Attempting to Stop Antipsychotic Medication: Success, Supports and Efforts to Cope

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Abstract

Purpose: To explore supports and coping strategies used during attempts to discontinue antipsychotic medication and test for associations with success.

Method: 144 people who were taking or had taken antipsychotics completed The Experiences of Antipsychotic Medication Survey. Among them, 105 people had made at least one discontinuation attempt and answered a series of questions about their most recent attempt to stop. Content analysis and chi square tests of independence were used to categorise the data and explore associations. Success was defined as stopping all AM use irrespective of the duration of the medication-free period or whether relapse occurred, which were explored separately.

Results: Among the 105 people who had attempted discontinuation, 61.9% described unwanted withdrawal effects and 27.6% of the group described psychotic or manic relapse during the withdrawal period. Within this group 55% described successfully stopping all AM for varying lengths of time, half reported no current use, and half described having some form of professional, family, friend, and/or service-user or peer support for their attempt. Having support was positively associated with success and negatively associated with both current use, and relapse during withdrawal. A range of coping efforts were described, but having coping strategies failed to show significant associations with any of the dependent variables explored. Among those who described successfully stopping, some described returning to AM for short periods when needed while others reported managing well with alternative methods alone.

Conclusions: Findings cannot be readily generalised due to sampling constraints, but results suggest a wide range of supports and coping strategies may be used when attempting to discontinue antipsychotics. Many people may attempt to discontinue antipsychotics without any support. Those who have support for their attempts may be significantly less likely to relapse during withdrawal and more likely to succeed in their attempt. There is a pressing need for further research in this area.

Keywords: Antipsychotics; Medication Withdrawal Syndromes; Psychoses Substance-Induced; Human Rights; Social Support; Coping Behaviour

Introduction

It is well established that most people who take antipsychotic medication (AM) will attempt to discontinue them [1,2]. In one large sample, 74% had attempted to discontinue within 18 months of treatment initiation [1]. Other studies suggest many who stop eventually resume the medication [3], but that 30%-40% of people remain off antipsychotics long-term [4]. Withdrawal effects can span somatic, cognitive, and emotional domains, and symptomatic relapse is common [5,6], particularly in the first three months following discontinuation [7]. Longitudinal studies show it is possible for some people to stop taking AMs and experience equivalent or better recovery outcomes than those who persist with them, but that it can take several years for these favourable outcomes to appear [4,8,9]. Despite the high risk of relapse during withdrawal and the first years following discontinuation, many people make multiple attempts [3]and appear to persist with their goal to manage without AMs [4].

It is problematic to determine whether relapse during or proximal to discontinuation represents a withdrawal syndrome or the re-emergence of a chronic mental-health problem, or both. Some researchers hypothesise that relapse proximal to withdrawal is the result of neurological adjustments to the removal of, or reduction in, the dopamine blockade, which produce a subsequent surge of excitation [10-13]. Whatever the cause, relapse is a challenge faced by many people who attempt discontinuation.

Relapse prevention is an admirable aim, but qualitative studies suggest service-users prioritise measures of quality of life and daily functioning over the presence or absence of symptoms alone [14]. It has been argued that “although certainly not desirable, a contained relapse is rarely the end of the world” [15, p 898]. Unfortunately, there is a lack of evidence regarding what helps people prevent or contain relapses. Much of the research has focused on clinical and medication factors and as such little is known about how people manage their attempts to stop or whether psycho-social factors like coping and support make a difference to their ability to successfully achieve their intended goal of discontinuing AMs, or prevent relapse during withdrawal.

There are no widely accepted guidelines for safely managing the withdrawal process, though several books and websites have been produced by experienced clinicians and service-user groups that suggest support and coping strategies are important [16-18]. Briefly resuming prior doses during the reduction process has also been described as potentially helpful [16]. This medication-based coping strategy will be referred to as temporary or intermittent use here, and is distinguished from resuming maintenance treatment. A lack of information about what is needed to safely manage withdrawal effects poses practical and ethical considerations for treatment systems aiming to align their practice with the principle of informed consent. It is difficult to freely choose to persist with AMs without knowledge of how to stop them.

