

Service-user efforts to maintain their wellbeing during and after successful withdrawal from antipsychotic medication

Miriam Larsen-Barr  and Fred Seymour

Ther Adv Psychopharmacol

2021, Vol. 11: 1–16

DOI: 10.1177/
2045125321989133

© The Author(s), 2021.
Article reuse guidelines:
[sagepub.com/journals-
permissions](https://sagepub.com/journals-permissions)

Abstract

Background: It is well-known that attempting antipsychotic withdrawal can be a fraught process, with a high risk of relapse that often leads people to resume the medication. Nonetheless, there is a group of people who appear to be able to discontinue successfully. Relatively little is known about how people do this.

Methods: A convenience sample of adults who had stopped taking antipsychotic medication for more than a year were recruited to participate in semi-structured interviews through an anonymous online survey that investigated antipsychotic medication experiences in New Zealand. Thematic analysis explored participant descriptions of their efforts to maintain their wellbeing during and after the withdrawal process.

Results: Of the seven women who volunteered to participate, six reported bipolar disorder diagnoses and one reported diagnoses of obsessive compulsive disorder and depression. The women reported successfully discontinuing antipsychotics for 1.25–25 years; six followed a gradual withdrawal method and had support to prepare for and manage this. Participants defined wellbeing in terms of their ability to manage the impact of any difficulties faced rather than their ability to prevent them entirely, and saw this as something that evolved over time. 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’. Sub-themes expand on the way in which they did this. For example, ‘finding what works for me’ included using a tool-box of strategies to flexibly meet their needs, practicing acceptance, drawing on persistence and curiosity and creating positive life experiences.

Conclusion: This is a small, qualitative study and results should be interpreted with caution. This sample shows it is possible for people who experience mania and psychosis to successfully discontinue antipsychotics and safely manage the impact of any symptoms that emerge as a result of the withdrawal process or other life stressors that arise afterwards. Findings suggest internal resources and systemic factors play a role in the outcomes observed among people who attempt to stop taking antipsychotics and a preoccupation with avoiding relapse may be counterproductive to these efforts. Professionals can play a valuable role in facilitating change.

Keywords: antipsychotic medication, bipolar disorder, medication withdrawal, psychosis, service-user research

Received: 19 July 2020; revised manuscript accepted: 28 December 2020.

Introduction

Antipsychotic medications are used routinely to manage symptoms of psychosis and mania in addition to other purposes including insomnia,

anxiety and obsessive compulsive behaviour.^{1–3} Antipsychotics are often helpful in the short term, but commonly cause serious adverse effects that can be barriers to recovery over the long term,^{4–8}

Correspondence to:
Miriam Larsen-Barr
School of Psychology, The
University of Auckland,
Auckland, New Zealand
[mbar114@aucklanduni.
ac.nz](mailto:mbar114@aucklanduni.ac.nz)

School of Psychology, The
University of Auckland,
Auckland, New Zealand

and do not prevent or reduce symptoms of psychosis or mania for everyone.⁹ Accordingly, there have been growing calls for improved information and support to assist people who experience psychosis or mania to withdraw safely from antipsychotics and reduce long-term maintenance use.^{10–13} But this is not a straightforward task.

Service-user groups have long advocated for the choice to stop taking medication.¹⁴ While many people attempt to stop antipsychotics,^{7,15,16} estimates suggest only 30–40% of people achieve their goal and multiple attempts are often required.^{10,17–20} Relapse is common across the year following discontinuation, particularly in the first 3 months. Although the high incidence of relapse reduces over time,^{21,22} the initial disruption can be great. In the absence of internationally accepted guidelines to facilitate withdrawal,²³ attempted discontinuation has often been discouraged.^{5,7,8,24–27}

Many factors can affect relapse during and after withdrawal from antipsychotics. Discontinuation carries the dual challenge of managing the withdrawal effects that often arise during the process alongside any mental health symptoms and other stressors people may continue to experience. Medication withdrawal, substance use and psycho-social stress, alone and in combination, can all precipitate relapse.²⁸ A range of somatic, cognitive and emotional withdrawal effects including symptoms of psychosis and mania are well documented,^{12,19,27,29–33} the extent of which appears to have a relationship with the degree of exposure to the antipsychotic agent.^{29,30,34,35} A gradual withdrawal method is recommended to assist but there is limited evidence available to guide these practices,^{13,17,36,37} people often lack the support of their prescriber to implement this and real-world definitions of ‘gradual’ vary widely.^{19,27,31}

Multiple longitudinal studies reveal people who discontinue antipsychotics successfully may have fewer periods of relapse and equal or better psycho-social functioning than those who persist with long-term use.^{21,22,38–45} While there have been contradictory findings,⁴⁶ a close examination of the reported results of these studies reveals a wide range of outcomes both among those who stop and those who persist. More favourable recovery outcomes can be partially predicted by employment status, age, lower medication dosage, shorter duration of use, social support, absence of substance use, and internal locus of control, alongside prognostic factors like initial

symptom severity.^{21,22,38–42,45,46} However, relatively little is known about what predicts successful discontinuation, how people practically manage the process, how they define success, or what psycho-social skills, strategies and environmental factors support success. Guidelines produced in Quebec and Germany prioritise access to psychotherapy, prescriber support for gradual withdrawal and family involvement.^{47,48} A number of studies suggest that talking therapy and other psycho-social interventions improve outcomes among those who experience psychosis and represent promising alternatives to antipsychotic treatment, but withdrawal research typically overlooks these treatments and their targets as potential covariates.^{49–54}

Several qualitative studies show people who attempt to stop antipsychotics ‘weave a safety net’ of additional psycho-social and physical health strategies to support their wellbeing. They view these to be crucial to both their general wellbeing and their withdrawal efforts but report a lack of information and guidance for managing the withdrawal process and coping without medication afterwards.^{5,18,19,25–27,31,49–52} Unfortunately, people who have stopped successfully tend to be absent or under-represented in these samples and there is often little attempt to differentiate the efforts of those who succeed from those who do not. To our knowledge only one small qualitative study has specifically explored how people who successfully stop taking antipsychotics manage the process.²⁷ Furthermore, most studies that explore the psycho-social efforts of those who stop taking antipsychotics limit their investigations to the decision-making process and the strategies and supports currently in place,^{18,19,42,52,53} but neglect to explore the critical withdrawal period or account for the evidence regarding the differential and interactive effects of various coping styles, cognitive processes and environments. These issues were addressed in the present study, in which interviews were conducted with people who had stopped taking antipsychotic medication successfully and believed themselves to be managing well. Participants provide detailed accounts of the processes involved in managing during and after successful withdrawal from antipsychotic medication.

Methodology

Participants and recruitment

A convenience sample of people who had discontinued antipsychotics was recruited through an

anonymous online survey exploring oral antipsychotic experiences among New Zealand residents aged 18 or older who had taken antipsychotics continuously for at least 3 months for any reason and were currently living in the community.⁶ Survey participants ($n=144$) who had attempted discontinuation ($n=105$) and remained off antipsychotics for 1 year or more ($n=52$) were presented with an invitation to take part in an interview about what had enabled them to maintain their wellbeing during and after withdrawal. People who expressed an interest in being interviewed had an opportunity to ask questions before providing written consent to take part and completed a confidential screening questionnaire to establish that they were not currently taking oral or depot antipsychotics, had not taken them on a daily basis for at least 1 year, and considered themselves well at the time of the interview. Consent was not sought to share the raw data with other researchers. Ethics approval was granted by The University of Auckland Human Participants Ethics Committee (Ref 010880).

