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Highlights

- Among 105 people who attempted to stop taking antipsychotic medication, less than half consulted a doctor in preparation and approximately a third used a gradual withdrawal method.
- Just over half described successfully stopping and half reported no current use.
- Unwanted withdrawal effects were reported by 61.9% of the group and spanned emotional, cognitive, physical, and functional domains.
- Withdrawing gradually across more than one month showed significant, positive associations with self-described success and no current use.

Attempting to discontinue antipsychotic medication: withdrawal methods, relapse and success

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Abstract

Few studies explore subjective experiences of attempting to discontinue antipsychotic medication, the withdrawal methods people use, or how their efforts affect their outcomes. People who take antipsychotics for off-label purposes are poorly represented in the literature. This study investigates experiences of attempting to discontinue antipsychotics in a cross-sectional sample and explores potential associations between withdrawal methods, relapse, and success. An anonymous online survey was completed by 105 adults who had taken antipsychotics for any reason and had attempted discontinuation at least once. A mixed methods approach was used to interpret the responses. Just over half (55.2%) described successfully stopping for varying lengths of time. Half (50.5%) reported no current use. People across diagnostic groups reported unwanted withdrawal effects, but these were not universal. Withdrawing gradually across more than one month was positively associated, and relapse was negatively associated with both self-defined successful discontinuation and no current use. Gradual withdrawal was negatively associated with relapse during withdrawal. We conclude it is possible to successfully discontinue antipsychotic medication, relapse during withdrawal presents a major obstacle to successfully stopping AMs, and people who withdraw gradually across more than one month may be more likely to stop and to avoid relapse during withdrawal.

Keywords: Neuroleptic Medications; Psychosis Treatment; Service User Research; Human Rights; Informed Choice;

1. Introduction

Antipsychotic medication (AM) is commonly used by people diagnosed with schizophrenia spectrum disorders and bipolar disorder to manage symptoms of psychosis and mania (Castle et al., 2002, Fountoulakis et al., 2012). They are also commonly prescribed to people with a range of other off-label conditions including depression, dysthymia, obsessive-compulsive disorder, other anxiety disorders, or specific symptoms like insomnia or agitation, often at lower doses or alongside other psychiatric medications, despite limited evidence to support these practices (Maher et al., 2011, Monasterio and McKean, 2011, Carton et al., 2015, Walton et al., 2008, Albert et al., 2016, Vanbronkhorst et al., 2018). Most of the existing AM research focuses exclusively on people diagnosed with psychotic disorders (Landolt et al., 2016, Wunderink et al., 2013, Jung et al., 2016, Wils et al., 2017) and little is known about whether the experiences and outcomes of this group represents the experiences of those who take AMs for other reasons.

It is well-documented that people taking AMs to manage psychosis often attempt to discontinue (Cooper et al., 2005, Moritz et al., 2009). AMs are often accompanied by serious adverse effects (Carrick et al., 2004, Waterreus et al., 2012), and do not effectively reduce psychotic symptoms or prevent relapse for everyone (Leucht et al., 2009). People frequently make independent changes to their prescribed medication regimes to manage the impact of adverse effects (Bülow et al., 2016) and reports of discontinuation rates around 60%-80% are common among samples with schizophrenia spectrum diagnoses (Lieberman et al., 2005, Cooper et al., 2005). A similar pattern of adverse effects, variable levels of effectiveness, and high rates of discontinuation also appears among people who take AMs for bipolar disorder (Sajatovic et al., 2006, Greene et al., 2018, Djebbi et al., 2012) depression, anxiety disorders, OCD, and post-traumatic stress disorder (PTSD: Painter et al., 2017 ,Albert et al., 2016), leading some researchers to conclude that attempted discontinuation should be considered the norm across different groups (Moritz et al., 2009).

Research has suggested people who experience psychosis and stop taking AMs show better functional outcomes and lower relapse rates in the long-term relative to those who maintain continuous use (Harrow et al., 2012, Landolt et al., 2016, Wunderink et al., 2013, Wils et al., 2017,

Jung et al., 2016). These more favourable results do not appear to emerge until four years after discontinuation and prior to this point groups with psychosis and bipolar disorder who stop taking AMs show higher rates of relapse than those who persist (Harrow et al., 2012). Such findings have led some researchers to argue that "long-term 'maintenance' treatment with antipsychotics is based on hope rather than evidence" and encourage prescribers to reduce this practice (Murray et al., 2016, p 362).

People taking AMs for bipolar disorder and other off-label purposes are poorly represented in the discontinuation literature, but several studies suggest they show a similar pattern of improved recovery outcomes following discontinuation of AMs. One longitudinal study compared participants with diagnoses of depression or bipolar with psychotic features to those with schizophrenia or schizoaffective disorder diagnoses and found improved remission and relapse rates for those who stopped AMs in both groups, with significantly more favourable outcomes for those with psychotic mood disorders than those with schizophrenia spectrum disorders (Harrow et al., 2012). An earlier AM discontinuation study among people with bipolar disorder diagnoses found that continued use of antipsychotics after achieving remission from an episode of acute mania was detrimental due to increased depressive symptoms (Zarate and Tohen, 2004). Other studies have found improved recovery outcomes for those who discontinue AMs following off-label use for non-psychotic depression (Mortimer et al., 2003) and challenging behaviour associated with intellectual disabilities (Ramerman et al., 2018).

In New Zealand, as in many other developed countries, government legislation upholds service-users' human right to informed choice, including the choice to stop taking medication, and details specific conditions that must be met to compel someone to continue treatment without their consent (Ministry of Health, 1992, The Health and Disability Commissioner, 1996). However, there is reason for caution when contemplating discontinuation and the choice to stop medication or consent to continuing use is not as straight forward as it may first seem. Discontinuation can entail a range of somatic, emotional, and cognitive withdrawal effects, and psychotic or manic relapse during the withdrawal period is common among those with schizophrenia spectrum and bipolar diagnoses

(Salomon and Hamilton, 2013, Gilbert et al., 1995, Harrow et al., 2012, Moncrieff, J., 2013, Boonstra et al., 2011, Gilbert et al., 1995, Harrow et al., 2012, Moncrieff, J., 2013, Buchanan et al., 1992). Little is known of whether psychotic or manic symptoms emerge during withdrawal following off-label use, but it may be common for the symptoms that were the original treatment targets to reappear during or following withdrawal of off-label AMs (Moncrieff, Joanna, 2006). In one study of 18 people with OCD who discontinued AM while continuing with an antidepressant, 83.3% reported a relapse of OCD symptoms, most within eight weeks of discontinuation (Maina et al., 2003).