Only two, small peer reviewed studies have explored how people cope during withdrawal from AMs. In the more recent of these, 12 people were interviewed about their decision to stop, their experience of attempting to stop, and their decision to resume or not [19]. Thematic analysis highlighted the importance of "weaving a safety net" to support wellbeing. Participants highlighted the value of building alliances with family, friends, and professionals, peer support, practical resources such as written indicators of relapse, access to talking therapy, relaxation skills, healthy lifestyles, access to information resources, and having knowledge of all these things [19].

All twelve reported needing alternative strategies and tools for coping during and after withdrawal. Sometimes a return to AMs was needed when those strategies were not working. This suggests studies seeking to explore how people manage discontinuation need to be designed to capture those who intermittently use AMs to manage when alternative approaches prove insufficient alone and those who successfully stop and later return, alongside those who stop long-term. In the larger of the two studies of subjective AM discontinuation experiences, a survey of 98 people, a similar range of supports and coping strategies were described as being helpful, but 22% described making their attempt in isolation [20,21]. In both studies, a minority of participants were no longer taking AMs, 21% and two people respectively [19,21]. Coping strategies and supports are

clearly experienced as important to those who attempt to stop AMs, though it remains unknown how these affect discontinuation outcomes.

One recent longitudinal discontinuation study found social integration was significantly predictive of improved recovery outcomes among people who had stopped taking AMs, but it is unclear whether those who have support for their attempt are more likely to successfully stop or not [9]. The only study to explore whether coping strategies and having support are associated with AM discontinuation found those who had stopped did not have significantly higher levels of support or use more effective coping strategies compared to those who persisted with AMs at the time they were interviewed [22]. Among the sample of 48 people diagnosed with schizophrenia spectrum disorders, 23 had successfully discontinued AMs. They did not explore the role of coping and support during the withdrawal process, which may represent a critical period in any attempt to discontinue AMs long-term. More research is needed to understand how these important psycho-social variables affect the success of attempts to discontinue AMs.

Method

This investigation aims to explore, with the largest sample to date, how people who attempt AM discontinuation manage during withdrawal and whether the availability of support and their personal efforts to cope are associated with successfully stopping. This study is based on responses to selected questions in *The Experiences of Antipsychotic Medication Survey* concerning people's efforts to manage attempted discontinuation of AMs. The anonymous survey was available for online completion in 2014 [23]. Ethical approval for the study was granted by the University of Auckland Human Participants Ethics Committee.

Participants

The online survey was open to New Zealand adults aged 18 years or older, 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 the 105 people who had made at least one attempt to stop taking AMs were presented with questions about attempted discontinuation, and form the sample of interest in the current investigation.

Instrument

The survey was constructed by adapting the survey used in the *Experiences of Antidepressants Study* [24], 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. Primary symptoms at first AM prescription were assessed via a check-list of major symptoms (hallucinations, delusions, mania, and depression) with the opportunity to specify others. Categories were collapsed to show how many people experienced the hallmark symptoms of psychosis or mania prior to starting AMs. Diagnosis was queried but responses did not provide sufficiently reliable information for further analysis and are not reported.

Withdrawal methods were assessed using a sequence of questions that allowed for the verification of participants' self-reported use of a gradual method, where only those who described reducing across more than one month were categorised as following a gradual withdrawal method.

Coping efforts, support and the outcome of the attempt were evaluated with open-ended questions asking, 'what did you do to cope with the unwanted effects of withdrawing from the medication?', 'what support did you have for your attempt to stop taking antipsychotic medication?', and 'what was the outcome of your most recent attempt to stop taking AMs?' Success was evaluated by analysing outcome descriptions for references to stopping or resuming AM use.