Data collection

Participants took part in 2-hour, semi-structured interviews over the phone or face-to-face, depending on their location. All interviews were carried out and recorded by the first author, then transcribed, de-identified and provided to participants to check for accuracy before analysis. A semi-structured interview schedule established participant demographics (age, ethnicity, gender, sexuality, employment, education, income, relationship status) alongside mental-health and medication history (including current and past medication regimes, time on and time off antipsychotics), and explored the detail of their withdrawal attempt, their efforts to maintain their wellbeing, and their current recovery outcomes. Current wellbeing was assessed by self-report and supplemented with demographic data associated with quality of life. Participants were asked how they defined recovery and wellbeing then asked to rate, on a scale of zero to five, their satisfaction with their current wellbeing using this definition, where a rating of five represented 100% satisfaction.

Successfully stopping antipsychotic medication was defined as the cessation of regular, daily use of antipsychotic medication for more than 12 months, regardless of the use of other psychiatric medications. Participants were asked whether

they currently took daily antipsychotic medication, and to provide their best self-reported estimate of the amount of time that had passed since they stopped.

Data analysis

Thematic analysis was used to identify semantic patterns within participant descriptions of maintaining their wellbeing during and after withdrawal from antipsychotics, following the six-step process outlined by Braun and Clarke.⁵⁴ This was initially carried out several years ago as part of a larger doctoral study⁶ and was further reviewed and refined for the purposes of strengthening the results for publication. Only references to the process of maintaining mental health during and after withdrawal were selected for thematic analysis. An inductive approach was used and themes were generated on the basis of explicit semantic content and surface meanings within the transcribed text. Exemplar quotes are reported verbatim aside from minor editing to preserve participant confidentiality, improve ease of reading or clarify what was said.

Findings

Participants

Seven women volunteered to participate. Table 1 summarises their characteristics and outcomes. Six were mothers of teenage or adult children. A diagnosis of bipolar disorder was reported by six participants, all of whom described psychotic elements to their experiences; two also noted differential diagnoses, including dissociative disorders and schizophrenia, and were not sure which best fit for them. Two participants disagreed with their diagnoses of bipolar disorder, although they recognised experiences of mania and psychosis. Six reported a history of full manic episodes, but Jan noted she initially experienced only hypomanic episodes and that manic episodes arose only in response to antidepressants. Karen reported a history of depression and severe obsessive-compulsive disorder (OCD).

Six had received compulsory treatment in hospital at least once prior to their attempt to discontinue. Jan had never received compulsory treatment or been hospitalised, but described a prescribing situation initiated by the occupational health service at her place of work and reported a conflict of interest that left her feeling unable to freely choose. Most participants had taken

Table 1. Interview participant characteristics, withdrawal methods, and current outcomes (names have been changed to protect participant identity).

	Sarah	Joanne	Carly	Jan	Karen	Rebecca	Theresa
Current age	35	49	53	52	63	48	52
Ethnicity	NZE	NZE	NZE	Maori	NZE	Maori	NZE
Employment	Employed	Employed	Student	Employed	Employed	Student	Employed
Education	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary
Relationship status	Partner	Married	Partner	Single	Married	Married	Married
Primary symptoms	Psychosis, mania, dep	Psychosis, mania	Psychosis, mania, dep	Hypomania mania, dep	OCD, dep	Mania, dep	Mania, dep
Age of onset	17	23	31	15	10	16	17
Age first AM	17	23	31	43	18	41	47
Time on AMs ^a	17 years	1 year	4 years ^b	9 years ^c	9 years ^d	2 years	8 months
Most recent AM	Quet.	Halo.	Quet.	Quet.	Quet.	Risp	Olanz.
Concurrent polypharmacy	MS, AD	Nil	Sleep aid	AD, MS, Benzo	AD, MS, Benzo	MS, Benzo	MS, Benzo
Withdrawal method	Gradual 4 years	Abrupt	Gradual 3 months	Gradual x months ^e	Gradual 6 months	Gradual 2.5 months	Gradual 6 months
Prescriber support	Yes	No	Yes	Yes	Yes	Yes	Yes
Relapse ^f	Yes; at 3 months	Yes; rapid onset	Yes; at 6 months	Yes; at >1 year	No	No	Yes; at >1 year
Hospitalisation ^g	No	No	No	No	No	No	No
Other withdrawal effects	Sleep	Sleep	Sleep	Sleep	Nil	Anxiety	Sleep
Current meds	Zero	Zero	Zero	Zero	AD	MS	MS
Time off AMs	1 year 3 months	25 years	2 years 6 months	5 years	4 years	2 years	3 years
Recovery rating ^h	5	5	4.75	4.8	4	5	4

^aTime on antipsychotics: longest duration of continuous use based on medication history obtained during interview.

^bCarly reported initial continuous use of a typical antipsychotic for 7 months, followed by a medication-free period of 15 years, then continuous antipsychotic use for 4 years.

^cJan's continuous use took the form of alternating 1- to 2-week periods of daily use separated by 1- to 2-week gaps over 9 years.

^dKaren had a brief experience with chlorpromazine in hospital during late adolescence and later took antipsychotics continuously for 9 years.

^eJan could not recall the number of months she withdrew across but recalled that it was several.

^fRelapse refers to relapse reported after discontinuation and includes reported time to relapse. No one described relapsing during the tapering process. Jan's relapse coincided with later MS withdrawal.

^gHospitalisation as a result of relapse after discontinuation.

^hSelf-rated satisfaction with current recovery outcome on a scale of 0–5 where 5 = 100% satisfaction.

AD, antidepressant; AM, antipsychotic medication; benzo, benzodiazepines; dep, depression; Halo, Haloperidol; MS, Mood Stabiliser; NZE, New Zealand European; OCD, obsessive compulsive disorder; Olanz, Olanzapine; Quet, Quetiapine; Risp, Risperidone.

antipsychotics continuously over several years, alongside other psychiatric medications, and some had changed antipsychotic agents in that

time. Table 1 lists only the most recent antipsychotic agent they had taken and other medications they used alongside this.

Prescriber involvement

Six people reported withdrawing with some level of support from their prescribing clinician including assistance with planning and adjusting the taper, regular reviews, supportive psychotherapy and/or referrals for therapy. Joanne did not seek the approval or support of a prescriber. Most initiated the discussion about withdrawal themselves, but for Theresa, her prescriber initially suggested this. Sarah, Karen, Rebecca and Theresa received the willing support of their prescribers. Jan and Carly described a hard-won process to secure prescriber support, contending that they were equipped to try this, would be safer with guidance and monitoring and would proceed independently if they must. Jan noted that another clinician had advocated on her behalf. Carly engaged the additional support of a specialised nutritional supplement from an international organisation that provided phone support and an online journal to assist her in monitoring the reduction process in collaboration with her prescribing doctor.

