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The need for antidepressant withdrawal support services: Recommendations from 708 patients

John Read [a,*], Stevie Lewis [b], Mark Horowitz [c], Joanna Moncrieff [d]

[a] School of Psychology, University of East London, London, UK
[b] Unaffiliated Researcher, Lived Experience of Prescribed Drug Dependence, Cardiff, UK
[c] Mental Health Sciences Unit, University College London, London, UK
[d] Division of Psychiatry, University College London, London, UK

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ABSTRACT

Approximately half of the tens of millions of people currently taking antidepressants will experience withdrawal symptoms when they try to reduce or come off them. Nearly half of these describe their symptoms as severe in surveys. Many prescribing doctors seem ill-informed and unprepared to provide effective discontinuation advice and support, often misdiagnosing withdrawal as a relapse of depression or anxiety. 708 members of online support groups for people on antidepressants, from 31 countries, completed a sentence in an online survey: 'A public health service to help people come off antidepressants should include .....'. Two independent researchers categorised their responses into themes, and then reached consensus via discussion. Seven themes emerged: 'Prescriber Role', 'Information', 'Other Supports/Services', 'Strong Negative Feelings re Doctors/Services etc.', Informed Consent When Prescribed', 'Drug Companies' and: 'Public Health Campaign'. The most frequently mentioned requirements of the Prescriber Role were that prescribers be properly informed, provide small doses/liquid/tapering strips, develop a withdrawal plan and believe patients about their withdrawal experiences. The most frequently recommended other services were psychotherapy/counselling, support groups, patient led/informed services, nutrition advice, 24-hour crisis support and 'holistic/lifestyle' approaches. Many respondents were angry about how uninformed their doctors were and how they had been treated.

1. Introduction

1.1. Antidepressant prescribing

Annual antidepressant prescribing in the U.K. recently doubled in ten years (Iacobucci, 2019). A government enquiry found that 7.3 million adults (17% of the population) had been prescribed at least one prescription of antidepressants in 2017–2018 in England alone; with particularly high rates for women, poorer people and older people (Public Health England, 2019). The latest government figures for England show that between October 2021 and September 2022 there were 84.8 million antidepressant prescriptions prescribed, an increase of 2.9 million (3.6%) on the preceding year (NHS-BSA, 2022).

Similar rates of prescribing occur elsewhere, including Australia, Belgium, Canada, Denmark, Finland, Iceland, Northern Ireland, Portugal, Sweden and Wales (OECD, 2017; Iacobucci, 2019). In the USA, during 2015–2018, 13.2% of adults used antidepressant medications 'in the past 30 days', with use reaching 24.3% for women aged 60 and over (Brody and Gu, 2020).

Increased prescribing is due not only to increases in the number of people being prescribed antidepressants but also to individuals being prescribed them for longer (Kendrick, 2021). For example, between September 2017 and September 2022 the number of people in England prescribed antidepressants rose by 23%, but the number of prescriptions rose by 28% (NHS-BSA, 2022). By 2011, half of antidepressant users in England had been taking antidepressants for more than two years (Johnson et al., 2012). Average duration of use has doubled since the mid-2000s in the U.K. (NHS Digital, 2018). In the U.S. half of antidepressant users have been taking them for at least five years (Mojtabai and Olfson, 2014).

1.2. Withdrawal

Recent reviews (Fava et al. 2018; Davies and Read, 2019) have

* Corresponding author.
E-mail address: john@uel.ac.uk (J. Read).

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revealed the prevalence, severity and duration of antidepressant withdrawal. One review (Davies and Read, 2019) was undertaken for the All-Party Parliamentary Group for Prescribed Drug Dependence in the UK, to inform a government enquiry by Public Health England (2019). Fourteen studies, using a range of methodologies, found that, on average, 56% of people experience withdrawal symptoms when withdrawing from, or reducing, antidepressants. Four surveys assessing severity found that an average of 46% of people described their withdrawal symptoms as 'severe'. Of the ten studies measuring duration, seven found that a substantial proportion of patients have withdrawal symptoms for weeks, months or, more rarely, several years. The most recent review concurs that withdrawal from antidepressants 'represents a quite frequent and burdensome outcome', despite several authors having conflicts of interest relating to drug companies and using the outdated industry euphemism of 'discontinuation syndrome' (Fornaro et al., 2023)

Antidepressant withdrawal is characterised by physical and emotional symptoms (Davies and Read, 2019; Fornaro et al., 2023; Moncrieff, 2020; Read et al., 2014, 2019) that can emerge days, weeks or months after stopping antidepressants, and which sometimes surpass the problems for which the drugs were prescribed (Cosci and Chouinard, 2020; Davies and Read, 2019; Fava, 2021; Fava et al., 2018; Horowitz and Taylor, 2019; Jha et al., 2018). Many doctors are unaware of this evidence and therefore do not understand their patients are presenting with withdrawal symptoms (Cosci and Chouinard, 2020; Davies et al., 2018; Hengartner and Plöderl, 2018). They often, therefore, misdiagnose relapse of depression or anxiety instead (Framer, 2021; White et al., 2021). Most of a small sample of British GPs reported that their knowledge about withdrawal was inadequate (Read et al., 2020). Furthermore, international surveys of antidepressant users find that less than 1% are told anything about withdrawal by the prescriber (Read et al., 2018, 2020).