It is difficult to determine whether relapse of psychosis or other symptoms proximal to discontinuation represents a withdrawal syndrome, the re-emergence of a chronic mental-health problem, or both. Some researchers hypothesise that relapse of psychosis following withdrawal is the result of neurological adjustments to the dopamine blockade, which produce a subsequent surge of excitation when the AM is withdrawn (Steiner et al., 1990, Chouinard, 1991, Moncrieff, J., 2006). They note AMs also act on a range of neurotransmitter systems which appear to be associated with other physical, cognitive and emotional withdrawal effects (Moncrieff, J., 2013).

Gradual withdrawal is recommended to curb and potentially prevent withdrawal effects, regardless of diagnosis, but there is little available research regarding whether or how people implement this advice. Some writers advocate for reductions of no more than 10% of the previous dose (Breggin, 2013,Hall, 2012), but most of the clinical withdrawal studies have employed relatively swift tapering protocols in comparison. All of the clinical studies of withdrawal among people who experience psychosis conducted up to 1995 tapered people off their medication within 60 days, the vast majority within 30 days or less (Gilbert et al., 1995). More recent trials have used longer withdrawal protocols and appear to show improved outcomes, both in terms of success and safety (Nishikawa et al., 2007), but only two discontinuation studies have tested whether the reduction period is associated with the outcomes of attempts to stop taking AMs. One meta-analysis found an increased risk of early relapse for those who withdrew abruptly compared to those who reduced gradually over three weeks or more (Viguera et al., 1997), while a more recent meta-analysis using the same definitions found no significant difference (Leucht et al., 2012). To our knowledge, none of

the withdrawal studies have explored whether gradual withdrawal is associated with successful discontinuation.

A small handful of studies represent the only existing information about how people attempt to withdraw from AMs (Roe et al., 2009, Salomon and Hamilton, 2013, Salomon et al., 2014, Geyt et al., 2016). Two small interview studies investigating the decision-making process found people with psychosis or bipolar disorder highlight the importance of 'weaving a safety net' of coping skills and supportive alliances (Geyt et al., 2016, Roe et al., 2009). One larger survey study explored withdrawal methods and effects alongside people's personal efforts to manage and their chosen withdrawal methods (Salomon and Hamilton, 2013, Salomon et al., 2014). Among the sample of 88 people who had taken AMs for any reason, 54.7% stopped without consulting their prescriber, 40.9% withdrew abruptly, 27.3% withdrew in under a month, and 22.7% withdrew in one to six months, 78% experienced withdrawal effects, and 21% were no longer taking AMs (Salomon et al., 2014). It was not specified how many of the participants had been taking AMs for psychosis, bipolar disorder or off-label purposes. Again none of these studies explored what characterises the efforts and outcomes of those who succeed in their attempts to stop taking AMs. However, when considered in conjunction with the longitudinal research and studies exploring psychiatric medication withdrawal in general they suggest that discontinuation is "a legitimate choice that requires and justifies appropriate support" (Katz et al., 2018, p1).

The problem is that there is little clarity about what the appropriate support needs to be. Several guidelines have been put forth (e.g. Breggin, 2013, Hall, 2012, Gupta et al., 2018, Reeve et al., 2014), but these are based on scarce data and none are considered widely accepted as best practice at this point in time. It remains unknown whether there is an association between gradual withdrawal methods, withdrawal effects and successful outcomes, or how experiences might differ across groups with different diagnoses. Such information is important for everyone who attempts discontinuation, regardless of their diagnosis, and for the people they turn to for support, including clinicians and personal networks. Research exploring how people manage their attempts to discontinue and what affects their outcomes may help guide people who wish to stop AMs and their

support systems towards strategies that will minimise the costs and maximise their chances of success. A mixed-methods exploratory study was designed in an attempt to address these issues.

2. Methods

This mixed-methods investigation aimed to describe the discontinuation experiences of people who take or have taken AMs for different purposes, and to explore the possible associations between withdrawal methods, withdrawal effects, and success. This article draws on the results of questions concerning attempted discontinuation of AMs in The Experiences of Antipsychotic Medication Survey. The anonymous survey was available for online completion in 2014. Ethical approval for the study was granted by the University of Auckland Human Participants Ethics Committee.

2.1 Participants

The online survey was open to New Zealand adults over the age of 18, who were taking, or had taken, AMs for at least three months, for any reason, and who were not currently residing in an in-patient unit. Recruitment was carried out through mainstream radio media and service-user networks across New Zealand. The entire sample answered questions about the experience of taking AMs, and whether they had contemplated or attempted stopping AMs (n=144). Only people who had made at least one attempt to stop taking AMs were presented with questions about attempted discontinuation (n=105); they form the sample of interest in the current investigation.

2.2 Instrument

The survey was constructed by adapting the survey used in the Experiences of Antidepressants Study (Read et al., 2014), then expanding it to include measures of quality of life and psycho-social resources, and an additional section exploring attempted discontinuation. Those who had made at least one attempt to stop taking AMs answered a series of questions about their most recent attempt to stop including their withdrawal methods, preparations, use of doctor consultation, Pro Re Nata (PRN) use of AMs during withdrawal, supports, coping efforts, and outcomes. The survey was piloted with a small convenience sample of people who had experienced attempted discontinuation.

Alongside demographic information, participants were asked whether they had received a formal diagnosis and if so to list the diagnoses they had received. They were also asked to select, from a check-list, the primary symptom types they were experiencing when they first began taking antipsychotics (hallucinations, delusions, mania, and/or depression), with an option to describe others not listed. The survey asked about medication history, including age at treatment initiation and most recent medication regime, but did not ask participants if they also withdrew from other medications they were taking alongside AMs. Number of prior attempts and age at most recent attempt were both queried and participants were asked to focus on their most recent attempt to discontinue as they responded to questions about their experiences. Duration of treatment with AMs was estimated by subtracting the participant's reported age at treatment initiation from their stated age at the time of their most recent attempt to stop. The survey did not ask whether AM use was continuous during this period.

An open question elicited a subjective evaluation of each participant's outcome and whether they successfully stopped or not ('what was the outcome of your most recent attempt to stop taking AMs?'). A closed question ('are you still taking oral antipsychotic medication?') assessed current AM use as a supplementary measure of success. Withdrawal methods were investigated with a multiple choice question that asked participants to self-define the method they followed by selecting from one of two options, ('I slowly reduced my dose over a period of time before stopping entirely' / 'I stopped the medication abruptly all in one go'), or indicating that they did not remember. Those who self-identified as following a gradual withdrawal method were presented with a follow-up question asking them 'approximately how long did it take you to reduce to no medication?' Withdrawal effects were explored through an open-ended question asking 'What were the effects of withdrawing from the medication?' and supplemented with relevant responses to the open-ended question exploring the outcome of the attempt. Specific relapse experiences were not directly asked about but emerged as content categories within the general withdrawal effects analysis. See supplementary materials to review the survey instrument in more detail.