[When I raised stopping the antipsychotic] she said, oh, that sounds wonderful. Let's go for it. [. . .] She had drawn diagrams and told me to shave bits of pills off and all that sort of thing. [. . .] She planned it all out and wrote it all out and spoke to me about it. And said, don't rush it, there's always a temptation to rush it but don't. [. . .] She was also someone you could email if there were any problems with it. Actually at that time when we were trying to do that, she also sent me off to a psychologist. – Karen

I got my doctor's permission but I had to absolutely twist his arm. I had to fight [. . .] I went to other doctors who said they didn't know me and weren't going to take that risk. I went back to my doctor and said look, I'm going to come off the drugs. I threatened him. I said I'm going to come off them, I can either do it this safer way with your permission and guidance, or I can just do what I've done before and gone off them and risk getting unwell again. I said I think I've taken care of most things now [. . .] so he said okay, alright it is better that you're monitored. [. . .] I was getting phone calls as well from Canada. It was all part of the cost [of the supplement]. The phone calls were fantastic, very supportive and they were guiding me. I felt a lot safer. – Carly

Withdrawal methods

Six participants undertook a gradual reduction across a period of months or years. No one described simultaneously reducing multiple

medications at once. Five participants continued to take other medications when withdrawing from antipsychotics. Sarah had already successfully withdrawn from the other medications she was taking. At the time of withdrawing from antipsychotics, Karen continued taking an antidepressant and a mood stabiliser but had discontinued the benzodiazepines, and Jan, Rebecca and Theresa continued to take a mood stabiliser. Theresa also continued with lorazepam, Rebecca with temazepam, and Carly with zopiclone for sleep on an as needed basis of reducing frequency, with all noting this was either no longer or rarely used.

Abrupt withdrawal. Joanne described an abrupt withdrawal, without any input from professional support or family. At the time she was living with another person who was also experiencing psychosis and did not notice or respond to her behaviour. She eventually identified a service-user collective that allowed her to use their back room as a safe space to 'move through' her experiences. Joanne noted that while she has achieved her recovery goals, in hindsight she would not proceed in this manner now due to the hardship and personal risks this had entailed.

Gradual withdrawal. Participants described a range of strategies for tapering gradually. All six reported a willingness to adjust their reduction plan if they struggled during the process, or something stressful happened. This meant returning to a previous dose for anywhere from a day to a few weeks, delaying the next reduction, or reducing the size of the next step.

My psychiatrist gave me that [written plan] as a guide. We always said if there's some crisis happening or whatever, don't do a drop. [. . .] Just wait for a week or wait until it's over. And then do it or just do half of it. [. . .] Make sure you look after yourself when you're doing this, no heroics. [. . .] And by doing that I didn't suffer any side effects from coming off it because it was so slow, [. . .] because it [the reductions] varied. It depended on what was going on in my life. – Karen

Gradually reducing the daily dose. Sarah, Carly, Karen and Theresa employed a stepwise reduction method. Sarah withdrew in 25 mg increments from a maintenance dose of 600 mg daily quetiapine over a period of years and then reduced from 25 mg to zero because there were no smaller tablets available. Theresa was also limited by the

standard doses available. She reduced from a maintenance dose of 10 mg daily olanzapine in 2.5 mg increments, followed by a period of gradually reducing as-needed use. Karen and Carly both used pill-cutters and/or shavers to reduce in smaller increments than their tablets allowed. Karen could not recall precisely how much she reduced her dose at each step but described spacing reductions by at least a month and exchanging a pill-cutter for a pill-shaver to cut down in 'tiny' increments. Carly describes her method of reducing from 12.5 mg of daily quetiapine below. No one reported being offered or using liquid preparations or tapering strips.

I got a pill-cutter. I was already cutting my tablets in half [to take 12.5 mg daily]. Then what I did was I cut the whole lot up into quarters and then I would choose the biggest quarter, and the next night I would choose the biggest quarter, until I was down to the littlest quarters. Then when I went to eighths, I'd chop the whole lot up into eighths again, and work my way down to the smallest one. [. . .] When you're eating a crumb the size of a pinhead you're wondering what the hell you're doing. But actually if you don't have it the next day you can feel it. – Carly

Gradually reducing the frequency of use. Rebecca and Jan described reducing gradually by switching to alternate days, and then shifting to as-needed use for sleep and anxiety until no longer required. Jan could not recall how long this had taken but noted it was a period of several months. Jan's previous antipsychotic dose varied from 25 mg to 500 mg daily depending on her current state and she continued to vary her dose based on need as she spaced her doses further apart. Rebecca described following a schedule of alternating doses for 2 weeks and then switching to as-needed use for times of anxiety across approximately 2 months. She could not recall her initial dose but noted it was 'not big'.

Instead of every day, it became a dose that was once every second day for a while and then just stopped. [. . .] I just left it as a PRN thing. [. . .] I've actually got to the stage where I prefer to use just self-awareness. And just, you know, managing the anxiety in other ways. – Rebecca

Withdrawal effects and experiences of relapse

Among the six participants who reduced gradually, none reported relapsing during the reduction

process. Karen experienced no withdrawal effects, while the remaining five had difficulties with sleep and/or anxiety that eventually resolved.

Carly and Sarah described brief relapses 4–6 months after they completely stopped. Carly managed without resuming antipsychotics. Sarah briefly resumed 25 mg then 50 mg of quetiapine for a period of 5 weeks and then tapered this back over a period of 6 weeks. Jan and Theresa did not relapse until more than 1 year after stopping antipsychotics. Jan had withdrawn from a mood stabiliser and reported two further brief relapses, which she managed by resuming the mood stabiliser briefly. Theresa described a brief manic relapse she attributed to life stressors, which she managed by resuming Olanzapine for 2 weeks and then tapering back over four. All six avoided further hospitalisation.

Joanne, who withdrew abruptly, experienced florid psychosis and mania for a period of approximately 3 months then residual symptoms with two further full episodes across the following years, managed without any psychiatric medication or periods of hospitalisation, and noted that 'extreme states' had become a thing of the past with no reported manic or psychotic symptoms for several years.

Recovery outcomes

Table 1 shows participants were highly satisfied with their current recovery outcomes and had remained off antipsychotics for periods ranging 1.25–25 years. Four were not taking any psychiatric medications and the remaining three were taking either a single antidepressant or mood stabiliser, with Karen and Jan reporting much lower doses of these than previously. Definitions of recovery described a constantly evolving, multi-dimensional experience of positive emotion, fulfilling relationships, meaningful activity, and being able to cope and function in the presence of mental-health difficulties, rather than referring to static outcomes defined by an absence of symptoms.

I don't think zero symptoms is either expected or kind of reasonable. [. . .] It's a fine balancing act of managing the severity of that symptom to make sure that it isn't majorly impacting on life in a way that prevents [me] doing what I need to do or want to do. – Sarah

Efforts to maintain wellbeing

Thematic analysis was used to explore how participants were able to implement the withdrawal methods and achieve the recovery outcomes described above. Three central themes were constructed from the participant narratives about what they did to maintain their mental health during and after withdrawal. These were shared by all participants with some variation across the sub-themes. Themes are presented separately but participants described them as interconnected and developing over time. Six had these elements in place to some degree prior to their successful discontinuation attempt, while Joanne described developing them after she stopped. Most described developing these understandings, strategies and supports as part of their general efforts to maintain their wellbeing and utilising these throughout their withdrawal attempt. Carly sought therapy and specialised nutritional support as a deliberate part of her preparations to discontinue.

Understanding myself and my needs. Participants developed the ability to use their own self-knowledge and reflective skills to observe and make sense of their internal experiences and personal needs. This involved being aware of their personal patterns, responses and shifting needs, discovering meaningful frames of reference for their mental-health experiences, awareness of their identity and values and resolving underlying issues.