Multiple choice questions assessed the length of time participants remained AM-free, current use of AMs (‘are you still taking oral antipsychotic medication?’), doctor consultation, whether any other advanced preparations were made, and whether they intermittently used the AM to cope during withdrawal. A multiple choice question from the medication experiences section of the survey asked participants to select when they had most recently taken AMs (response options ranging from ‘current use’ to ‘more than five years ago’). This item was designed to gauge the historic nature of medication experiences being reported, but was here used to provide further detail on the length of time participants discontinued AM for.

Relapse during withdrawal was not directly queried in the survey and was assessed by analysing responses to the open questions about the effect of withdrawing from AMs (‘what were the effects of withdrawing from the medication?’) and the outcome of the attempt.

Data Analysis

Content analysis was used to categorise descriptions of the coping strategies people used, the support they had for their attempt, withdrawal effects, experiences of relapse during withdrawal, and the subjective success of their attempt. Coding was checked for reliability by two independent raters who used a written coding protocol to review and code 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 a simple agreement rate of 96.7%.

A deductive procedure was used to identify success, where those who described resuming AMs when asked about the outcome of their attempt were deemed unsuccessful and those who described stopping without resuming AMs soon after were categorised as successful, regardless of whether they were currently taking AMs or not, the length of time they remained off AMs, or whether they relapsed during the process or not, all of which were queried separately. Therefore, success should be read as a measure of whether people initially stopped taking AMs successfully, while current use provides a supplementary measure of whether they had sustained that result at

the time of survey completion, which is more directly comparable to other measures of success used in the existing studies [19,21,22].

A similar deductive analysis was used to assess relapse during withdrawal. Relapse was defined as the emergence or re-emergence of psychotic or manic symptoms during or proximal to withdrawal, and was inferred from participant descriptions of withdrawal effects and discontinuation outcomes that directly referred to psychosis or mania, detailed symptoms of psychosis or mania, or explicitly referred to "relapse," "getting unwell" or "hospitalisation" against a prior history of psychosis and/or mania. Psychotic symptoms were defined as voices and other hallucinations or perceptual disturbances, delusions and other unusual beliefs, and/or racing thoughts indicative of thought disorder. Mania was defined as a description of expansive mood, reduced need for sleep, uncharacteristic striving behaviour, and failure to meet a sufficient standard of self-care. References to relapse that occurred years after the withdrawal process were left uncoded. We use the term 'withdrawal during relapse' to emphasise that this measure of relapse is specific to the withdrawal period and does not include all experiences of relapse over time.

Content analysis was used to categorise the availability of support and the level, sources and forms of support people reported. A code of no support was only assigned to participants who explicitly stated that support was not available to them. Each coping strategy participants described using during withdrawal was identified, similar strategies were grouped together and labelled accordingly. Those who explicitly described having no coping strategies were coded into a zero strategies group. For the purposes of statistical analysis, participants were then dichotomised into sub-groups distinguishing those who described having coping strategies from those who reported having no strategies or did not describe strategies. The methods used to assess relapse and dichotomise coping during withdrawal mean there is a high chance of false negatives and these results should be interpreted with particular caution.

Pearson's Chi Square tests were used to explore whether coping and support were associated with initial success (0 unsuccessful resumed, 1 successful stopped) and current use of

AMs (0 no current use, 1 current use). Two-by-two cross-tabulations were conducted for each of the independent variables of interest: consulting a doctor (0 No, 1 Yes), making preparations (0 No, 1 Yes), having support (0 No, 1 Yes), intermittent use of AMs to cope during withdrawal (0 No, 1 Yes), use of any coping strategies excluding substance-use (0 No, 1 Yes) and use of personal thought- or behaviour-based coping strategies during withdrawal (0 No, 1 Yes). Follow-up analyses were carried out to evaluate associations with relapse during withdrawal (0 No, 1 Yes). To ensure groups were exhaustive, participants with missing data were excluded from the statistical analyses. Those who reported being in progress with their attempts to stop were excluded from statistical analyses. No cross-tabulations contained cells with expected counts below five, and the data met the assumptions required for Chi Square.