Cosci and Chouinard (2020) reviewed the literature on withdrawal symptoms of a range of psychiatric drugs, including antidepressants, and concluded that 'The likelihood of withdrawal manifestations that may be severe and persistent should be taken into account in clinical practice and also in children and adolescents' (p. 283). In 2019 Public Health England produced a report on 'Dependence and withdrawal associated with some prescribed medications: An evidence review.' It acknowledged the full extent of problems withdrawing from antidepressants, and recommended targeted withdrawal services and a helpline to assist people coming off antidepressants and other psychiatric drugs, and more accurate national guidelines. The Royal College of Psychiatrists published a new, evidence-based position statement (Iacobucci, 2019; Royal College of Psychiatrists, 2019) which recommended that patients should be informed of 'the potential in some people for severe and long-lasting withdrawal symptoms on and after stopping antidepressants'. They also produced guidance on 'Stopping Antidepressants' recommending that long-term antidepressants are stopped 'over a period of months or longer' and that tapering plans 'should allow you to reduce the dose at a rate that you find comfortable – as slowly as you need to avoid distressing withdrawal symptoms' (Burn et al., 2020).

The UK's National Institute for Health and Care Excellence also updated its guidelines (National Institute of Clinical Excellence (NICE), 2022), pointing out that:

> '- withdrawal can sometimes be more difficult, with symptoms lasting longer (in some cases several weeks, and occasionally several months)
>
> - withdrawal symptoms can sometimes be severe, particularly if the antidepressant medication is stopped suddenly.'

1.3. Facebook groups

Prescribers' lack of knowledge about withdrawal symptoms (Read et al., 2020) means many patients are left without meaningful professional support when reducing or coming off antidepressants. Because their doctors struggle to help them withdraw safely, or mis-diagnose their withdrawal symptoms as relapse (Hengartner and Plöderl, 2018), many patients turn to the internet for guidance and support..

A recent study of 13 of these withdrawal Facebook groups reported a total membership of over 67,000, mostly women, increasing at about 25% annually (White et al., 2021). The most common reason for pursuing online support was failed clinician-led withdrawal attempts. For example, *Surviving Antidepressants,* has around 13,000 members, with 6,000 case reports publicly accessible on the site, and receives about 750,000 visits to its site monthly. Forum posts have been used to estimate longevity and time of onset of withdrawal from antidepressants (Stockmann et al., 2018) and instances of drug-induced withdrawal anxiety and mood disorders (Belaise et al., 2012).

A previous publication has reported the quantitative findings from the same online survey of Facebook group members that is used in the current paper. It found that 71% of respondents experienced their doctors' advice regarding stopping an antidepressant as 'unhelpful' (57% 'very unhelpful') (Read et al. 2023). The main reasons endorsed were: 'Recommended a reduction rate that was too quick for me', 'Not familiar enough with withdrawal symptoms to advise me' and 'Suggested stopping antidepressants would not cause withdrawal symptoms'.

The current study explores the participants' views in more depth, by reporting the qualitative findings about what sorts of services and support they recommend should be provided by public health services.

2. Methods

2.1. The survey

The anonymous online survey, for adults (18 or over), was entitled the 'International Online Survey of Members of Peer Support Groups About Their Experiences of Withdrawing from Antidepressants' (Read et al., 2023). The first page informs potential participants that:

'The purpose is to understand the experience of coming off antidepressants so we can inform UK health services (and other health services around the world) what sort of services need to be provided. This is your opportunity to share your experience of coming off these medications and what you have learned in the process to help others going through similar experiences.

We are interested in people around the world who have the following experiences

1 You have stopped an antidepressant in the past
2 OR you are currently trying to stop an antidepressant with the help of an online peer support group
3 OR you tried to stop an antidepressant in the past and had to go back on the antidepressant and you are now seeking help to taper safely from an online peer support group.'

The survey asks quantitative and qualitative questions about why people had tried to withdraw, withdrawal symptoms experienced, the process of withdrawal, the role of online support groups, and how useful a list of potential services would be. The current paper reports responses to the following item:

Please complete the following sentence:

'A public health service to help people come off antidepressants should include .....'

2.2. Procedures

The study was approved by the University of East London's Research Ethics Sub-Committee (Application ID: ETH2021–0120).

The administrators of 15 online support groups for people taking

antidepressants were asked to inform their members about the survey. Thirteen of these had been the subject of a previous study (White et al., 2021). We do not know how many administrators did publicise the survey as our colleague undertaking this part of the project, and liaising with the groups, Ed White, has sadly died. The survey, which used the *Qualtrics* platform, was online from May 2021 to April 2022.

2.3. Data analysis

The methodology used to summarise the data was content analysis (Bengtsson, 2016), which aims to give direct voice to participants, with minimal interpretation from the researchers. One researcher read the first half (1–354) of the 708 responses and another read the second half. Each developed themes and subthemes independently from the other researcher. One proposed 11 themes, with 27 subthemes. The other identified eight potential themes and 16 subthemes. Discussion between the two researchers led to agreement on nine themes and 29 subthemes. It was decided that only themes or subthemes with at least ten examples should be included.

One of the researchers then scored all 708 responses on the agreed themes and subthemes. One of the original themes ('Need for more research') did not reach the threshold of ten. Another theme ('Support or information for family or employer') became two separate sub themes of the theme 'Other support/services', scoring services for families and employers separately, since both passed the threshold of ten. Three subthemes of the 'Other support/services' theme (Meditation/Acupuncture/Homeopathy; Lifestyle/Holistic; Exercise/Yoga) were integrated into one, called 'Holistic/Lifestyle'. The sub themes 'Patient-led Services' and 'Services with Patient Input' were merged into one, 'Patient Led/Informed Services'. This left seven themes, and 27 subthemes.