[I learned to] check in with where I'm at and kind of internally communicate, as well as externally, figuring out actually this is what's going on, this is where I'm at. [. . .] As opposed to it being an overwhelming distress that you are not entirely sure where it's come from, what's going on, or even how to manage it. Sometimes I think in the past, that's when for lack of any other way of dealing with it, I was medicated. – Sarah

Awareness of my responses, early indicators, and shifting needs. Participants cultivated the knowledge and abilities needed to observe, identify and reflect on their own stress responses, how mental-health symptoms present for them, what impacts on them and what they needed. This was likened to carrying out 'self-therapy' through regular dialogue with a kind of internal 'counsellor' who knew their history and personal needs well. Six described being aware of the withdrawal period as a time of risk and used this self-knowledge and reflection to help them direct their efforts to cope

and recognise when to adjust the rate of reduction. Some kept written journals to aid their reflective process and memory of their observations over time.

It's really important to be aware of your triggers and know what signs of unwellness look like. If I've been really busy, feeling a bit stressed, have had not a good night's sleep, I will actually reality-check. I will check in. I know the kinds of thinking that go with being unwell. So, I'll run through like a tick-list in my head and go, how do I feel about this? How do I feel about that? [. . .] It's about what goes on inside and developing that awareness. [. . .] Because at the end of the day only you know what's going on in your head. – Rebecca

Discovering meaningful frames of reference for my experiences. Participants gathered information about mental-health problems that enabled them to make sense of their experiences as meaningful responses they could address. This included information about medication and withdrawal, physical health issues like nutrition, exercise and the impact of different medical conditions, and psycho-social understandings which included references to encountering ACT, CBT, DBT, Buddhist, spiritual, and service-user literature, and information about a wide range of topics that were relevant to their context.

I feel like I've got a framework which enables me to make sense of the world. – Rebecca

The first thing I ever read or came across that made any sense whatsoever was a book that framed those mental health experiences in something other than illness or a medicalised approach. Because I'd never come across any other frame of reference for it. So as soon as I read that, this kind of world opened up, that there are different ways of thinking about these experiences that actually fitted how I felt about what had happened. – Joanne

Understanding who I am and what is important to me. Several participants spoke of being guided in their efforts by knowledge of their values, identity, purpose and aspirations. This included awareness of identities they were motivated to avoid, such as the stereotype of 'being a mental patient'.

I have this picture in my mind of me sitting in my rocking chair on my porch [. . .] and talking to my grandchildren. If things get tough then that is the picture that I pull forwards. Well hopefully I live

that long, but I want to see what this world is like when I'm old. And it's like if I don't keep myself well I won't get there. – Theresa

Healing and resolution of underlying issues. Participants identified and addressed the primary causes of the symptoms they experienced. Sarah described being underway with this process while four others described a sense of having achieved this. Most focused on addressing psycho-social causes, but Carly also identified and found treatments for a physical health condition called pyroluria that was believed to contribute to her experiences. Four noted that distancing themselves from unhealthy relationships helped their healing, that it took time and that it unfolded within long-term psychotherapeutic relationships, although it was not limited to that relationship. Carly's journey of healing called on a supportive medical team.

I got to the core of why that happened. [. . .] There's not the need for the extremes that there was because through the psychotherapy, through a lot of other things, and through those experiences themselves, what I needed to resolve has been resolved. [. . .] You know, the early grief and trauma and all that kind of stuff. There's resolution of all of that. So, I'm free to let that rear up and feel overwhelmed by the fact our cat just died, and let that come without having any worry that it's gonna be something that I can't cope with. – Joanne

Finding what works for me. Participants described a commitment to engaging in a continual process of discovery and experimentation with what works to address their personal needs, reduce the impact of mental-health difficulties or withdrawal symptoms, and increase their subjective experience of wellbeing. This involved using a tool-box of strategies to flexibly meet their needs, practicing acceptance, drawing on persistence and curiosity and creating positive life experiences.

I think when it all clicked into place was sort of when I did that journey myself. Very self-directed. Your own decision to try and find things that work for you. – Rebecca

There wouldn't be anything I couldn't [cope with]. Oh, it doesn't mean that I'd try and staunch it out [. . .] I've got any amount of ways that I would deal with whatever crisis happened [. . .] Who knows what I would do? But I would come up with whatever it was. [. . .] I'm quite good at

getting my needs met, whatever they might be. – Joanne

Using a tool-box of strategies to flexibly support myself and meet my needs. All described being equipped with a multitude of strategies to flexibly manage the challenges they faced and address their bio-psycho-social needs. They likened this to having a tool-box from which they could select a range of different problem-solving, expression, self-soothing, distraction, displacement, self-care and health strategies depending on the situation. This was true for each of the difficulties they discussed from trouble sleeping without the sedative effects of antipsychotics to anxiety and elevated mood. Six participants adjusted the rate of reduction and used sleeping pills to cope during withdrawal, and five noted that infrequent, brief use of sleeping pills or antipsychotics remained a back-up strategy at times when none of their other strategies were working. Several participants had written plans to prompt them to use their strategies in times of distress; one had an actual box filled with physical reminders and resources for self-soothing.

You've just got to chip at all sides. Diet, sleep, exercise, who you spend your time with, what you spend your time doing. I've tried lots of modalities. I would glean just a few things from each one. Mental health is like all these different things keep your head above the water, and mental health [problems] is like you drown. And then things get your head above the water again. [. . .] It is flexibility isn't it. It's emotional and physical flexibility. – Carly

Acceptance instead of resistance. Participants described accepting experiences of mental-health symptoms, withdrawal effects and other challenges when they arose and finding harm-free strategies for allowing, 'using', 'channelling' or otherwise responding to these experiences rather than attempting to 'suppress', 'deny', 'mask', avoid or 'fight' against what was happening for them, which was viewed as exacerbating their distress.

You know, people drown in shallow water just fighting it the whole time, rather than just go I'm going to be depressed for a few days, I'm just going to let it be. [. . .] I don't try and suppress adrenalin, I use it. It's there to be used. It's acceptance. It is a few simple words, you know. Like close your eyes, where in your body do you feel this emotion, is it

okay for it to be there. It's just so easy. Fighting something is so hard, accepting something is so much easier. – Carly

Persistence and curiosity to find my own way. Participants described drawing on determination and their inquisitive, questioning natures to continue through the many challenges they faced and discover their own, individualised way of understanding and managing their wellbeing. Two emphasised academic abilities enabled this, while Theresa commented that curiosity allowed her to make up for a perceived lack of academic ability by seeking answers from others.

There's just something that's like, I am my own person and I'll fit your school system and I'll fit your whatever, but something deep down will always forge my own way. – Joanne

Building positive life experiences and routines. Participants said it helped to establish daily routines and activities that created a sense of meaning, purpose, interest and enjoyment.

The routine part is my most important part in life. Even when I wasn't formally working, then I was doing something every day, having something to look forward to, going out of the house. – Theresa

All of those things [symptoms] gradually diminished as my engagement in my life and my busy-ness with my kids and stuff gradually grew. And then that kind of took over. – Joanne

Connecting with supports. All described forming relationships they could turn to for practical and emotional assistance with their efforts to maintain their wellbeing during and after withdrawal. This involved selectively trusting people to support their mental-health journey and the withdrawal process, connecting with peer support, and building meaningful relationships and valued roles within their families and communities. Six described recruiting small teams of supporters to help them create conditions of safety for their withdrawal attempt, including their prescribers. Joanne had no support for withdrawal at the outset of her attempt and gathered this over time. Six had participated in long-term talking therapy and all seven had used multiple other forms of support including personal development workshops, support groups, exercise groups, specialist nutritional supplements, creative groups, meditation

and mindfulness courses, self-help resources including cognitive behavioural therapy (CBT) and acceptance and commitment therapy (ACT) books, self-directed research, conference attendance, church activities and service-user initiatives like Wellness Recovery Action Plan (WRAP) groups.