Results

Participants

The participants were 105 New Zealand adults who had taken AMs for more than three months and had made at least one attempt to stop. The majority of the group was female, employed in paid or unpaid, part-time or full-time work or study, and of New Zealand European ethnicity (Table 1). Most participants reported taking other psychiatric medications alongside their most recent AM, and it is unknown when or if these medications were also discontinued.

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

Participant characteristics	**Count**	**(%)**	**Participant characteristics**	**Count**	**(%)**
Gender			**Age of Primary Symptom Onset**		
Female	78	(74.3%)	Under 18 Years	45	(48.9%)
Male	25	(23.8%)	18-29 Years	28	(30.4%)
Gender Diverse	2	(1.9%)	30-39 Years	11	(12.0%)
Ethnicity			40-49 Years	4	(4.3%)
NZ-European	88	(83.8%)	50-65 Years	4	(4.3%)
Maori or Part Maori	9	(8.6%)	**Age First Started AMs (mean 29 yrs; range 12-63 yrs)**		
Other	8	(7.6%)	Under 18 Years	15	(14.4%)
Current age (mean 41 yrs; range 18-70 yrs)			18-29 Years	47	(45.2%)
18-29 years	25	(23.8%)	30-39 Years	23	(22.1%)
30-39 years	25	(23.8%)	40-49 Years	12	(11.5%)
40-49 years	22	(21.0%)	50-65 Years	7	(6.7%)
50-59 years	23	(21.9%)	**Most recent or current AM type(s)**		
60-70 years	10	(9.5%)	Typical AM Only	9	(8.8%)
Occupational Status			Atypical AM Only	90	(88.2%)
Not Employed	21	(20.0%)	Both Typical and Atypical AM	3	(2.9%)
Yes Employed	84	(80.0%)	**Polypharmacy – multiple simultaneous psych meds**		
Highest level of education			No polypharmacy single oral AM only	22	(21.0%)

Did not complete high school	6	(5.7%)	Yes Polypharmacy	76	(72.4%)
Completed high school	10	(9.5%)	**Age at Last Attempt to Stop (mean 36 yrs; range 16-70 yrs)**		
Diploma/cert. after high school	37	(35.2%)	Under 18 years	1	(1.0%)
University degree	52	(49.5%)	18-29 years	35	(34.3%)
Hallmark Symptoms of Bipolar or Psychosis			30-39 years	27	(26.5%)
Yes	84	(80.0%)	40-49 years	22	(21.6%)
No	21	(20.0%)	50-70 years	17	(16.7%)

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.

Initial Success and Current Use

When asked about the outcome of their most recent attempt to discontinue AMs, 55% of participants described stopping all AM use for some period of time and were coded into the Successful group. As shown in Table 2, at the time they completed the survey, 50.5% of the sample reported no current use of AMs, and 51.4% reported remaining off AMs for more than one year, and 26.8% reported remaining off AMs for less than a month. While not the focus of this article, the qualitative outcome descriptions revealed some participants who successfully stopped periodically resumed AM use when their alternative approaches were proving insufficient alone. Those who described successfully stopping referred to improved or unchanged wellbeing, but the majority of those who described being unsuccessful in their attempts described a range of negative outcomes such as hospitalisation, increased suicidality, disrupted employment and relationships, and compulsory treatment orders.