2.3 Data analysis

Content analysis (Crowe et al., 2015) was used to categorise the range of experiences described in response to open-ended questions regarding withdrawal methods, effects, and discontinuation outcomes. Categories were created by grouping data-derived content units described by three or more participants, collapsing meaningfully similar groupings together and dummy-coding participants into exclusive groups for further analysis. Categories were defined in a written protocol, before coding participant responses accordingly. Coding was checked for reliability by two independent raters who reviewed and coded 20% of the participant responses to each question. Discrepancies were discussed and definitions refined before the data was re-coded and again compared for discrepancies, resulting in an overall agreement rate of 96.7%.

The central outcome of interest was whether people successfully stopped taking AMs or not. Success was defined as achieving the goal of stopping AM use, irrespective of relapse rates, impact on wellbeing, or descriptions of returning to AMs at a later time. Those who described resuming AMs were categorised as unsuccessful/resumed and those who described stopping were categorised as successful/stopped. The inter-rater reliability of success using this definition was 100%. Additional outcomes described by those who successfully stopped and those who resumed were then categorised using the data-driven approach described above.

Using the data-driven process described above, relapse of psychosis and/or mania was identified as a distinct withdrawal effect category that allowed for the exploration of whether this form of relapse during withdrawal is associated with withdrawal methods or success. Content analysis identified a group of comments describing the emergence of psychotic and manic symptoms during withdrawal and others describing "relapse" and "getting unwell again" "hospital" without added detail. The latter group of comments all came from people with schizophrenia spectrum diagnoses, bipolar disorder, or initial symptoms of mania or psychosis. After seeking service-user consultation these were interpreted as intending to communicate returning psychosis or mania, based on information already provided earlier in the survey. As such, these were grouped together with the more specific descriptions to create a content category titled ‘Relapse: psychosis, mania and/or hospital’. For brevity this is often referred to as ‘relapse of psychosis or mania’. Psychotic

symptoms were defined as voices and other hallucinations or perceptual disturbances, delusions and other unusual beliefs, and/or thought disorder. Mania was defined as a description of expansive mood, reduced need for sleep, and uncharacteristic striving behaviour. The inter-rater reliability of relapse of psychosis and/or mania using this definition was 88%. Other emotional withdrawal effects were coded separately into their own content category, and may also be considered signs of relapse in a cross-sectional sample such as this.

Gradual withdrawal was defined as reducing across more than one month. Those who self-identified as tapering slowly and indicated a reduction time over one month were categorised as withdrawing gradually. Those who indicated withdrawing abruptly and those who self-identified as tapering slowly but indicated a reduction time of one month or less were categorised as following an abrupt or swift method.

To explore the possible role of initial symptoms, participants were coded according to whether they experienced the hallmark symptoms of psychosis or mania at the time they began antipsychotics, defined as reports of hallucinations, delusions, mania, or hypomania. Participants were further categorised into symptom groups according to whether they reported symptoms of psychosis alone, mania alone, psychosis and mania together, or other symptoms alone.

To explore diagnosis, each diagnostic label referred to by participants was coded into diagnostic categories based on DSM-5 definitions. Participants were then dummy-coded into three exclusive diagnostic groups to differentiate those who received bipolar diagnoses, schizophrenia spectrum diagnoses, and other diagnoses only. Participants who referred to multiple differential diagnoses were not coded into diagnostic categories or diagnostic groups and are missing from this analysis (n=10) along with those who reported not receiving a diagnosis (n=11). A written protocol defined the rules for differential diagnoses and each of the diagnostic categories.

The diagnostic group labelled schizophrenia spectrum disorders included people who had received diagnoses of schizophrenia, schizoaffective disorder (with or without bipolar features), psychosis NOS, drug-induced psychosis, brief psychotic disorder, delusional disorder, schizophreniform disorder, and schizotypal personality disorder, irrespective of other comorbidities.

The bipolar disorders diagnostic group included those who had received a Bipolar I or II (with or without psychotic features), their variants manic depression and bipolar affective disorder, and cyclothymia, irrespective of other comorbidities. Other diagnoses only included those who reported receiving diagnoses of anxiety, obsessive compulsive, or post-traumatic stress disorders, depressive disorders, personality disorders, substance use disorders, autism spectrum disorders, or others without receiving a bipolar or schizophrenia spectrum disorder. Using these definitions the inter-rater reliability for diagnostic group was 96%.

Pearson's chi square tests of independence ($H_0: \phi=0$)(Franke et al., 2012) were conducted to explore associations between the categorical variables of hallmark symptoms of mania and/or psychosis at first prescription (0 No vs. 1 Yes), diagnostic group (0 Other Only vs. 1 Bipolar vs. 2 Schizophrenia Spectrum), withdrawal methods (0 abrupt/swift vs. 1 gradual), consulting a doctor (0 No vs. 1 Yes), unwanted withdrawal effects (0 No, 1 Yes), relapse during withdrawal (0 No, 1 Yes), success (0 resumed/unsuccessful vs. 1 stopped/successful) and current use (0 no current use vs. 1 current use). None of the cross-tabulations had expected cell counts below five and the data-set met the assumptions required for Chi Square. For all two-by-two cross-tabulations results are based on Phi to allow an analysis of the strength and direction of the associations observed. The larger cross-tabulations rely on Cramer's V and the descriptive data is used to identify where the differences lie.

3. Results

3.1 Sample characteristics

Participants were 105 New Zealand adults who completed the Experiences of Antipsychotic Medication Survey and indicated having made at least one attempt to stop taking AMs. Sample characteristics are summarised in Table 1. The majority were women (74%), European (84%), and employed (80%). Most had been taking atypical AMs at the time of their most recent attempt to stop and over half had begun taking AMs before age 30. As a whole, the sample had been taking AMs for an average of 8.1 years at the time they attempted to discontinue (range 0 – 46 years), though they may not have taken them continuously across that period.