The theme 'Strong negative feelings towards doctors/services etc.' was considered sufficiently subjective to warrant two researchers rating it independently from each other. In 577 cases both raters scored the participant as not fitting the theme; in 66 both scored participants as fitting the theme; and another 65 participants were adjudged to fit the theme by one of the two. This represents a 90.8% agreement rate; and a *kappa* inter-rater reliability score (which allows for agreement by chance) of 0.62, classified as 'substantial agreement' (Landis and Koch, 1977). Following discussion, 26 of those considered to fit the theme by only one of the two researchers were excluded, leaving 105 participants being deemed to fit this theme.

In exploring possible relationships between themes or subthemes and demographics we ran 136 tests [34 (27 subthemes, 7 subthemes) X 4 (gender, age, USA vs others, UK vs others) = 136] and, therefore, applied a p value of 0.004 for a result to be deemed significant, according to the Bonferonni method, in order to correct for Type 1 errors (false positives) (Armstrong, 2014).

3. Results

3.1. Sample characteristics

Most participants, 81.4%, were women. 17.5% were men, and 0.8% non-binary. Average age was 47.0 (sd 13.6). Participants were from 31 countries. More than half (56.9%) lived in either the USA (35.7%) or the UK (21.2%). Three other countries provided 50 or more participants: Germany (8.7%), Canada (8.0%) and Australia (7.8%). The others were Austria, Belgium, Brazil, Denmark, Finland, France, Greece, Hungary, Ireland, Israel, Italy, Luxembourg, Mexico, Nepal, Netherlands, New Zealand, Norway, Pakistan, Poland, Portugal, South Africa, Spain, Sweden, Switzerland, and the United Arab Emirates. Most (92.9%) identified as White/Caucasian, with 2.7% Asian, 1.7% Hispanic and 1.1% Black/African American. Most (67.4%) had a degree (35.7% undergraduate, 31.5% postgraduate), 30.0% had only completed high school and 2.5% had not.

The most frequent diagnoses for which the antidepressants were prescribed were: depression (58.7%), anxiety (48.2%), chronic pain (12.4%), social anxiety disorder (6.4%), OCD (4.7%), insomnia (3.1%), fibromyalgia (3.0%) and menopause (1.3%).

All respondents had tried to stop or reduce one or more antidepressants. Half (50.8%) were 'currently reducing/tapering'. A third (32.8%) had tried at least twice to come off an antidepressant and failed. One in eight (12.4%) had tried unsuccessfully five or more times.

When asked 'When first prescribing the antidepressant medication did the doctor tell you anything about withdrawal effects from stopping the medication?' 93.5% responded 'no', 4.3% 'yes' and 2.2% 'don't know/can't remember'.

When asked 'Did the antidepressants help you with the problem they were prescribed for?' 48.7% responded 'yes', 32.8% 'no' and 18.5% 'don't know/not sure'.

3.2. Themes and subthemes

The largest theme (349 responses) delineates the expectations that patients have of prescribers. By far the most frequent recommendation is that doctors need to be better informed. The second largest theme shows that the two types of information needed, and currently missing, are about withdrawal symptoms and about how to help patients withdraw gradually and safely. The third theme reports the numerous other services that are needed.

Table 1 lists the final set of seven themes, and the 27 subthemes that were spread across the first three, largest, themes. Tables 2–4 give examples of the 27 subthemes. Table 5 provides examples of the four smaller themes. The gender, age and country of participants are given.

What is striking when reading the survey responses is how angry, frustrated, disappointed, and let down people feel (Theme 4; Table 5). These feelings came from being disbelieved by their prescriber that they were in withdrawal to their own disbelief at the lack of accurate

Table 1
Themes and subthemes.

	n	%
1. PRESCRIBER ROLE	**349**	**49.2**
Be Informed/Educated	141	19.9
Small Doses/Liquid/Tapering Strips	88	12.4
Create Plan/Schedule	77	10.9
Believe/Acknowledge	71	10.0
Monitor	47	6.6
Be Supportive/Compassionate	47	6.6
Tailor/Individualise	41	5.8
Post-withdrawal Support	13	1.8
2. INFORMATION	**326**	**46.0%**
How to withdraw	226	31.9
Withdrawal Symptoms	106	15.0
Evidence-based	17	2.4
Written	16	2.3
Patient-based	14	2.0
Not Drug Companies	10	1.4
3. OTHER SUPPORT/SERVICES	**283**	**40.0**
Counselling/Psychotherapy	74	10.5
Support Group	70	9.9
Patient-led/informed Services	60	8.5
Nutrition/Dietician/Supplements	47	6.6
Crisis Support/24 hours	39	5.5
'Holistic'/'Lifestyle'	39	5.5
Support/Information for Families	32	4.5
Specialist Services	28	4.0
Financial Support/Services	25	3.5
Clinic/Centre/Safe Space	15	2.1
Residential/Inpatient/Detox	15	2.1
Liaison/Information for Employers	14	2.0
Pharmacist	11	1.6
4. STRONG NEGATIVE FEELINGS RE DOCTORS/SERVICES ETC	**105**	**14.8**
5. INFORMED CONSENT WHEN PRESCRIBED	**87**	**12.3**
6. DRUG COMPANIES	**17**	**2.4**
7. PUBLIC HEALTH CAMPAIGN	**16**	**2.3**

Table 2
Examples of theme 1: Prescriber role.