I chose to let people support me, and I also chose to support myself a lot more. – Carly

Selectively trusting others so I don't have to do it alone. Participants developed an ability to trust people to support them so they were not isolated in their efforts, and an associated ability to move away from those they did not trust to be helpful. This allowed them to create 'safe spaces with safe people' when needed and involved communicating their experiences and needs to others, accessing the perspectives of others and being selective about who they involved, when and how.

There's a thing that comes in there that I think is really important and that's the ability to trust that there are other people that have got your best interests at heart. [. . .] This is a very hard process to do alone. – Rebecca

In my plan I've got five supporters. Some of them don't know each other. Some of them do know each other. And all of them have very different roles. – Theresa

[Family] start either avoiding you or crowding in on you, because your spontaneity is seen as being sort of a danger signal. [. . . The last time] I went way up a friend came and stayed for four days. [. . .] It was a bit out there but it wasn't doing anyone any harm. He didn't try and impose on me at all. If I wanted to talk about a topic he just listened. He would just light the fire and prompt me for when it was time to cook. [. . .] It felt like experiences in my past come up to be healed rather than suppressed. And I just came right. [. . .] So I now know I can go through a manic episode without medication, as long as I make sure I'm in a safe space with a safe person. – Carly

Several participants discussed having supporters they trusted to help them observe and reflect on their wellbeing should their own awareness become impaired. For six this included their prescribers. Four had spoken with family and friends about what objective signs they might notice leading up to a psychotic or manic episode, the best

way to let them or other supporters to know what they observed, and what strategies to suggest. Two had written plans they had shared with selected family. Three excluded their families to varying degrees.

I have a whole lot of [supporters] in my personal life and I have a long-term psychotherapist and a few others in a team that have worked with me for many years that know me well and are able to say, do you think you need to slow down or whatever the prior agreed course of action might be. [. . .] Family would have been more of an after-the-fact telling. [. . .] Often, I've found that, particularly people that haven't had their own personal experience, talking about [it] can often distress them rather than help me. – Sarah

Making connections with people who have similar experiences. Participants described finding hope, new knowledge, and a sense of acceptance in being able to openly share their experiences with other people who had also faced mental-health challenges or medication withdrawal.

I realised there were other people going through exactly the same thing I was going through. [. . .] It gave me major, major hope [. . .] Different people would say I do this when this happens, when I have a panic attack I do this. It's like oh, I can try that. So I then stole their ideas. – Theresa

Social support was just not even a factor [during withdrawal]. I don't know that I would have even considered mentioning it to friends. I don't think it would have meant anything to them. I've got some very good friends who are very Pollyanna-ish and their solution is just to make everything okay. And that's not how things work. I've got some newer friends that I've made recently who have had experience of mental health [problems] and probably would be in a far better decision to pick if things were going wrong and say, hey, you need to do something here. – Rebecca

Building meaningful relationships. Engaging in their roles as parents, spouses, friends and community members aided their self-knowledge, helped create positive life experiences, and motivated a deep commitment to their own functioning and safety for the higher purpose of being there for others.

Probably hooking up with [my partner] helped with that [initial period after withdrawal]. Just the

distraction of a relationship I think, you know? We didn't ever really talk about this kind of stuff. But we did talk quite deeply about other things. [. . .] He attaches me to the ground. – Joanne

When you walked in the door [at the art space] you were an artist, you were a musician, you were whatever you were there for, rather than what was wrong in your life. – Sarah

Discussion

While this is a small exploratory study it offers a rare description of seven successful efforts to manage antipsychotic withdrawal and expands on the research demonstrating it is possible to live well without antipsychotics^{21,22,41,42} by detailing the process involved. These findings are consistent with the existing qualitative research suggesting a 'safety net' of information, strategies and supports is needed to successfully withdraw from antipsychotics.^{5,18,19,25,27,53} However, studies of attempted withdrawal show people frequently lack the information, skills and support needed to build this kind of safety net,^{18,26,52} and often taper off too rapidly, relapse and resume the medication.^{11,17,24} The reverse was true for this group. This is a stark contrast that highlights the need to facilitate access to the kinds of prescriber support, talking therapy, peer support, occupational activities and information that this group described, and the costs of neglecting to do so.

This group defined a good outcome as being able to manage the impact mental-health symptoms and withdrawal effects had on their lives and the lives of others. Accordingly they described maintaining their wellbeing in ways that allowed for the occasional mental-health problem and focussed on adapting to their current needs. They were clear that they were undertaking a life process, not a medication process, and that their outcomes were not static, finished end-points that could be measured by their last relapse. Similar to the results of the longitudinal research, outcomes improved over time^{21,22,41,42} as they learned more about themselves, how to manage and who could help. Relapse experiences often arose months after withdrawing and supports were needed intermittently beyond the withdrawal period itself.

Gradual withdrawal appeared to moderate and delay relapse but did not eliminate it for everyone. Yet relapse did not necessarily stand in the way of success. It was possible to curtail relapse

experiences and to safely move through them until they reduced, with or without briefly resuming antipsychotics. Withdrawal periods varied widely as plans were defined by flexibility to current needs and coping capacity rather than fixed time-frames and dose increments. Special pill-cutters and shavers helped enable greater flexibility but could be cumbersome to use, suggesting innovations like Tapering Strips may help simplify this process.^{37,55} Those who described having knowledge, skills and support prior to withdrawal described a much less disruptive experience than the single participant who lacked these at the outset of her attempt and developed them later. Efforts to improve antipsychotic withdrawal outcomes may need to begin well before the reduction period and extend beyond it.

Participants described a circular process of learning and self-reflection, flexible coping and relational support that enabled them to observe, identify make sense of and safely respond to their experiences and personal needs. Participants were able to recognise and attend to the full range of their bio-psycho-social needs. This included adjusting the rate of reduction during withdrawal. In step with existing psycho-social evidence regarding the paradoxical effects of experiential avoidance on a wide range of symptoms including psychosis and mania,^{56–63} participants emphasised acceptance of distress as part of their efforts to cope, finding other people who could hold this position and withdrawing from those who could not. Different groups will face different challenges as they attempt to do this. Participants in this study were cognitively able, psychologically minded women who reported primarily bipolar disorder diagnoses. However, evidence suggests these strategies also hold relevance to people who experience first episode psychosis and schizophrenia.^{50,52,67,70} The only other study of this nature elucidates similar processes with a larger sample of 21 men and women with diagnoses of schizophrenia, major depression, bipolar and OCD.²⁷ Treatment systems that help people prepare for and respond to relapses when they do occur may be more effective than those that adopt symptom prevention as their primary goal.