Table 1. *Characteristics of the Subsample who had Attempted to Stop Taking AMs*

Participant characteristics	Count	(%)	Participant characteristics	Count	(%)
Gender			**Initial Hallmark Symptoms of Mania and/or Psychosis**		
Female	78	(74.3%)	Yes	84	(80.0%)
Male	25	(23.8%)	No	21	(20.0%)
Gender Diverse	2	(1.9%)	**Diagnostic Group**		
Ethnicity			Bipolar Disorders	37	(35.2%)
NZ-European	88	(83.8%)	Schizophrenia Spectrum Disorders	19	(18.1%)
NZ-Maori	9	(8.6%)	Other Only	28	(26.7%)
Other	8	(7.6%)	**Age First Started AMs (mean 29 yrs; range 12-63 yrs)**		
Current age (mean 41 yrs; range 18-70 yrs)			Under 18 Years	15	(14.4%)
18-29 years	25	(23.8%)	18-29 Years	47	(45.2%)
30-39 years	25	(23.8%)	30-39 Years	23	(22.1%)
40-49 years	22	(21.0%)	40-49 Years	12	(11.5%)
50-59 years	23	(21.9%)	50-65 Years	7	(6.7%)
60-70 years	10	(9.5%)	**Most recent or current AM type(s)**		
Occupational Status			Atypical AM Only	90	(88.2%)
Yes Employed	84	(80.0%)	Typical AM Only	9	(8.8%)
Not Employed	21	(20.0%)	Both Typical and Atypical AM	3	(2.9%)
Highest level of education			**Polypharmacy – multiple concurrent psych meds**		
University degree	52	(49.5%)	Yes Polypharmacy	76	(72.4%)
Diploma/cert. after high school	37	(35.2%)	No polypharmacy single oral AM only	22	(21.0%)
Completed high school	10	(9.5%)	**Age at Most Recent Attempt to Stop**		
Did not complete high school	6	(5.7%)	Under 18 years	1	(1.0%)
Initial Primary Symptoms			18-29 years	35	(34.3%)
Psychosis and Mania	33	(31.4%)	30-39 years	27	(26.5%)
Psychosis, No Mania	29	(27.6%)	40-49 years	22	(21.6%)
Mania, No Psychosis	22	(21.0%)	50-70 years	17	(16.7%)
Other Symptoms Only	21	(20.0%)	**Mean Years Start to Stop**	8.15	

This table presents the demographic and clinical characteristics of the subsample of survey participants who indicated making an attempt to stop taking AMs. Percentages are expressed as a proportion of the whole sub-sample of 105.

Most of this sample had been experiencing the hallmark symptoms of psychosis and/or mania at first prescription. Specifically, 34.3% of the sample selected hallucinations (n=36) from a check-list of options, 45.7% selected delusions (n=48), and 48.6% selected mania (n=51), while a further 5.7% used the comment field to describe psychosis in general (n=6), and 4.8% hypomania (n=5). Most participants reported experiencing other symptoms at the time they began taking AMs. One fifth of the group reported other symptoms alone, without mania or psychosis (n=21), 60% of the group reported other primary symptoms alongside mania and/or psychosis (n=63), and 19% reported the hallmark symptoms of mania and/or psychosis alone (n=20), including ten participants who reported psychosis alone without mania or other affective symptoms. In total, 73.3% selected depression (n=77) from the check-list of options, and 17.1% specified anxiety and trauma symptoms (n=18), 8.6% described intrusive and racing thoughts (n=9), 8.6% described emotional distress (n=9),

7.6% described insomnia (n=8), 2.9% described destructive and self-destructive behaviour (n=3), 1.9% specified antidepressant side effects (n=2), and 4.8% reported others (n=5) such as spiritual crises and eating issues.

Most of the sample reported receiving one or more formal diagnosis (n=94) and 10.5% reported never having received a diagnosis (n=11). Among those who reported receiving a diagnosis, ten people described multiple differential diagnoses that could not be coded into diagnostic categories or diagnostic groups. As shown in Table 1, 35.2% described receiving a bipolar diagnosis, 18.1% reported schizophrenia spectrum diagnoses, and 26.7% reported other diagnoses only, which comprised 23 reports of unipolar depression, 16 reports of anxiety disorders including OCD and PTSD, nine reports of personality disorder, two reports of eating disorder and one report of autism spectrum disorder. Those with schizophrenia spectrum diagnoses reported on average 13.6 years between starting AMs and their most recent attempt to stop compared to 8.4 years in the bipolar disorder group, and 4.9 years in the other diagnoses only group.

3.2 Discontinuation outcomes

Details of the participants' most recent attempt to discontinue AMs are summarised in Table 2. Just under half the group (48.6%) reported consulting a doctor about their most recent attempt and just over half the group (55.2%) described successfully stopping AMs. Half (50.5%) were not currently taking AMs at the time of survey completion.

Table 2. *Details of Most Recent Attempt to Discontinue AMs*

Responses	Total (% n=105)
Consulted a Dr	51 (48.6%)
Time Taken for Withdrawal [a]	
Abrupt	44 (41.9%)
< 1 month	10 (9.5%)
1-2 months	15 (14.3%)
3-6 months	13 (12.4%)
> 6 months	9 (8.6%)
Uncertain, Unspecified or In Progress	14 (13.3%)
Withdrawal Method [b]	
Gradual Withdrawal (> 1 month) [c]	32 (30.5%)
Abrupt or Swift Withdrawal	59 (55.2%)
Multiple Attempts	
First attempt to stop	37 (35.2%)
Previous attempts to stop	67 (63.8%)
Time off AMs	
< 1 month	28 (26.8%)
1-6 months	16 (15.2%)

Responses	Total (% n=105)
Success of Most Recent Attempt	
Stopped/Successful	58 (55.2%)
Resumed/Unsuccessful	37 (35.2%)
In Progress or Uncoded	10 (9.5%)
Stopped/Successful Outcome Elements	
Stopped - No Qualifiers	36 (34.3%)
Stopped and Have Not Taken Since	12 (11.4%)
Stopped and Take When Needed	5 (4.8%)
Stopped for Extended Time then Resumed AMs	4 (3.8%)
Other: Stopped and Switched to Different Class	1 (1.0%)
Effect on Health and Wellbeing	29 (27.6%)
- Improved Health and Wellbeing	23 (21.9%)
- Ongoing Difficulties to Manage	9 (8.6%)
Resumed/Unsuccessful Outcome Elements	
Resumed AMs - No Qualifiers	26 (24.8%)
Resumed AMs with Changes	6 (5.7%)
Compulsory Treatment or Hospitalisation	8 (7.6%)

6-12 months	7 (6.7%)	New Realisations and Understanding	7 (6.7%)
More than a year	54 (51.4%)	Other: E.G, health, job loss, sense of failure	3 (2.9%)
Current Use of AMs			
Yes Current Use of AMs	52 (49.5%)		
No Current Use of AMs	53 (50.5%)		

Withdrawal methods, time off AMs, current use and success for survey respondents who had made attempts to stop (n=105). Percentages are expressed as a proportion of the entire sample of 105. (a) range was one week to eight years; (b) Gradual withdrawal comprises those who self-identified as following a gradual withdrawal method and specified reducing across more than one month; abrupt or swift withdrawal comprises those who self-identified as withdrawing abruptly (n=44) or described a swift taper across one month (n=5) or less (n=10). (c) Gradual withdrawal includes two In Progress participants who were withdrawing across several months to years and were excluded from statistical analyses.