Be Informed/ Educated	**141**	Well educated doctors who understand that antidepressant withdrawal can have long-term, severe consequences and that withdrawal symptoms can be vast and affect both physical and mental health.	65 F Canada
		More training for doctors about withdrawals, side effects and how to come off antidepressants, there are too many ignorant doctors.	59 F Australia
		Teaching doctors about withdrawal and making sure they understand what a great responsibility they have when they prescribe psychiatric drugs, because I don't think many of them understand the effects that these drugs have on the brain.	43 F South Africa
		To actually know how to taper and advise accordingly.	53 F Greece
		Professionals being well informed about how withdrawal is affecting people.	45 F Luxembourg
Small Doses/ Liquid/Tapering Strips	**88**	Tapering strips payed by insurence companies.	32 M Netherlands
		Liquid versions of antidepressants so that tapering can be accurate and safe.	27 F UK
		User friendly methods of cutting pills, liquid or tapering stripes.	59 F UK
		Access to liquid medication to enable accurate and very small tapering, safer than the current method of counting tiny beads or grinding up tablets and weighing powder.	43 F UK
Create Plan/ Schedule	**77**	We need very detailed instructions.	53 F USA
		Taper plan and taper doses.	33 F Pakistan
		A tapering schedule.	55 F UAE
		Precise instructions on dose reduction. How long to wait between reductions.	85 F USA
Believe/ Acknowledge	**71**	People who are qualified in knowing exactly what withdrawal problems there are and actually believe you.	84 F UK
		People being listened to and taken seriously about what is happening to them, one of the worst things about this has been being dismissed and treated like I could not be more irrelevant or like I am the one who is acting in an unsafe way when I have tried to advocate for myself for a safe taper. It's not just GP's – I have to hide this from my CPN and the psychiatrist they made me see a couple times as well. …. To have to make sure you keep it a secret from people who are supposed to be helping keep you safe – because what they will do is even worse than what is already happening to you is just horrific.	29 F UK
		Support from anybody that believes in the effects of withdrawal and who doesn't just want to add more medications into the process.	34 F UK
		Understanding and belief that the patient is experiencing what they say they are. Providers need to trust that people know their own bodies.	38 F USA
		Validation that the patient's voice is being heard and what they are going through is real (stop minimizing it or dismissing it as "anxiety" or something else).	62 F Australia
Monitor	**47**	Ongoing support to monitor and provide guidance during the taper.	54 M USA
		Very close monitor and tracking the withdrawal symptoms.	21 M Nepal
		A very closely monitored and evidence based safe tapering protocol.	38 F UK
		Weekly monitoring.	72 F USA
Be Supportive/ Compassionate	**47**	Emotional support which would entail validating the patient's experience rather than ridiculing and dismissing them.	27 F Sweden
		Humanity. Compassion.	?? F Brazil
		Humility. The ability to really "see" the patient, to listen to the history being told with all its layers (it's not easy, it's not quick).	
		Support and compassion.	61 F Switzerland
		Doctors who understand and empathize with their suffering patients.	66 M USA
Tailor/ Individualise	**41**	An understanding that withdrawal is REAL and that everyone's experience is different. There is no "one size fits all".	54 F USA
		Personalized advice on a safe tapering schedule.	48 F UK
		Personalized tapering plan.	48 F Germany
Post-withdrawal Support	**13**	monitoring of patient … Drs that believe that withdrawal is very real and very dangerous and can last for a very long time after cessation of the drug	52 F Australia
		Severe physical and emotional effects WILL HAPPEN after discontinuation.	56 F USA
		Being supportive and helpful with the whole process and also for a while afterwards.	53 F Netherlands

information provided to them and the poor level of care they were given once they became ill with withdrawal symptoms.

None of the relationships between the themes or subthemes with gender, age or country (UK or USA) reached the $p = .0004$ level required because of multiple testing (see Methods). Only two relationships came close to reaching the threshold. The 147 UK respondents were more likely than participants from all other countries combined to mention the need for 'small doses/liquid/tapering strips' (20.1% vs 10.5%; $X2 = 10.0$, $p = .002$). They were also more likely (14.1% vs 4.5%) to recommend 'crisis support/24-hour/hotline' ($X2 = 17.6$, $p < .001$).

3.3. Complex responses

Many respondents gave lengthy, thoughtful responses that contributed to multiple subthemes and illustrated how the various issues related to one another. We present just two examples here:

> Emergency helpline if you are feeling suicidal or the urge to self harm. People who have or are successfully tapering to talk to for support rather than a counsellor who still doesn't really get it. And

Table 3
Examples of theme 2: Information.

How to withdraw	**226**	Full information on how to come off slowly and why this is so important.	61 F USA
		Information about how to come off (how the reduction steps should be).	45 F Germany
		Doctors/nurses that are up-to-date with withdrawal methods.	60 F UK
		Very clear tapering instructions for doctors like "5% or less of the already reduced previous dose, not of the original dose, every 10 to 14 days", and that it may take years.	37 F USA
		Explanation of what to expect and how to use coping skills and supplements.	75 F Mexico
Withdrawal Symptoms	**106**	First and foremost should Include accurate information about what to expect from antidepressants withdrawals.	38 F Australia
		Comprehensive Information on withdrawal side effects.	25 F USA
		Lots of information about the withdrawal symptoms.	43 F France
Evidence-based	**17**	Evidence based guidance for slow taper.	42 F UK
		Guidelines for reducing which are backed by the research into hyperbolic tapering.	37 M Canada
		Information about scientific research regarding tapering and withdrawal issues.	35 F Austria
Written	**16**	Written information outlining the dangers of cold turkey and fast withdrawal and an extensive list of potential withdrawal symptoms.	62 F UK
		Printed guidance on the best tapering regime. A list of all possible withdrawal symptoms, arranged into categories such as 'rare', likely etc. Printed material providing reassurance, including reminders that what you are feeling are the effects of withdrawal, they will pass. Where to get help.	65 F Australia
		List of symptoms, durations, and ways to cope.	57 F USA
Patient-based	**14**	Expert advice and support based on patient experience not on made up conclusions by psychiatrists who are completely out of touch with what is actually happening to people on these drugs.	54 F UK
		Tapering doses. All the information and support my online group gives.	67 F Canada
		Taking in new information, mainly from patients, because who is supposed to tell us about the problems from the drugs if not the people using them?	27 F Sweden
Not Drug Companies	**10**	Not stupid vague information like "a gradual taper" which is what USA pharmaceutical manufacturers say as well as the FDA.	37 F USA
		Better information for doctors, provided from trusted sources. It seems that pharmaceutical companies don't properly inform doctors about these issues.	48 F Italy
		Realistic knowledge of what truly happens. Not what drug companies say.	68 F USA