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

Responses	**Total (% n=105)**
Consulted a Dr	51 (48.6%)
Made Other Advanced Preparations	64 (61.0%)
Had Support	52 (49.5%)
Intermittent AM Use to Cope	34 (32.4%)
Withdrawal Method [a]	
Abrupt or swift withdrawal across one month or less	58 (55.2%)
Gradual withdrawal across more than one month	34 (32.4%)
Multiple Attempts	
First attempt to stop	37 (35.2%)
Previous attempts to stop	67 (63.8%)
Relapse during Withdrawal (Psychosis, Mania and/or Hospitalisation) [b]	
Yes, Described Relapse	29 (27.6%)
No, Did Not Describe Relapse	68 (54.8%)
Success	
Stopped – Successful	58 (55.2%)
Resumed – Unsuccessful	37 (35.2%)
In Progress or Uncoded	10 (9.5%)
Time off AMs	
< 1 month	28 (26.8%)

1 – 6 months	16 (15.2%)
6 – 12 months	7 (6.7%)
More than a year	54 (51.4%)
Current AM Use	
Yes Current Use of AMs	52 (49.5%)
No Current Use of AMs	53 (50.5%)

Withdrawal methods, doctor consultation, intermittent use of AMs to cope during withdrawal, time off AMs, success, and current AM use for the whole sample (n=105). (a) Excludes those who selected 'Do Not Remember' from the multiple-choice options or described not knowing how long they took to withdraw; (b) Participants who described relapse of psychosis, mania or hospitalisation as effects or outcomes of their attempt to withdraw from AMs were coded into the Relapse group. Those who described other effects and outcomes but did not describe relapse of psychosis, mania or hospitalisation were coded into the No Relapse Described group. Eight participants gave ambiguous responses that were left uncoded and total does not sum to 100%.

As shown in Table 3, among those who were currently taking AMs (and were not still in progress with their attempts; n=48), 14.6% reported remaining off AMs for over a year (n=7), 4.2% for six to twelve months (n=2), 29.2% for one to six months (n=14) and 52.1% reported having remained off AMs for less than one month (n=25). Among those who were not currently taking AMs at the time they completed the survey (n=53), 88.7% reported having remained off AMs for over a year (n=47), 7.5% for six to twelve months (n=4), and 3.8% for one to six months (n=2). No-one in this group reported remaining off AMs for less than one month. Of those who stopped for more than a year and reported no current use (n=47), 42.6% had most recently used AM more than five years ago (n=20), 21.3% three to five years ago (n=10), 29.8% had most recently used AM one to two years ago (n=14) and 6.4% reported most recently using AMs within the last year (n=3).

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

	Relapse		**Success**		**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
Gender						
Female (n=75)	51	18	24	49	42	33
Male (n=24)	12	10	12	9	10	14
Other (n=2)	1	1	1	0	1	1
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 [a]						
No (n=21)	14	5	9	11	12	9
Yes (n=80)	50	24	28	47	41	39
Consulted a Doctor [a]						
No (n=53)	27*	21*	22	26	25	28
Yes (n=48)	37*	8*	15	32	28	20
Made Other Preparations [a]						
No (n=29)	17	9	12	16	16	13
Yes (n=60)	41	16	19	37	33	27

Had Support [a]						
No (n=52)	25*	21*	25*	24*	21*	31*
Yes (n=49)	39*	8*	12*	34*	32*	17*
Described 1> Coping Strategies [a]						
No (n=46)	26	16	20	23	20	23
Yes (n=54)	38	12	16	35	20	21
Intermittent Use During Withdrawal [a]						
No (n=69)	51*	11*	14*	50*	45*	24*
Yes (n=32)	13*	18*	23*	8*	8*	24*
Time Off AMs						
< 1 month (n=25)	9	15	24	1	0	25
1 – 6 months (n=16)	7	9	11	2	2	14
6 – 12 months (n=6)	5	0	1	4	4	2
More than a year (n=54)	43	5	1	51	47	7

This table presents the distribution of the data across the three outcome groups of interest, self-reported relapse during withdrawal, success of the attempt, 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) Two-by-two Pearson Chi Square Tests of Independence were conducted for all dichotomous, categorical variables displayed here.
* Statistically significant difference; all p values < 0.05.