Table 3 shows the distribution of the data across the three central outcomes of interest, relapse during withdrawal, success, and current use, after excluding those who reported being in progress with their attempt to stop (n=4). Among those who described successfully stopping (n=58), 81.0% reported the hallmark symptoms of mania or psychosis at first prescription (n=47), 8.6% reported schizophrenia spectrum diagnoses (n=5), 36.2% reported receiving a bipolar diagnosis (n=21), 31.0% reported other diagnoses only (n=18), 55.2% reported consulting a doctor prior to their attempt (n=32), and 39.7% withdrew gradually across more than a month (n=23). Table 3 further shows that 26.3% of those with schizophrenia spectrum disorder diagnoses described successfully stopping and 26.3% reported no current use, whereas among those with bipolar disorder diagnoses 61.8% described success and 55.9% reported no current use, and among those with other diagnoses 64.3% described success and 57.1% reported no current use. Chi Square tests failed to show a significant association between successfully stopping and hallmark symptoms of mania or psychosis at first prescription, consulting a doctor, or diagnostic group. Similarly there was no association between current use and hallmark symptoms of psychosis and/or mania, consulting a doctor, or diagnostic group. Associations with relapse and withdrawal methods are presented separately following a summary of the participant's subjective descriptions of their outcomes.

Table 3. *Distribution of the Data across Relapse, Success, and Current Use Groups*

	Relapse During Withdrawal [a]		**Success of Attempt**		**Current Use**	
	No (n=64)	Yes (n=29)	No (n=37)	Yes (n=58)	No (n=53)	Yes (n=48)
Years Start to Stop	7.73	8.31	7.27	7.40	6.25	10.38
Initial Primary Symptoms						
Psychosis, No Mania (n=28)	15	12	9	17	14	14
Psychosis and Mania (n=32)	19	10	14	16	15	17
Mania, No Psychosis (n=20)	16	2	5	14	12	8

Other Sx Only (n=21)	14	5	9	11	12	9
Hallmark Symptoms of Mania and/or Psychosis [b]						
No (n=21)	14	5	9	11	12	9
Yes (n=80)	50	24	28	47	41	39
Diagnostic Groups [b]		*				
Other Only (n=28)	19	7	10	18	16	12
Bipolar Disorders (n=34)	24	6	11	21	19	15
Schizophrenia Spectrum (n=19)	9	10	11	5	5	14
Consulted a Doctor [b]						
No (n=53)	27	21	22	26	25	28
Yes (n=48)	37	8	15	32	28	20
Withdrawal Method [b]		*		*		*
Abrupt/Swift (n=59)	35	20	26	30	27	32
Gradual > 1 month (n=30)	23	4	5	23	23	7
Unwanted Withdrawal Effects [b]				*		*
No (zero or positive only)	-	-	2	26	23	8
Yes (one or more negative effect)	-	-	34	27	24	39
Relapse During Withdrawal [a] [b]				*		*
No (n=64)	-	-	15	45	41	23
Yes (n=29)	-	-	22	6	6	23

This table presents the distribution of the data across the three outcome groups of interest, self-reported withdrawal related relapse, successful discontinuation, and current use of oral antipsychotics, excluding those who were in progress with their attempts (n=4) and those who had missing data on either variable; rows and/or columns do not always sum to 100% of the stated subgroup size (in brackets). a) Relapse During Withdrawal refers only to descriptions of relapse of psychotic and/or manic symptoms during the period of withdrawal, relapse of other emotional symptoms were categorised separately. Relapse beyond the withdrawal period was not explored.
b) Observed differences were analysed using Pearson's Chi Square. Significant differences marked by an asterisk.
* $p < .05$

3.2.1 Accounts of successful outcomes: As shown in Table 2, among those who described successfully stopping, some specified they never took AMs again, and others referred to occasionally returning to AMs when needed, even after prolonged periods of no use, for example, *"I was medication free for about 10yrs and have only recently had to go back on them as experienced a relapse"* and "*briefly re-taking the drug at a much lower dosage to manage an episode that was seasonally expected.*" In addition to the information in Table 2, 37.9% (n=22/58) of those who successfully stopped indicated they had last regularly used AMs two-five years ago, and 34.5% (n=20/58) had last used AMs regularly over five years ago.

Among those who successfully stopped, half provided comments about what successfully stopping had meant for their recovery (n=29). Most comments about the recovery outcomes of successfully stopping referred to living with improved mental health and wellbeing (n=23), which comprised references to improved psycho-social wellbeing (n=19) for example "*I experience no psychosis and only occasional anxiety […] I am (reasonably) physically healthy, extremely mentally healthy, working and enjoying life*", the resolution of adverse effects (n=5), for example "*I felt less*

sedated" and "*am now within the normal weight range*", and coping well with other strategies (n=4), for example, "*I manage my mental health well. I have occasionally visited [a] counsellor since stopping medication, but mostly use my support network for help now.*"

A minority among those who successfully stopped referred to dealing with ongoing difficulties (n=9), including ongoing mental-health problems (n=7) and unresolved adverse effects of AMs (n=2). Those who referred to ongoing mental-health problems, predominantly described the persistence of primary symptoms (n=6) at varying levels of manageability with one sub-threshold reference to continuing insomnia. These participants commented *"I wasn't better but at least I wasn't taking it anymore unnecessarily"* and *"I still have mental health issues, but I cope in other ways*".

3.2.2 Accounts of unsuccessful outcomes: Among the 37 who resumed taking AMs, most gave brief descriptions using words like *"hospital"*, *"failure"* and *"restarted"*, and phrases like *"went back on them"*, and *"stay on prescribed dose".*

A small group provided further information about what resuming had meant for them (n=11). Most of these comments described hospitalisation or compulsory treatment, or described resuming to prevent that (n=8), for example, "*I am still on the meds and on a CTO as I relapsed,"* and *"got back on it just before I would have been back on the ward"*. Some described subsequent changes to medications or doses (n=6), sometimes via changes in clinician, for example, *"changed psychiatrist, correct diagnosis and prescribed different drugs"*. This could involve changes to more preferred medications and lower doses, but also increased doses and medication agents, for example, *"relapse followed by subsequent compulsory increases in my medication"*. Another group of comments described accepting or becoming resigned to taking AMs (n=7), for example, *"Greater self-knowledge. Gratitude that I have the medication to keep stable,*" and *"I have to stay on it for life I can't cope without it"*.

Three participants made reference to other adverse impacts such as lost job or training opportunities, relationship breakdown, and a sense of failure, for example "*felt very deflated*" and

"*It was unpleasant and set my recovery back. Also I dropped out of my study programme at the time because of the relapse*".

3.3 Withdrawal methods

Half the group self-identified as following a gradual withdrawal method when presented with a multiple-choice question, but the time they took to reduce ranged from one week to several years (see Table 2). Responses were recoded into two groups according to those who reduced abruptly or within a month or less (abrupt or swift withdrawal; n=58, 55.2%), and those who reduced across more than one month (gradual withdrawal; n=32, 30.5%). Those who reported being uncertain or in progress were not coded into withdrawal groups (n=14, 13.3%). Two people who were included in the gradual withdrawal group reported being in progress with their attempts elsewhere in the survey and were excluded from further statistical analyses along with two other participants who also described still being in progress with their attempts. As shown in Table 3, the majority of those who reduced gradually did not report relapse, described successfully stopping, and were not currently taking antipsychotics at the time they completed the survey.