MORE AWARENESS of how severe the withdrawal can really be. Educate these doctors! [44 F UK]

Safe and slow tapering guidelines which can be adjusted at any point when it gets harder at the lower doses. Help with working out a tapering schedule. Literature for family and friends to read about what we are experiencing mentally and physically.

Validating the patients experience with side effects that the drugs caused, educated and empathetic doctors who create customized

Table 4
Examples of theme 3: Other support/services.

Counselling/ Psychotherapy	**74**	PSYCHOTHERAPY! my psychotherapist saved me. Due to the withdrawal syndromes I fell into a spiral of thought, anxiety and suicidal thoughts, and I was stuck in it. She saved me from it..	31 F Belgium
		Better access to psychological support on a one to one but open ended.	63 F UK
		Affordable psychologist services to give practical (non pharma drug) coping techniques.	63 F Canada
		Counselling (both one to one and in groups).	27 F UK
		Specialist counselling that is built around the unique features of withdrawal symptoms.	41 F UK
		Trauma counselling as all of life's trauma is relived in the withdrawal process, family therapy to educate the family and friends of the process and save relationships.	55 F UK
Support Group	**70**	Small local support groups for both withdrawer and any family member/ friend supporting the person withdrawing.	56 M UK
		Group meetings in person for people who are tapering.	58 F USA
		Support groups to learn better coping skills.	42 F NZ
		Support group of others who are or have discontinued psych meds.	70 F USA
Peer-led/informed Services	**60**	Someone who has gone through it themselves, that knows the hell we are going through.	51 F Canada
		Well-informed practitioners, ideally those who have experienced antidepressant withdrawals themselves.	72 F USA
		It should definitely include support from people that have lived this nightmare.	56 F UK
		Understanding support perhaps from people who have been through tapering and withdrawal themselves and not a medic who blindly believes what the pharmaceutical companies say.	58 F Ireland
		Peer support if possible....from trained people who have been through withdrawal.	73 F Australia
		I would have more faith in someone who has successfully tapered themself as I feel they would be more understanding and empathetic.	43 F Italy
		Input from patients- not just western educated MDs and "big pharma".	67 F USA
		In person support groups, could be peer run but have invited speakers plus access to pharmacists etc who can advise and support the group.	63 F UK
Nutrition/ Dietician/ Supplements	**47**	dietician/nutritionists with withdrawal knowledge and how the gut/body are affected by withdrawal.	56 F UK
		A nutritionist who can help with food and supplements to lessen withdrawal symptoms.	47 F USA
		Dietary guidance on what food and supplements would help during withdrawal and which to avoid.	85 F USA
Crisis Support/24 hours/hotline	**44**	24hr helpline.	56 F UK
		A hotline that you can access for immediate advice.	48 F Australia
		A safety net for those days that suicide might be better than suffering.	53 F USA
		A 24 hr helpline manned by trained professionals and associated website	66 F UK

(*continued on next page*)

Table 4 (*continued*)

'Holistic'/'Lifestyle'	**39**	Access to 24 hour care and support from an integrative team of conventional and natural/holistic practitioners that are well educated in the field of antidepressant dependence, tolerance and withdrawal.	36 F Australia
		Holistic approach, covered by health insurance.	46 F Canada
		Multiple therapeutic modalities as options to help people cope with symptoms including yoga, meditation, vagus nerve work, acupuncture, massage, creative arts therapies.	31 F USA
		Support should include things like yoga, tai chi or qi gong plus professionals such as acupuncturists, massage therapists, that have been thoroughly trained to understand what withdrawal is.	67 F Canada
		Homeopathy remedies to help with withdrawal.	44 F UK
		Should include physical movement exercise support from fitness professionals who are qualified to work with people who have a sensitized nervous system.	47 F USA
Support/ Informationfor Families	**32**	Information and support for family and friends to help them to understand what you are going through. It's a rough ride for everyone	57 F Australia
		Support groups for family members.	59 F UK
		Education for family and friends for proper care for the patient.	27 F USA
		Family counseling.	72 F USA
Specialist Services	**28**	A professional who actually SPECIALISES in antidepressant withdrawals!	48 F France
		Specialist counselling that is built around the unique features of withdrawal symptoms.	41 F UK
		An MD that specializes in withdrawal off AD's.	59 M USA
Financial Support/ Services	**25**	Centers that will take health insurance.	37 M USA
		Should include financial support/or help with financial support in case withdrawals are so bad you cannot work.	40 F USA
		Disability allowance.	52 F UK
		Help with disability claim (which would have prevented the loss of my job). I now have no income.	59 F USA
Clinic/Centre/Safe Space	**15**	It would be really useful to be able to call someone or have a place you can walk into to just be able to tell someone how desperate you feel without the fear of having the mental health services becoming involved and forcing medications onto you.	34 F UK
		A safe supported space for recovery.	55 F UK
		A safe place to experience all feelings and thoughts that come with withdrawal.	38 F Canada
Residential/ Inpatient/'Detox'	**15**	Residential program with staff support.	35 F USA
		Retreat (in Australia the only option is a $15k retreat for seven days).	39 F Australia
		An inpatient rehab/detox centre.	60 F UK
Liaison/ Informationfor Employers	**14**	Outreach to employers advocating for employees disabled by antidepressant withdrawal.	72 F USA
		Assistance with managing the patient's relationship with their employer.	39 FS. Africa
		Letters to employers.	42 F Australia
Pharmacist	**11**	Close links to a pharmacy that can supply liquid formulations / other means of tapering safely.	42 F UK
		Fully trained pharmacists who are aware that you can order liquid suspensions or "specials".	26 F UK
		Going slow (working with pharmacy to lower doses at each step of the way).	53 F Canada