Experiences of Withdrawal

Details of the participants' most recent attempt to discontinue AMs and rates of success they reported are summarised in Table 2. When asked about the effects of withdrawal, 61.9% reported experiencing unwanted withdrawal effects across the full-range of physical, emotional, cognitive, and functional domains. Relapse in the form of psychosis, mania, or hospitalisation was described by 27.6% of the group at the time of withdrawal. Within the physical domain, 21.0% described insomnia or disturbed sleep. Within the emotional domain, a small group of five people reported suicidal thoughts, urges and/or acts. Additionally, 2.9% of the group specified that the negative withdrawal effects were short-lived for them, 18.1% specified they experienced zero withdrawal effects, and 13.3% reported only positive withdrawal effects, including improvements in cognitive clarity and energy levels.

The Availability of Support

Half the group (49.5%) reported some form of support from at least one professional, family member, friend, or other social contact. Specific sources of support included family members and spouses (n=22), prescribers (n=13), friends and colleagues (n=9), social workers, nurses and case-workers (n=4), therapists and counsellors (n=9), peer support groups and online networks (n=4),

mental-health services in general (n=4), and a range of others (n=5) including telephone help lines for example:

"Support of long-term therapist, doctor (GP) and others was essential."

"*Support from wife to encourage walking, breathing, healthy eating, re-framing negative experiences and visualising a positive future."*

"*Family supported me by allowing me to stay with them, helped me with cooking, encouraging me to exercise, reassuring me.*"

"*I joined an internet support group which gave me confidence that there were others like me […] They were peers that I could talk to, receive encouragement from, and I could encourage them too."*

The level of support described varied, with only one source of support reported by 14.3% (n=15) of the sample, two supports reported by 21.9% (n=23), and 9.5% describing three or more sources of support (n=10). Some described personal barriers to seeking help from their available supports, or having to convince people to support them in their efforts. Half of the group (50.5%) reported feeling they had no support for their attempt; some kept their attempt a secret to avoid discouraging reactions from others or faced barriers to help-seeking.

"*No support, just decided to do it on my own. [I] thought others would advise against this*."

"People in my life knew that it was my plan, but I was too proud to ask for help [...]"

Several forms of support were described. These were encouragement, validation and reassurance (n=9), someone to talk to about the experience (n=5), the provision of somewhere to stay (n=4), support with activities of daily living (n=3), information to understand withdrawal (n=3), assistance with self-monitoring (n=2), support to use healthy coping strategies (n=2) and access to other medications to take as needed (n=1).

Supports were reported by 58.6% of the 58 who described successfully stopping AMs and 32.4% of the 37 who resumed. Results of Pearson's Chi Square Test showed support held a small but significant positive association with success (phi=.256, p=.013, n=95) and a small but significant

negative association with current use (phi=-.249, p=.012, n=101). Table 3 shows those who had support were more likely to describe successfully stopping and less likely to report current use of AMs. There was a significant, negative association of moderate magnitude between support and relapse of psychosis or mania during withdrawal (phi=-.309, p=.003, n=93). People who had support reported psychotic or manic relapse during withdrawal significantly less often than those without support.

Preparing to Stop

Almost half the group (48.5%) reported consulting a doctor in preparation of their attempt (Table 2). Nearly two thirds indicated making other advanced preparations, listed in Table 4. Consulting a doctor showed no significant association with success, or current use, but did show a small, significant negative association with relapse during withdrawal (phi=-.280, p=.007, n=93). Making any other preparations showed no significant association with success, current use, or relapse during withdrawal.