There was a significant, positive association between gradual withdrawal and successfully stopping (phi=.279, p=.011, n=84) and a negative association with current use (phi=-.295, p=.005, n=89). Those who followed a gradual withdrawal method were less likely to report current use at the time they completed the survey. In addition, there was a significant, positive association between following a gradual withdrawal method and consulting a doctor (phi=.359, p=<.001, n=89). Among those who consulted a doctor, 47.5% withdrew abruptly or swiftly (n=19/40) and 52.5% withdrew gradually (n=21/40). In comparison, 81.6% of those who did not consult a doctor followed an abrupt or swift withdrawal method (n=40/49), while 18.3% withdrew gradually (n=9/49).

3.4 Withdrawal effects

As shown in Table 4, when asked what they experienced during the reduction process, around two thirds of the sample described unwanted withdrawal effects, 18.1% reported zero withdrawal effects, and 13.3% reported positive effects only. Unwanted withdrawal effects spanned physical, emotional, cognitive and functional domains and included descriptions of psychotic and

manic relapse. Participants gave descriptions such as, "*Extreme panic, dissociative episodes, hallucinations, delusions, lasting 24-72 hours per dose reduction, then resolving completely at the end of that period*" and "*Insomnia. Nausea. Headaches. Irritability increased. Increased episodes of despair.*" The most commonly reported unwanted withdrawal effects were in the emotional domain, which comprised feelings of anxiety and fear (n=15/105; 14.3%), low mood, sadness and depression (n=13/105; 12.4%), irritability and agitation (n=7/105; 6.7%), suicidality (n=5/105; 4.8%) and, within the 'other' category, mood swings (n=2/105; 1.9%).

Table 4. *Subjective Withdrawal Effects and Withdrawal-Related Relapse*

Overall Withdrawal Effects	Count (%)
Negative Effects Only	59 (56.2%)
Zero Withdrawal Effects	19 (18.1%)
Positive Effects Only	14 (13.3%)
Mixed Positive and Negative	6 (5.7%)
Other (Do Not Remember)	7 (6.7%)
Negative Withdrawal Effect Elements	65 (61.9%)
Emotional Withdrawal Effects	35 (33.3 %)
Relapse, Psychosis, Mania and/or Hospital	29 (27.6%)
Physical Withdrawal Effects	23 (22.0%)
Sleep Problems / Insomnia	22 (21.0%)
Confusion, Dissociation, Disorientation	6 (5.7%)
Difficulty with Functioning and Rels	3 (2.9%)
Short Lived Negative Effects	3 (2.9%)
Positive Withdrawal Effect Elements	20 (19.0%)
General positive description	7 (6.7%)
Emotional Benefits	6 (5.7%)
Clearer Thinking – More Alert	5 (4.8%)
More Energy	3 (2.9%)
Short Lived Positive Effects	2 (1.9%)

This table presents the content analysis results for withdrawal effects and withdrawal-related relapse. All percentages expressed as a proportion of n=105.

The physical domain comprised feelings of physical illness like nausea, diarrhoea, vomiting and headaches (n=9/105; 8.6%), unpleasant physical sensations (n=7/105; 6.7%), appetite and rapid weight loss (n=6/105; 5.7%), shaking (n=3/105; 2.9%), sweating (n=3/105; 2.9%), and one single reference to seizures. Approximately one fifth reported insomnia or disturbed sleep.

Chi square tests revealed those who described experiencing one or more unwanted withdrawal effects were significantly less likely to successfully stop (phi=-.460, p=.000, n=89) and significantly more likely to report current use (phi=.339, p=.001, n=94) than those who described experiencing zero withdrawal effects or positive effects alone. Hallmark symptoms at first

prescription, diagnostic group, and withdrawal method all failed to show significant associations with whether or not someone experienced any unwanted withdrawal effects.

3.4.1 Relapse during withdrawal

As shown in Table 4, when asked about withdrawal effects, 27.6% of the whole sample described experiencing a relapse of psychosis or mania during withdrawal, detailing specific relapse experiences of psychosis, and/or mania during withdrawal or referring generally to "relapse", "getting unwell" or "hospital" against a history of psychosis or mania. Table 3 shows that 13.3% of those who reduced gradually reported experiencing a relapse in this manner, compared to 33.9% of those who stopped abruptly or swiftly. There was a small but significant, negative association between relapse of psychosis or mania and withdrawal method (phi=-.223, p=.044, n=82), where those who followed a gradual withdrawal method were less likely to report psychotic or manic symptoms during the process than those who stopped abruptly.

Relapse of psychosis or mania during withdrawal was reported by 31.1% of those with hallmark symptoms of psychosis or mania at first prescription (n=24/80), and 23.8% of those without those symptoms (n=5/21). The diagnostic analysis showed 17.6% of those in the bipolar diagnoses group (n=6/34), 25% of those in the other diagnoses only group (n=7/28), and 52.4% of those in the schizophrenia spectrum group (n=10/19) reported psychotic or manic relapse during withdrawal. Relapse of psychosis or mania was not significantly associated with experiencing the hallmark symptoms of psychosis and/or mania at the time of first prescription, but showed a small, significant association with diagnostic group (Cramer's V=.285, p=.048, n=75). Those who had received schizophrenia spectrum diagnoses were significantly more likely to report relapse during withdrawal than those with bipolar disorders, or other diagnoses. The seven participants with other diagnoses who described relapse during withdrawal, had all specified the presence of psychotic or manic symptoms at initial prescription or as features of their diagnosis such as "extreme panic, dissociative episodes, hallucinations, delusions, lasting 24-72 hours per dose reduction, resolving at the end of that period" and "bad hallucinations, feeling very depressed, voices increasing, vomiting, stopped sleeping."

Among the group who reported relapse of psychosis or mania, 20.7% reported successfully stopping AMs (n=6/29), and 75.7% had resumed AMs (n=22/29). Relapse showed a large, significant, negative association with successfully stopping AMs (phi=-.505, p<.000, n=88), and a significant, positive association of moderate magnitude with current use (phi=.402, p<.000, n=93). That is, people who reported relapse, as it was defined here, were less likely to describe successfully stopping and more likely to report current use of AMs. However this definition does not account for the relapse of emotional symptoms, which were reported by a third of the group. Combining those who reported exacerbation of other emotional symptoms with those who reported psychotic or manic relapse during withdrawal showed 55 participants, or 52.4% of the whole sample, could be considered to have experienced some form of relapse. An exploratory analysis using this broader definition of relapse revealed similar associations with success and current use, but did not show a statistically significant association with withdrawal method.