tapered schedules, inform the patients of alternative supports (counselling, supplements, CBD, dietary changes), education for family and friends for proper care for the patient. [27 F USA]

4. Discussion

Respondents felt that currently doctors do not know much about withdrawal, don't believe them, and don't know how to support them. They also thought that services do not provide the sort of measures needed to help people withdraw successfully, including pharmacological preparations required for a gradual tapering process, and other sorts of support considered useful. They described the importance of knowledge of withdrawal and of other sources of support that has been available for some years now but has not been disseminated or implemented.

4.1. Uninformed doctors

Perhaps the most powerful finding from this study is that there is a clear divide between prescribers' knowledge and beliefs about antidepressants, and the distressing experiences of their patients. Several of the sub-themes of themes 1, 4 and 5, show that respondents were highly critical of their doctors and the service received, starting at the initial prescribing (Read et al., 2016). Respondents felt their prescribers were unaware of the extent to which antidepressants cause withdrawal, leaving patients feeling initially misinformed and subsequently disbelieved. Respondents also mentioned that they would like doctors to be better informed about tolerance effects from antidepressants, closely related to withdrawal effects, as well as the myriad side effects and consequences of antidepressant use over the long-term (Fava, 2020; Fava et al. 2020; Read et al., 2017).

The results of our survey mirror previous surveys. A survey of 319 UK antidepressant users, by the All-Party Parliamentary Group for Prescribed Drug Dependence (APPG-PDD, 2018), revealed 'a deep deficit in the current understanding of the potential harms of antidepressants by doctors and psychiatrists'. Most patients (64%) had not received any information on withdrawal or other risks, 9% had been told to stop cold turkey and 40% had been advised to withdraw over 'a few weeks'. Another survey, of 752 British antidepressant users, confirmed that patients often find the information and support offered by prescribers when they are trying to withdraw to be very varied (Read, Gee et al. 2018) and frequently inadequate (Read, Grigoriu et al., 2020). A smaller (n = 158) British analysis of submissions to parliament (Guy et al., 2020) found:

> '…. a lack of information given to patients about the risk of antidepressant withdrawal; doctors failing to recognise the symptoms of withdrawal; doctors being poorly informed about the best method of tapering prescribed medications; patients being diagnosed with relapse of the underlying condition or medical illnesses other than withdrawal; patients seeking advice outside of mainstream healthcare, including from online forums; and significant effects on functioning for those experiencing withdrawal.'

Two other surveys, of 1,829 New Zealand patients (Read et al., 2018) and 867 patients from 31 countries (Read, 2020), both found that only

Table 5
Examples of themes 4–7.

4. STRONG NEGATIVE FEELINGS/OPINIONS RE DOCTORS/ SERVICES ETC	**105**	MAKING IT ILLEGAL TO PRESCRIBE THESE EVER AGAIN. …. I truly believe no one should ever take these pills	24 M USA
		NOT TELLING ME IT'S ALL IN MY HEAD. SUPPORT FROM SOMEONE WHO REALLY KNOWS WHAT IT'S ABOUT. MOST DOCTORS DON'T HAVE A CLUE	71 F USA
		I still have not got my head around how I am accurately going to divide one small table into 10 identical size pieces. Angry brewing again over this issue. It is criminal !!!!!	71 F NZ
		In my opinion, the way that some doctors and psychiatrists prescribe psychiatric drugs, are akin to criminal. Doctors are simply not aware of protracted withdrawal and very ill-equipped to help patients come off these drugs.	43 F S. Africa
		The truth!!!	35 F Germany
		Trying every avenue before going on them!!	42 F Australia
		Educated help! Dr's and the pharmacist seem to know nothing helpful and their comments and advise regarding the effects of the medication is more harmful than good, not to mention quick to make one feel like an idiot.	48 F Canada
		A check on pharmaceutical companies to be honest and open about their products, and force them to write withdrawal dangers ON THE BOX!	52 F Germany
5. INFORMED CONSENT WHEN PRESCRIBED	**87**	Honest communication of how long and how severe withdrawal side effects can be when first offered the drug.	48 M UK
		Comprehensive warning provided at the time of initial prescription about the possible long-term harmful effects of the drug as well as potential difficulties coming off of the drug. without this information provided upfront at the time of initial prescription a patient is not equipped to give informed consent. i cannot know for sure but it seems to me that had i known beforehand about withdrawal syndrome and its variations i would have reconsidered ever taking the drug in the first place. every time of the many times psychotropic meds were prescribed to me, they were presented as entirely safe.	48 NB Denmark
		It should start at the front end with prescribing and made very clear that these drugs can be extremely tough to come off of and potentially destroy your life.	33 M Canada
		Informed consent BEFORE prescribing, informed consent about what may happen after withdrawal.	18 M Mexico
		Should be told of problems before issuing.	81 M UK
6. DRUG COMPANIES	**17**	At some point in time somebody is going to take this fight to where it needs to be - at the throat of big pharma - I hope to live to see that day.	62 M Spain
		Health professionals who learn from their patients, not from drug companies.	33 F UK
		It is actually a crime that pharma companies can have these drugs on the market for 30++ years and not make it blatantly obvious the effects they can have on the human body.	33 M Canada
7. PUBLIC HEALTH CAMPAIGN	**16**	Public information campaign about withdrawal symptoms and side effects of ssri mediation.	32 M Netherlands
		Education of the mass population (no one believes us, its so disheartening).	55 F Australia
		Public service announcements regarding dangers of AD usage.	80 F USA

1% had been told anything about withdrawal when first prescribed antidepressants.