Navigating the responses of others played a key role in participants' efforts to manage safely. Trusted prescribers, therapists, family and other people with personal experience held valuable roles in people's efforts to understand themselves and meet their needs. However, in line with

previous research,^{5,24,26,52} potential supporters often became anxious and vigilant for signs of relapse or attempted to suppress people's experiences in a way that escalated distress at a time when their capacity to cope was already disrupted. Participants learned to selectively exclude these people from their efforts to manage.²⁷ Further research is needed to understand family member experiences within this process, particularly where children are involved. Improving individual withdrawal outcomes may call on support for the family system alongside support options that sit outside of the family system, similar to the medication-free treatment hospitals in Norway and the Soteria Houses in the United States.^{20,69}

The elements described here share many similarities with descriptions of recovery from psychosis and mania in general and emphasise the critical role that modifiable psycho-social processes play in the outcomes observed during and after withdrawal from antipsychotics. Several psycho-social interventions target these same internal and interpersonal processes among people who experience psychosis and mania with good results. For example ACT, CBT, family therapy and peer support initiatives like the Hearing Voices Network,^{443,44,50,52,54,67,70,72–79} may represent promising interventions to support discontinuation alongside prescriber support to manage gradual withdrawal,^{18,19,25,31,47} and physical health interventions like the nutritional supplements and associated follow-up that Carly found invaluable.⁸⁰ Participants appeared to benefit from access to information specific to antipsychotic withdrawal, special tools to enable finer control of the reduction process, and prescriber follow up during and after the withdrawal period. Improving antipsychotic withdrawal outcomes calls on improved access to information and support. In the absence of guidelines and targeted interventions, resources created by service-users and clinicians are available to facilitate this.^{13,36,81–86}

Strengths and limitations

This study is one of the first to provide detailed personal accounts of the processes involved in managing successful withdrawal from antipsychotic medication. Using a qualitative methodology yielded a rich data-set and enabled an exploration of the components of withdrawal in context with attention to the meaning and function of the personal efforts reported by a group who tend to be underrepresented in much of the existing research.

Findings are drawn from a small, self-selected sample of educated, employed women aged 35–63 that does not represent the general population who attempt to stop taking antipsychotics or those who succeed in their attempts. This group reported primarily episodic experiences of mania and psychosis. It may be more difficult to develop the strengths described here in the presence of more continuous symptoms. Female gender, education and employment have been found to partially predict more favourable long-term outcomes among those who discontinue.^{38,42} Men, people of colour, gender diverse communities, youth and people with lower levels of educational achievement may face additional challenges and report strategies, needs and preferences that were not highlighted by this group.

This study was exploratory in nature and did not explicitly probe all areas of potential relevance. Time restrictions during the recruitment period meant that data saturation was not reached and these findings cannot be considered exhaustive of all possible themes. As with any study based on self-report and historic recall, people likely neglected to mention some relevant information. Like all research using qualitative methods these findings are open to the influence of the researchers' interpretations and values. Results are descriptive in nature and it is not possible to know that the processes described here caused the outcomes reported or to know that others would have the same outcomes using these techniques.

Conclusion

This study highlights the complexity involved in antipsychotic withdrawal and the multiple forms of knowledge and support that can assist with this. A range of psycho-social resources are called on to track, make sense of, regulate and access support with the experiences that arise during and after antipsychotic withdrawal. These are strengths most people can develop, and the current results suggest those who do so may be empowered in their attempts to manage withdrawal and reduce the impact of any later relapses. Planning for relapse may assist people to reduce the risk-factors they face and address their needs at different stages of relapse if this occurs, but a preoccupation with avoiding relapse entirely may be counterproductive. People may find it helpful to have the choice of briefly resuming antipsychotics, using other medications as needed and/or having access to 'safe places with safe people' who

are able to respond without engaging in patterns of vigilance, avoidance, intrusive control or expressions of distress. This may require support from family, for family, and outside of the family. Targeted guidance and interventions should attend to developing psycho-social strengths in preparation, the challenges faced during the withdrawal period, the interpersonal context that these attempts unfold within and support for times of relapse in the years after discontinuation. Larger, systematic studies are warranted to explore these issues further.

Conflict of interest statement

The authors declare that there is no conflict of interest.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Miriam Larsen-Barr  <https://orcid.org/0000-0001-7515-2701>

References

1. Maina G, Albert U, Ziero S, *et al.* Antipsychotic augmentation for treatment resistant obsessive-compulsive disorder: what if antipsychotic is discontinued? *Int Clin Psychopharmacol* 2003; 18: 23–28.
2. Depping AM, Komossa K, Kissling W, *et al.* Second-generation antipsychotics for anxiety disorders. *Cochrane Database Syst Rev* 2010; 12: CD008120.
3. Komossa K, Depping AM, Gaudchau A, *et al.* Second-generation antipsychotics for major depressive disorder and dysthymia. *Cochrane Database Syst Reviews* 2010; 12: CD008121.
4. Waterreus A, Morgan VA, Castle D, *et al.* Medication for psychosis – consumption and consequences: the second Australian national survey of psychosis. *Aust N Z J Psychiatry* 2012; 46: 762–773.
5. Carrick R, Mitchell A, Powell RA, *et al.* The quest for well-being: a qualitative study of the experience of taking antipsychotic medication. *Psychol Psychother* 2004; 77: 19–33.
6. Larsen-Barr M. *Experiencing antipsychotic medication: from first prescriptions to attempted discontinuation.* Doctoral thesis, University of

- Auckland, New Zealand, <http://hdl.handle.net/2292/30888> (2016, accessed 18 July 2020)
7. Read J and Williams J. Positive and negative effects of antipsychotic medication: an international online survey of 832 recipients. *Curr Drug Saf* 2019; 14: 173–181.
 8. Read J and Sacia A. Using open questions to understand 650 people's experiences with antipsychotic drugs. *Schizophr Bull* 2020; 46: 896–904.
 9. Leucht S, Arbter D, Engel RR, *et al.* How effective are second-generation antipsychotic drugs? A meta-analysis of placebo-controlled trials. *Mol Psychiatry* 2009; 14: 429.
 10. Murray RM, Quattrone D, Natesan S, *et al.* Should psychiatrists be more cautious about the long-term prophylactic use of antipsychotics? *Br J Psychiatr* 2016; 209: 361–365.
 11. Morrison AP, Hutton P, Shiers D, *et al.* Antipsychotics: is it time to introduce patient choice? *Br J Psychiatr* 2012; 201: 83–84.
 12. Moncrieff J, Gupta S and Horowitz MA. Barriers to stopping neuroleptic (antipsychotic) treatment in people with schizophrenia, psychosis or bipolar disorder. *Ther Adv Psychopharmacol* 2020; 10: 1–10.
 13. Breggin PR. *Psychiatric drug withdrawal: a guide for prescribers, therapists, patients and their families.* New York: Springer, 2013.
 14. Irwin E, Mitchell L, Durkin L, *et al.* *The need for a mental patients' union (The fish pamphlet).* London: Mental Patients Union, 1972.
 15. Cooper D, Moisan J, Gaudet M, *et al.* Ambulatory use of olanzapine and risperidone: a population-based study on persistence and the use of concomitant therapy in the treatment of schizophrenia. *The CJP* 2005; 50: 901–908.
 16. Sajatovic M, Valenstein M, Blow FC, *et al.* Treatment adherence with antipsychotic medications in bipolar disorder. *Bipolar Disord* 2006; 8: 232–241.
 17. Nishikawa T, Hayashi T, Koga I, *et al.* Neuroleptic withdrawal with remitted schizophrenics: a naturalistic follow-up study. *Psychiatry* 2007; 70: 68–79.
 18. Roe D, Goldblatt H, Baloush-Klienman V, *et al.* Why and how people decide to stop taking prescribed psychiatric medication: exploring the subjective process of choice. *Psychiatr Rehabil J* 2009; 33: 38–46.
 19. Salomon C, Hamilton B and Elsom S. Experiencing antipsychotic discontinuation: results from a survey of Australian consumers. *J Psychiatr Ment Health Nurs* 2014; 21: 917–923.
 20. Bola JR and Mosher LR. Predicting drug-free treatment response in acute psychosis from the Soteria Project. *Schizophr Bull* 2002; 28: 559–575.
 21. Harrow MH, Jobe TH and Faull RN. Do all schizophrenia patients need antipsychotic treatment continuously throughout their lifetime? A 20-year longitudinal study. *Psychol Med* 2012; 42: 2145–2155.
 22. Wunderink L, Nieboer RM, Wiersma D, *et al.* Recovery in remitted first-episode psychosis at 7 years of follow-up of an early dose reduction/discontinuation or maintenance treatment strategy: long-term follow-up of a 2-year randomized clinical trial. *JAMA Psychiatry* 2013; 70: 913–920.
 23. Cooper R, Grünwald LM and Horowitz M. The case for including antipsychotics in the UK NICE guideline: “Medicines associated with dependence or withdrawal symptoms: safe prescribing and withdrawal management for adults”. *Psychosis* 2020; 12: 1–5.
 24. Rogers A, Day JC, Williams B, *et al.* The meaning and management of neuroleptic medication: a study of patients with a diagnosis of schizophrenia. *Soc Sci Med* 1998; 47: 1313–1323.
 25. Geyt GL, Awenat Y, Tai S, *et al.* Personal accounts of discontinuing neuroleptic medication for psychosis. *Qual Health Res* 2016; 26: 1–16.
 26. Salomon C and Hamilton B. “All roads lead to medication?” Qualitative responses from an Australian first-person survey of antipsychotic discontinuation. *Psychiatr Rehabil J* 2013; 36: 160–165.
 27. Katz S, Goldblatt H, Hasson-Ohayon I, *et al.* Retrospective accounts of the process of using and discontinuing psychiatric medication. *Qual Health Res* 2018; 29: 198–210.
 28. Brown E, Bedi G, McGorry P, *et al.* Rates and predictors of relapse in first-episode psychosis: an Australian cohort study. *Schizo Bull Open* 2020; 1: sgaa017.
 29. Moncrieff J. Does antipsychotic withdrawal provoke psychosis? Review of the literature on rapid onset psychosis (supersensitivity psychosis) and withdrawal-related relapse. *Acta Psychiatr Scand* 2006; 114: 3–13.
 30. Moncrieff J. Why is it so difficult to stop psychiatric drug treatment? It may be nothing to do with the original problem. *Med Hypotheses* 2006; 67: 517–523.