4. Discussion

This cross-sectional study aimed to explore service-user experiences of attempting to stop AMs, and whether following a gradual withdrawal method is associated with success. While much of the existing withdrawal research has focused almost exclusively on those diagnosed with psychotic disorders, in this sample, 35.2% reported having received a bipolar diagnosis, 18.1% a schizophrenia spectrum diagnosis, 26.7% reported other diagnoses only, and 10.5% said they had never received a diagnosis at all. Participants were disproportionately New Zealand European, female, educated beyond high-school, employed, and middle-aged suggesting results may not be readily generalised to all who attempt to discontinue AMs. People with other ethnicities, gender identities, education and employment histories, age groups, and presenting problems may have experiences, needs and approaches that are not captured by the participants in this sample. Notably, older adults, people with intellectual disabilities, children and adolescents are absent from the current group.

4.1 Success and Current Use

Success was defined as achieving the intended goal of stopping the medication, regardless of how long the person stopped for, their current use AMs, whether they relapsed during withdrawal,

or the mental-health outcomes they experienced afterwards, which were explored as separate but related issues. Consistent with the longitudinal research focused primarily on groups who experience psychosis and bipolar disorder (Harrow et al., 2012, Wunderink et al., 2013, Landolt et al., 2016), this study shows that although attempted discontinuation is difficult, some people are successful in their attempts, remain off AMs long-term, and describe improved or unchanged mental health as a result. Among them some describe never returning to AMs again while others stop for prolonged periods and return to AMs when their other strategies prove ineffective or they wish to prevent a relapse at a known time of risk. Of the whole group, 55% described successfully stopping for varying lengths of time, some for more than five years, and half the group reported no current use of AMs at the time they completed the survey.

Participants across diagnostic groups described successfully stopping AMs and reported no current use of AMs while others reported the opposite. The observed differences in success and current use appeared to favour those with bipolar and other diagnoses over those who had received schizophrenia spectrum diagnoses. Approximately two thirds of those with bipolar disorder diagnoses and two thirds of those with other diagnoses only described successfully stopping, compared to 26.3% of those with schizophrenia spectrum diagnoses. This highlights the possibility that people with schizophrenia spectrum diagnoses may face additional challenges in attempting to discontinue AMs, but also shows that difficulty discontinuing can extend to people who take AMs for bipolar disorders and off-label purposes too.

It is impossible to tell whether any such added difficulty is due to factors relating to the diagnoses themselves or the wide variety of other factors that might make the process more or less challenging. For example, prior dose and duration of AM use may affect the profundity of the withdrawal effects people experience (Gilbert et al., 1995, Buchanan et al., 1992). Both dose and pattern of use may differ for people with different diagnoses, for example off-label doses tend to be much smaller than those recommended for the management of psychotic symptoms. In this sample, the time period between starting and stopping AMs was 5-9 years longer for those with schizophrenia spectrum diagnoses than those with bipolar disorder diagnoses or other diagnoses

only. It appears that medication factors may at least partially account for the differences between diagnostic groups observed here.

4.2 Withdrawal method

In this study, people who withdrew gradually across more than a month were significantly more likely than those who withdrew in a month or less to successfully stop AMs, and report no current use. They were also less likely to report experiencing relapse of psychosis or mania during withdrawal, consistent with an earlier meta-analysis that set the threshold for gradual withdrawal at three weeks or more (Viguera et al., 1997), but inconsistent with a more recent meta-analysis using the same three-week definition (Leucht et al., 2012). More research is needed to understand how the speed of reduction might impact the withdrawal effects people observe, and their severity, alongside the variables of traditional interest like dose and duration of use.

Results show that in practice gradual withdrawal methods take place across many weeks, months or years, and can be conceptualised as a staged series of reductions each of which begins with an abrupt shift from one dose to another that might trigger withdrawal effects. The few published resources recommend beginning each step with a 'test reduction' and returning to prior doses if withdrawal effects appear and do not stabilise within days, or cause undue distress to self or others (Breggin, 2013, Hall, 2012, Gupta et al., 2018). Withdrawal effects and the trajectories they follow would likely be influenced by the magnitude and timing of each reduction, the period of delay between them, and the duration of prior continuous use, none of which were explored here. The present investigation reveals wide variation in the practical implementation of self-reported gradual withdrawal and highlights that some people may believe they are following a gradual withdrawal method that is in reality a swift taper which is unlikely to provide them the opportunity to stabilise before the next reduction or adjust their plans as recommended. A range of psycho-social variables may also exert an influence in this process, which we explore further in another article (Larsen-Barr et al., 2018).

Consistent with the only other AM withdrawal study to explore the issue (Salomon et al., 2014), we found consulting a doctor may improve the likelihood that people follow a gradual

withdrawal method. However, as others have found (Salomon et al., 2014), only half the sample consulted a doctor or followed a gradual taper. Interview studies suggest some people are reluctant to disclose their plans to stop and others report feeling pressured to abandon their plans by clinicians when they do seek advice (Roe et al., 2009, Geyt et al., 2016). People may lack information and guidance about implementing gradual withdrawal methods and appear to commonly proceed with an abrupt or swift taper that may increase their risk of relapse and reduce their chances of successfully stopping.

4.3 The effects of withdrawal

Our results support other studies showing withdrawal can be associated with psychotic or manic relapse severe enough to require hospitalisation, alongside a range of physical and emotional effects including suicidality, with a subsequent impact on self-care and daily functioning (Dilsaver and Alessi, 1988, Moncrieff, 2013, Breggin, 2013, Lehman, 2002, Geyt et al., 2016, Salomon and Hamilton, 2013, Roe et al., 2009). Withdrawal symptoms were described by 61.9% of the group but were by no means universal, with a fifth stating they experienced no withdrawal effects at all, similar to the findings of the largest existing qualitative study of discontinuation to date (Salomon and Hamilton, 2013, N=98, Salomon et al., 2014).

Specifically, 27.6% described relapse of psychosis or mania or gave a general description of becoming unwell or hospitalised during withdrawal against a history of psychosis or mania. This translates into 52.4% of those with schizophrenia spectrum diagnoses, consistent with other studies among this population (Gilbert et al., 1995), 17.6% of those with bipolar diagnoses, and 25% of those with other diagnoses only. Those who reported relapse of psychosis or mania during withdrawal were significantly less likely to describe succeeding in their attempt or to have remained off AM at the time of survey completion and more likely to report schizophrenia spectrum diagnoses. Those who described relapse of psychosis or mania but did not have schizophrenia spectrum or bipolar disorder diagnoses all reported psychotic features accompanying their diagnoses or at the time of first prescription. This means those who reported relapse of psychosis or mania during withdrawal appear to have experienced these symptoms before. This is consistent with other claims that the

symptoms of relapse during withdrawal tend to mimic the original symptoms (Moncrieff, Joanna, 2006). A seemingly low rate of relapse among those with bipolar diagnoses is consistent with longitudinal findings suggesting relapse may occur later among this group (Harrow et al., 2012).