Theme 2 shows, unsurprisingly, that the two most important areas of information prescribers are thought to require concern withdrawal symptoms and how to support patients when they decide to reduce or withdraw (see Table 3). A few respondents stressed the importance of the integrity of the source of information, which should be based on patient experience and/or research, rather than on drug company claims.

A survey of British GPs (Read, Renton et al., 2020) is consistent with patients' views about GPs' knowledge. Almost half of the GPs underestimated the prevalence of withdrawal and most thought they did not have adequate knowledge about withdrawal effects and would like more training or information.

Besides expecting doctors to be better educated so that they can impart accurate information and appropriate advice, respondents had other recommendations. They suggested that if doctors were better trained in withdrawal identification and management, they would be more likely to meet another patient expectation, to be believed about their withdrawal symptoms rather than have them dismissed or misdiagnosed as a relapse of the original problem. Being disbelieved was experienced as invalidating and adding to the burden patients have to deal with on top of the withdrawal process itself. Furthermore, acknowledgement seems to be a perquisite for more compassionate support, something mentioned by numerous respondents.

Respondents also recommended that doctors be able to arrange the small doses, liquids or tapering strips so essential for gradual withdrawal, especially in the final stages of hyperbolic tapering (Horowitz and Taylor, 2019, 2021). They should develop a clear plan for withdrawal, individualised to the patient's situation and needs and the specific drug(s) involved. Some respondents emphasised the need for regular monitoring. These three recommendations were the most endorsed in an earlier, quantitative question in the same survey, completed by about 1,000 respondents, asking how helpful were eight specific aspects within and beyond the doctor's office: 'access to smaller

doses' (88% 'very helpful'); 'a personalised, flexible reduction plan' (79%) and regular follow-up to monitor reduction' (72%) (Read et al., 2023).

A few respondents in the current study recommended that monitoring continue after withdrawal is complete. This highlights findings that withdrawal syndromes can be protracted, and can last for months and sometimes years, after stopping medication (Cosci and Chouinard, 2020; Framer, 2021; Hengartner et al., 2020), likely due to the fact that the brain can take months and years for adaptations to antidepressants to resolve after stopping (Horowitz et al., 2022). Withdrawal effects may occasionally not begin until weeks or months after medication is ceased, for reason that are not well understood (Stockman et al., 2018).

4.2. Other services and supports

Theme 3 produced 13 recommendations beyond the role of the doctor, most frequently counselling/psychotherapy, support groups, services led or designed by patients, nutritional advice and 24-hour crisis support/hotlines (see Table 4). This is broadly consistent with the following rates of responses to the earlier question in the survey (Read et al., 2023): Online support group supervised by a professional (68% 'very helpful'), 'Individual therapy/counselling' (65%), 'Support/education for carers and/or families' (62%), 'Telephone/online, video/online chat help line' (62%). The open-ended question, however, highlighted needs not covered by our eight specific suggestions, including the importance of services run, or informed, by patients with experience of withdrawal, specialist services, financial support/services, residential 'detox' facilities, involving pharmacists and providing information for employers.

4.3. Anger

Respondents indicated their disillusionment in the system, their pain, their losses, which in many cases had been highly detrimental to their lives, relationships and health. Responses were sarcastic, disbelieving, highly critical, demonstrated by capital letters, exclamation marks and swearing. Levels of trust between prescriber and patient are clearly eroded and that damage is hard to put right. Some, understandably, focussed their anger on drug companies (Theme 5; Table 5).

4.4. Progress and barriers

The information missing from the depressing picture painted by our respondents is, belatedly, now readily available for those willing to use it. Our introduction summarised reviews about the incidence and severity of withdrawal symptoms. Guidelines for how to withdraw gradually and safely have been published (Horowitz and Taylor, 2019, 2021, 2022; Royal College of Psychiatrists, 2020). It would be helpful, however, if the Royal Colleges of Psychiatrists and General Practitioners would take institutional responsibility for actively disseminating the information. The International Institute for Psychiatric Drug Withdrawal (www.iipdw.org) has produced a free video on how to safely withdraw, and translated it in to five languages, featuring two of the current authors (SL, MH) (IIPDW, 2022). Facebook groups, from which our respondents were recruited, are full of information and advice (White et al., 2021), which has been invaluable to thousands of people while professional services have been so slow to act. An array of resources has been made available by The Lived Experience Advisory Panel for Prescribed Drug Dependence, which consists of people (including one of the current authors, SL) with both lived and professional experience of dependence and withdrawal from prescribed psychiatric and painkilling drugs (https://leap4pdd.org). A recent review has even been able to 'outline a preliminary rubric for determining the risk of withdrawal symptoms for a particular patient, which may have relevance for determining tapering rates (Horowitz et al., al., 2022; Taylor et al., 2021). The Maudsley Prescribing Guidelines has sections on safe tapering of major drug classes (Taylor et al., 2021). A textbook dedicated to safe deprescribing of psychiatric medication, including antidepressants, the Maudsley Deprescribing Guidelines is forthcoming (Horowitz and Taylor, 2023).