31. Larsen-Barr M, Seymour F, Read J, *et al.* Attempting to discontinue antipsychotic medication: withdrawal methods, relapse, and success. *Psychiatry Res* 2018; 270: 365–374.
32. Chouinard G and Chouinard V. Atypical antipsychotics: CATIE study, drug-induced movement disorder and resulting iatrogenic psychiatric-like symptoms, supersensitivity rebound psychosis and withdrawal discontinuation syndromes. *Psychother Psychosom* 2008; 77: 69–77.
33. Horowitz M, Murray R and Taylor D. Tapering antipsychotic treatment. *JAMA Psychiatry*. Epub ahead of print 5 August 2020. DOI: 10.1001/jamapsychiatry.2020.2166.
34. Steiner W, Laporta M and Chouinard G. Neuroleptic-induced supersensitivity psychosis in patients with bipolar affective disorder. *Acta Psychiatr Scand* 1990; 81: 437–440.
35. Chouinard G and Jones BD. Neuroleptic-induced supersensitivity psychosis: clinical and pharmacologic characteristics. *Am J Psychiatry* 1980; 137: 16–21.
36. Hall W. *The harm reduction guide to coming off psychiatric drugs*. 2nd ed. New York, NY: The Icarus Project and Freedom Centre, 2012.
37. Groot PC and van Os J. Antidepressant tapering strips to help people come off medication more safely. *Psychosis* 2018; 10: 142–145.
38. Harrow MH and Jobe TH. Factors involved in outcome and recovery in schizophrenia patients not on antipsychotic medications: a 15-year multifollow-up study. *J Nerv Ment Dis* 2007; 195: 406–414.
39. Wunderink L, Sytema S, Nienhuis FJ, *et al.* Clinical recovery in first-episode psychosis. *Schizophr Bull* 2009; 35: 362–369.
40. Wunderink A, Nienhuis FJ, Sytema S, *et al.* Treatment delay and response rate in first episode psychosis. *Acta Psychiatr Scand* 2006; 113: 332–339.
41. Landolt K, Rössler W, Ajdacic-Gross V, *et al.* Predictors of discontinuation of antipsychotic medication and subsequent outcomes in the European First Episode Schizophrenia Trial (EUFEST). *Schizophr Res* 2016; 172: 145–151.
42. Wils RS, Gotfredsen DR, Hjorthøj C, *et al.* Antipsychotic medication and remission of psychotic symptoms 10 years after a first-episode psychosis. *Schizophr Res* 2017; 182: 42–48.
43. Aaltonen J, Seikkula J and Lehtinen K. The comprehensive open-dialogue approach in Western Lapland: I. The incidence of non-affective psychosis and prodromal states. *Psychosis* 2011; 3: 179–191.
44. Seikkula J, Alakare B and Aaltonen J. The comprehensive open-dialogue approach in Western Lapland: II. Long-term stability of acute psychosis outcomes in advanced community care. *Psychosis* 2011; 3: 192–204.
45. Bergström T, Taskila JJ, Alakare B, *et al.* Five-year cumulative exposure to antipsychotic medication after first-episode psychosis and its association with 19-year outcomes. *Schizophr Bull Open* 2020; 1: 1–8.
46. Haro JM, Novick D, Perrin E, *et al.* Symptomatic remission and patient quality of life in an observational study of schizophrenia: is there a relationship? *Psychiatry Res* 2014; 220: 163–169.
47. Martínez-Hernández Á, Pié-Balaguer A, Serrano-Miguel M, *et al.* The collaborative management of antipsychotic medication and its obstacles: a qualitative study. *Soc Sci Med*. Epub ahead of print 23 January 2020. DOI: 10.1016/j.socscimed.2020.112811.
48. German Association for Psychiatry, Psychotherapy and Psychosomatics, DGPPN (Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde). *S3 Guideline for Schizophrenia Abbreviated Version (English)*. Düsseldorf: DGPPN, 2019.
49. Castle D, Morgan V and Jablensky A. Antipsychotic use in Australia: the patients' perspective. *Aust N Z J Psychiatry* 2002; 36: 633–641.
50. Cooper RE, Laxhman N, Crellin N, *et al.* Psychosocial interventions for people with schizophrenia or psychosis on minimal or no antipsychotic medication: A systematic review. *Schizophr Res* 2019. DOI: 10.1016/j.schres.2019.05.020.
51. Francey SM, O'Donoghue B, Nelson B, *et al.* Psychosocial intervention with or without antipsychotic medication for first-episode psychosis: a randomized noninferiority clinical trial. *Schiz Bull Open* 2020. 1. DOI:10.1093/schizbullopen/sgaa015.
52. Mosher LR and Bola JR. Soteria-California and its American successors: therapeutic ingredients. *Ethical Hum Psychiatry Psychol* 2004; 6: 7–23. DOI: 10.1891/1523-150X.6.1.7.
53. Morrison AP, Pyle M, Maughan D, *et al.* Antipsychotic medication versus psychological intervention versus a combination of both in adolescents with first-episode psychosis (MAPS): a multicentre, three-arm, randomised controlled pilot and feasibility study, *Lancet Psychiatry*