Participants who reported emotional withdrawal effects can also be considered to have experienced relapse during withdrawal. When emotional effects are combined with the reports of psychosis and/or mania, 52% of the current sample can be said to report a relapse of previously experienced symptoms during the attempt to withdraw. What appears to be unique to the withdrawal process is the set of physical symptoms that participants described, but not the specific mental health symptoms that appear during the withdrawal process. Our results suggest that if mental health symptoms arise during withdrawal they will likely do so in much the same form as they have in the past. This kind of information may help people predict and prepare to manage what might happen if they attempt to discontinue.

It is not within the scope of this paper to attempt to draw conclusions about whether these returning symptoms are the result of drug mechanisms, the influence of an underlying condition, or both. The presence of physical symptoms, the proximity to withdrawal, and the association between relapse of psychosis and/or mania with gradual withdrawal together lend weight to the argument set forth by others that drug mechanisms may be at least partially involved (Moncrieff, J., 2006, Breggin, 2013, Chouinard, and Jones, 1980, Steiner et al., 1990). While we cannot answer the question of what causes relapse during withdrawal, our results join a body of qualitative research that consistently shows people with lived experience perceive substantial changes in their physical, emotional, and cognitive state during withdrawal from AMs, and that they subjectively associate these changes with the reduction in medication, (Salomon and Hamilton, 2013, Gupta et al., 2018, Moncrieff, J. et al., 2009, Geyt et al., 2016, Roe et al., 2009).

Whatever the cause, the current results show that relapse of prior symptoms is one of several common challenges people might expect to encounter during withdrawal from AMs, and suggest that efforts to improve the safety and success of attempted discontinuation should include strategies to prevent and contain the impact of potential relapse during withdrawal, and beyond.

However, it is important to remember that relapse prevention may not be the service-user's primary recovery goal (Byrne et al., 2010) and efforts to discourage discontinuation in an attempt to prevent relapse may backfire by discouraging people from disclosing plans to stop or from seeking any support with their attempt (Salomon and Hamilton, 2013, Larsen-Barr et al., 2018).

4.4 Limitations

These results are based on a small, non-representative sample that cannot be easily generalised to all who attempt to discontinue AMs. Women, people of New Zealand European ethnicity, and people with tertiary qualifications are over-represented compared to the general population of New Zealand (Statistics New Zealand, 2014). The only other comparable study to date had a much more even gender distribution and very similar findings with respect to the range of withdrawal experiences reported, the proportion who stopped successfully, and gradual withdrawal periods that varied from days to years (Salomon and Hamilton, 2013), which lends some cautious confidence in the current results.

This study explored statistically significant associations between dichotomous variables using tests of independence that are non-directional in nature and cannot speak to the issue of causation. Small sub-groups and uneven subgroup numbers may exert an influence on the associations observed and restrict the power of the results. Chi square tests of independence are based on simple cross-tabulations that do not control for the influence of other co-variants. Other variables may mediate or account for the associations observed here. For example, polypharmacy was common in this group, but it is unknown whether people continued to take additional psychiatric medications during withdrawal from AMs. Dose and partial adherence prior to attempted discontinuation may affect the rates of relapse and success associated with different withdrawal methods and this information was not gathered here. Different AM agents may be more or less difficult to withdraw from than others. Duration of treatment may influence rates of relapse (Gilbert et al., 1995,Buchanan et al., 1992) and the ultimate success of attempts to discontinue but was not explored here. Diagnostic comorbidity and symptom severity were not considered in this investigation and may show a relationship with success where initial symptoms and diagnostic group

did not. Furthermore, diagnostic labels are not always reliable indicators of the specific symptoms people experience and can change over time. In this study several people reported changing diagnoses, never receiving a diagnosis, or receiving multiple conflicting diagnoses.

As with any study employing qualitative methods, these results are subject to the assumptions and biases of the researchers. When analysing open-text responses there is no way of being certain that the researchers' interpretation is true to the participants' intended meaning. For example, we cannot know how people use terms like "mania," "hallucinations," or "unwell", or whether their definitions would match the researchers' definitions. Service-user consultation was sought to minimise this, but it remains an issue that necessitates caution in interpreting the findings.

Finally, this is a self-report study and it is unlikely that every person recalled or was aware of every item of relevance to the research when responding to open-ended questions. For example, subtle withdrawal effects and outcomes pertinent to the study may have been overlooked. Furthermore some people were reporting on attempts that took place many years ago and may have been unable to recall all of the details that were relevant to them at the time, particularly where measures relied on free-recall rather than direct query, as was the case with relapse. Larger studies, using more reliable, standardised measures are needed to test whether the associations observed here hold when controlling for other factors thought to play a role.

4.5 Implications

Taken together these results appear to support the argument for choice and highlight the need for individualised approaches that address the specific challenges faced by different people. The evidence supports the potential for success across diagnostic groups and suggests the method of withdrawal may represent one way people might affect the outcomes of their attempts to stop. Wide variability in how people implemented recommendations to reduce gradually, suggests people expressing a desire to discontinue may benefit from focused clinical guidance in managing the reduction process and that general advice to withdraw slowly may be insufficient. The qualitative data shows discontinuation is not a simple issue of noncompliance or negative attitudes towards medication as much of the literature frames it. Some people who stop will later return to AMs if they

find their alternative strategies and supports to be insufficient or wish to safeguard themselves against relapse during a particularly stressful time. This underscores the potential value of both psycho-social approaches and intermittent medication options for those who attempt to discontinue.

Unfortunately unsuccessful attempts can be marked by adverse outcomes like disrupted relationships and role functioning, hospitalisation, and compulsory treatment. These are high costs to pay for choosing to attempt to manage recovery without AMs. The risk of such high costs further underscores the importance of providing adequate support for, and tools to cope during, withdrawal. Evidence it is possible to stop taking AMs and go on to experience positive outcomes warrants affording people the choice to stop if that is their preference. This necessitates delivering the support and tools needed to make the attempt safely. Prescribing doctors are well-placed to share information about how to implement gradual withdrawal methods that may improve people's chances of success. However, people may commonly avoid consulting their doctors, making it difficult to provide the information and support needed to make the attempt safely and with the greatest chance of success.

Clinicians wishing to support safety may need to actively ask people if they want to stop, and create a trusting therapeutic relationship that will encourage an open reply. Sharing information about how to plan and implement a gradual withdrawal method may help improve rates of success and relapse. However, the magnitude of the associations observed here was small, so withdrawal methods offer only part of the picture at best. The qualitative descriptions and existing research suggest a variety of other medication-related and psycho-social factors are also important to the outcomes of attempts to discontinue AMs. There is a pressing need for more research exploring what resources, strategies, forms of support and environmental factors are most effective in promoting safe, successful withdrawal from AM and how individual needs might differ.

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