Until recently, the availability of psychotherapy has seldom been addressed in the withdrawal literature, with the exception of Fava and Belaise (2018). 2019 saw the publication of 'Guidance for Psychological Therapists: Enabling conversations with clients taking or withdrawing from prescribed psychiatric drugs' (Guy et al., 2019). A manual for a psychotherapeutic approach to problems related to antidepressants dependence was published in 2021 (Fava, 2021).

Meanwhile, however, doctors, their professional bodies, politicians, health service managers and insurance companies around the world continue to ignore the suffering of, quite literally, millions of people. One partial exception is the UK, where the Royal College of Psychiatrists, after considerable pressure, published a helpful and broadly accurate position statement in 2019, followed, as mentioned, by some excellent information sheets aimed at the public (RCP, 2020), however, they have neglected to educate psychiatrists or GPs.

The previously mentioned comprehensive report published by Public Health England (PHE, 2019) recognised the need for both local services to support withdrawal and, in the short term, whilst waiting for such services to come on stream, a time-limited helpline to support those already impacted. A commissioning framework suggesting (not mandating) the implementation of local services was published by NHS England in early 2023 (NHS England, 2023). A request for funding for a National Helpline, however, was turned down in the government's most recent spending review.

Following the PHE review, a Withdrawal Services Working Group was convened to define patient needs for the implementation of PHE's recommendations. One of the recommendations is a dedicated Prescribed Medication Specialist associated with each doctor's practice who can ensure informed consent by advising the patient accurately on the risks and benefits of antidepressants (and other dependence-forming drugs), develop an exit plan and tapering schedule, advise and monitor the patient's progress. The probability of this being implemented is unknown.

Meanwhile the National Institute for Health and Care Excellence (2022) recently published a guideline on safe prescribing and withdrawal, but failed, despite much urging, to include detail on how to recognise withdrawal responses or provide step by step guidance on how to taper someone safely in clinical practice, so doctors relying on these national government guidelines still won't know how to do this. Furthermore, even if this detail were to be included there is a long lag time in new guidance to be implemented and so widespread education campaigns will be needed to upskill clinicians.

A partial explanation for the lack of action, for so long, is the powerful and pervasive influence of the pharmaceutical industry over medical and mental health practitioners, politicians, health care managers and the media (Davies, 2022; Healy, 2012; Moncrieff, 2006, 2022). This wasentioned by numerous respondents. One small, but relevant, example, comes from the survey of GPs in the UK, mentioned earlier. Only 7% acknowledged that their clinical practice had been influenced by contact with drug company reps. However, when asked how much *other* GPs were influenced, they reported that 82% of their colleagues had been influenced (Read, Renton et al., 2020).

Finally, it must be noted that although the question asked was about services, several respondents felt their lives had been so damaged by withdrawal experiences that they stressed the need for a public health campaign to warn the public about the dangers of these drugs and the difficulties experienced in coming off them. This emphasises the gap between what people were led to believe about these drugs and the actual experience of taking them, noting that the vast majority of studies on these drugs are short term (several weeks) and mostly conducted by their manufacturers (Munkholm, 2019),

4.5. Limitations

The population surveyed was not a randomised sample and may not be representative of the wider population of people using antidepressants. All respondents had the emotional and financial resources needed to find online advice on antidepressant withdrawal. Although respondents lived in many different countries, the vast majority identified as 'White/Caucasian' and two thirds had a university degree. The majority being female is less of a limitation since antidepressants are prescribed far more often to women than men.

The fact that our sample was selected from withdrawal websites means respondents' experiences are not likely to represent the withdrawal experiences of everyone who stops antidepressants. However, the point of our analysis is to highlight the needs of those who have more severe difficulties, and we know these are not uncommon (Davies & Read, 2019). Moreover, it is notable that almost half of our respondents 49% believed that antidepressants had helped them, despite the negative experiences of withdrawal reported by most participants, and hence they were not a group who held generally negative views about psychiatric treatment.

5. Conclusion

The recommendations of our respondents, based on bitter experience, and those of the previous surveys with which they concur, should no longer be ignored. They should be implemented as soon as possible (Davies et al., 2023). It is as simple, and as difficult, as that.

In particular, there is an urgent need to educate clinicians to recognise withdrawal and distinguish it from relapse, as well as having detailed knowledge on how to safely stop antidepressants. Patients need to be given access to formulations of medications (such as liquids or compounded medications) that allow for safe and individualised tapering and for some, specialist services that allow tapering to be carefully monitored and adjusted. The consequences of not providing these services are loss of faith in the medical system.

CRediT authorship contribution statement

John Read: Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Data curation, Writing – original draft, Project administration. **Stevie Lewis:** Conceptualization, Methodology, Formal analysis, Writing – original draft. **Mark Horowitz:** Conceptualization, Data curation, Writing – review & editing, Methodology, Software, Validation, Formal analysis, Investigation. **Joanna Moncrieff:** Conceptualization, Data curation, Writing – review & editing, Methodology, Software, Validation, Formal analysis, Investigation.

Declaration of Competing Interest

MAH and JM are collaborating investigators on the RELEASE trial funded by the Medical Research Future Fund in Australia (MRFAR000079). MAH is co-founder of a digital health clinic which helps people to safely stop unnecessary antidepressants in Canada. MAH has been commissioned to write the Maudsley Deprescribing Guidelines in Psychiatry by Wiley Blackwell. JM is a co-investigator on the NIHR-funded REDUCE trial and collects modest royalties from five books about psychiatric drugs. JR and SL report no conflicts of interest.

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