- 2020; 7: 788-800. DOI: 10.1016/S2215-0366(20)30248-0.
54. Morrison AP, Hutton P, Wardle M, *et al.* Cognitive therapy for people with a schizophrenia spectrum diagnosis not taking antipsychotic medication: an exploratory trial. *Psychol Med* 2015; 42: 1049-1056. DOI: 10.1017/S0033291711001899.
 55. Castle D, Morgan V and Jablensky A. Antipsychotic use in Australia: the patients' perspective, *Aust NZ J Psychiatry* 2002; 36: 633-641. DOI: 10.1046/j.1440-1614.2002.01037.x.
 56. Rofail D, Heelis R and Gournay K. Results of a thematic analysis to explore the experiences of patients with schizophrenia taking antipsychotic medication. *Clin Ther* 2009; 31: 1488-1496. DOI: 10.1016/j.clinthera.2009.07.001.
 57. Gibson S, Brand S, Burt S, *et al.* Understanding treatment non-adherence in schizophrenia and bipolar disorder: a survey of what service users do and why *BMC Psychiatry* 2013; 13: 153. DOI: 10.1186/1471-244X-13-153.
 58. Larsen-Barr M, Seymour F, Read J and Gibson K. Attempting to stop antipsychotic medication: Success, supports, and efforts to cope. *Soc Psychiatry Psychiatr Epidemiol* 2018; 53: 745-756. DOI: 10.1007/s00127-018-1518-x.
 60. Jung E, Wiesjahn M, Wendt H, *et al.* Symptoms, functioning and coping strategies in individuals with schizophrenia spectrum disorders who do not take antipsychotic medication: a comparative interview study. *Psychol Med* 2016; 46: 2179-2188. DOI: 10.1017/S0033291716000775.
 61. Braun V and Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3: 77-101. DOI: 10.1191/1478088706qp063oa.
 62. Groot P, and van Os J. How user knowledge of psychotropic drug withdrawal resulted in the development of person-specific tapering medication, *Ther Adv Psychopharmacol* 2020; 10: 1-13. DOI: 10.1001/jamapsychiatry.2020.2166.
 63. Bach P, Hayes SC and Gallop R. Long-term effects of acceptance and commitment therapy for psychosis. *Behav Modif* 2012; 36: 165-181. DOI: 10.1177/0145445511427193.
 64. Roth S and Cohen LJ. Approach, avoidance, and coping with stress. *Am Psychol* 1986; 41: 813-819. DOI: 10.1037/0003-066X.41.7.813.
 65. Udachina A, Thewissen V, Myin-Germeys I, *et al.* Understanding the relationships between self-esteem, experiential avoidance, and paranoia: structural equation modelling and experience sampling studies. *J Nerv Ment Dis* 2009; 197: 661-667. DOI: 10.1097/NMD.0b013e3181b3b2ef.
 66. Wegner DM, Schneider DJ, Carter SR *et al.* Paradoxical effects of thought suppression. *J Pers Soc Psychol* 1987; 53: 5-13. DOI: 10.1037/0022-3514.53.1.5.
 67. Pankey J and Hayes SC. Acceptance and Commitment Therapy for psychosis. *Intern Jour Psych Psychol Ther* 2003; 3: 311-328. Digital identifier: redalyc.org/articulo.oa?id=56030212.
 68. Valiente C, Provencio M, Espinosa R, *et al.* Insight in paranoia: The role of experiential avoidance and internalized stigma. *Schizophr Res* 2015; 164: 214-220. doi.org/10.1016.
 69. Goldstone E, Farhall J and Ong B. Life hassles, experiential avoidance and distressing delusional experiences. *Behav Res Ther* 2011; 49: 260-266. doi.org/10.1016/j.brat.2011.02.002.
 70. Weinstock LM, Chou T, Celis-deHoyos C, *et al.* Reward and punishment sensitivity and emotion regulation processes differentiate bipolar and unipolar depression. *Cognit Ther Res* 2018; 42: 794-802. doi.org/10.1007/s10608-018-9945-2.
 71. Dillon J and Hornstein GA. Hearing voices peer support groups: a powerful alternative for people in distress. *Psychosis* 2013; 5: 286-295. doi.org/10.1080/17522439.2013.843020.
 72. Oedegaard CH, Davidson L, Stige B *et al.* "It means so much for me to have a choice": a qualitative study providing first-person perspectives on medication-free treatment in mental health care. *BMC Psychiatry* 2020; 20: 399. DOI: 10.1186/s12888-020-02770-2.
 73. Morrison AP, French P, Walford L, *et al.* Cognitive therapy for the prevention of psychosis in people at ultra-high risk: randomised controlled trial. *British J Psychiatry* 2004; 185: 291-297. DOI: 10.1192/bjp.185.4.291.
 74. Bustillo JR, Lauriello J and Horan WP. Review: social skills training, supported employment programmes, and cognitive behaviour therapy improve some outcomes in schizophrenia. *Evid Based Nurs* 2001; 4: 115.
 75. Chung Y, Yoon K, Park T, *et al.* Group cognitive-behavioral therapy for early psychosis. *Cogn Ther Res* 2013; 37: 403-411.
 76. Howard A, Forsyth A, Spencer H, *et al.* Do voice hearers naturally use focusing and metacognitive coping techniques? *Psychosis* 2012; 5: 119-126.

77. Tuori T, Lehtinen V, Hakkarainen A, *et al.* The Finnish national schizophrenia project 1981–1987: 10-year evaluation of its results. *Acta Psychiatr Scand* 1998; 97: 10–17.
78. Khoury B, Lecomte T, Gaudiano BA, *et al.* Mindfulness interventions for psychosis: a meta-analysis. *Schizophr Res* 2013; 150: 176–184.
79. Hornstein GA, Robinson Putnam E and Branitsky A. How do hearing voices peer-support groups work? A three-phase model of transformation. *Psychosis* 2020; 12: 201–211.
80. Kaplan BJ, Simpson JS, Ferre RC, *et al.* Effective mood stabilization with a chelated mineral supplement: an open-label trial in bipolar disorder. *J Clin Psychiatry* 2001; 62: 936–944.
81. Moncrieff J. *A straight talking introduction to psychiatric drugs: the truth about how they work and how to come off them*. 2nd ed. Monmouth, UK: PCCS Books, 2020.
82. Lehman P. *Coming off psychiatric drugs*. American ed. Berlin, Germany: Peter Lehman Publishing, 2002.
83. Cassani M. *Beyond meds*, <https://beyondmeds.com/> (2020, accessed 18 July 2020).
84. Inner Compass Initiative. *The withdrawal project*, <https://withdrawal.theinnercompass.org/> (2019, accessed 18 July 2020).
85. Quebec Coalition of Alternative Mental Health Organizations/Regroupement des ressources alternatives en santé mine du Québec (RRASMQ), Association of intervention groups for the defense of mental health rights of Quebec (AGIDD-SMQ), and Team for Research and Action in Mental Health and Culture/Équipe de recherche et d'action en santé mentale et culture (ÉRASME). *My personal guide: Autonomous medication management in mental health, English ed.*, GAM Implementation Project, Quebec, www.rrasmq.com/GAM/documents/GuideGAM-EN-2019.pdf (2017, accessed 18 July 2020)
86. Quebec Coalition of Alternative Mental Health Organizations/Regroupement des ressources alternatives en santé mentale du Québec (RRASMQ), and Team for Research and Action in Mental Health and Culture/Équipe de recherche et d'action en santé mentale et culture (ÉRASME), *Supporting GAM practices: gaining autonomy and medication management in mental health: a handbook, English ed.*, GAM Implementation Project, Quebec, www.rrasmq.com/GAM/documents/GuideREP-ANG_2014-04.pdf (2014, accessed 18 July 2020)