmes are, therefore, urgently needed. The first ever Maudsley Deprescribing Guidelines (Horowitz & Taylor, 2024) has just been published, outlining the principles of gradual, hyperbolic tapering to minimise withdrawal effects. It covers benzodiazepines, antidepressants, gabapentinoids and Z-drugs. The tapering of antipsychotics will be included in a forthcoming volume (Horowitz & Taylor, 2025). Guidance for psychological therapists, including for antipsychotics, is, as noted, now available (Guy et al., 2019a).

Meanwhile, an evidence-based, respectful, collaborative response to patients' concerns about adverse effects and desires to withdraw, from prescribers and non-medical staff alike, would probably reduce relapse rates and improve long term outcomes. It would definitely help to end the current pervasive breaching of the ethical principle of informed consent and human rights legislation.

Practitioner Points

- Prescribers should fully inform potential users of antipsychotic drugs about all their adverse effects, including the high risk of withdrawal effects.
- Prescribers should educate themselves about withdrawal effects and learn how to support people to gradually and safely withdraw if they so wish.
- Psychologists, and other non-medical mental health staff, should also inform. themselves about withdrawal and be prepared to engage with and support clients
- Professional organisations, of psychiatry, psychology, nursing. etc., should take a lead on training their member on these issues.

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