Table 4 *Advanced Preparations for Most Recent Attempt to Discontinue AMs*

Response Options	**Total (%) n=105**
Gathering information about withdrawal	33 (31.4%)
Informing family, partner or spouse of plans to stop and support needs	33 (31.4%)
Making a plan for gradual withdrawal before making any changes	32 (30.4%)
Establishing a stable, regular daily routine	25 (23.8%)
Reducing environmental stressors	24 (22.9%)
Establishing a regular sleeping pattern	19 (18.1%)
Seeing a counsellor, psychologist or psychotherapist	18 (17.1%)
Informing friends of plans to stop and support needs	17 (16.2%)
Creating a formal advanced directive	14 (13.3%)
Stopping or reducing use of illicit drugs	13 (8.6%)
Taking time off work or study	9 (8.6%)
Learning meditation	7 (6.7%)
Arranging a safe, quiet place to go in case the need arose	7 (6.7%)
Stopping or reducing use of alcohol	5 (4.8%)
Joining a support group	3 (2.9%)

Those who reported making advanced preparations (61%) were asked to select from a check-list all of the advanced preparations they made for their most recent attempt to stop (additional to consulting a doctor which was queried separately first). Percentages are expressed as a proportion of the total sample of 105.

Intermittent Use during Withdrawal

Approximately one third (32.4%) reported intermittent use of AMs to manage the effects of withdrawal. There was a large, significant negative association between intermittent use to cope

during withdrawal and success (phi=-.503, p=.000, n=95) and moderate, positive associations with both relapse during withdrawal (phi=.410, p=.000, n=93), and current use (phi=.375, p=.000 n=101).

Coping Strategies Used during Withdrawal

Most people (75.2%) provided a description of their use of coping strategies. These are detailed in Table 5. Around a sixth of the sample (17.1%) described using no coping strategies, including seven who reported experiencing negative withdrawal effects, four who reported positive withdrawal effects, seven who reported zero withdrawal effects, and one who could not recall the withdrawal effects they experienced. In addition, 30.5% (n=32) named one coping strategy, 17.1% (n=18) named two to three strategies, and 4.8% (n=5) named four or more coping efforts together (range 0-7).

Table 5 *Coping Strategies Used During Withdrawal* [a]

Content categories	**Total (%) n=105**
Personal Strategies	38 (36.2%)
- Psychological Strategies	37 (35.2%)
- Health Behaviours	12 (11.4%)
Nothing or No Coping Strategies [b]	18 (17.1%)
Support Strategies	13 (12.4%)
Medication Strategies	9 (8.6%
Environmental Strategies	8 (7.6%)
Substance Use Strategies	8 (7.6%)
Other	4 (3.8%)
Do Not Remember	4 (3.8%)
Uncoded	22 (21.0%)

This table presents (a) the full list of major content categories referenced in participant descriptions of coping during withdrawal, and (b) Nothing or No Coping Strategies includes those who did and did not experience withdrawal effects.

Personal Strategies were defined as the use of thought-based and/or behaviour-based activities for managing withdrawal experiences. Within this category, one group of responses described health behaviours (n=12) and comprised exercise and walking (n=8), eating well and drinking water (n=4), and one reference to taking supplements.

A second group of responses described the use of psychological strategies (n=37) aimed at curbing the difficult aspects of the process, including activities for self-care and comfort (n=14), attitudinal factors of determination, willpower and perseverance (n=9), distraction (n=7), meditation, mindful breathing and prayer (n=6), routine and living life (n=5), therapy techniques

(n=3), and self-expression (n=3). Activities for Self-Care and Comfort comprised Getting Extra Rest (n=9), Showers and Baths (n=3), Herbal Teas (n=2), Heat Bags (n=1), Personal Grooming (n=1) and Sleep Hygiene (n=1).

"*Had lots of baths. Cried. Created. Prayed. Psychology appts. Ate well. Held on for dear life.*"

"*Holding on to the hope that things will get better and these are only side effects from the medication withdrawal.*"

Medication strategies were defined as the use of a medicine, pill or tablet to curb unwanted withdrawal effects; this could include temporary or intermittent use of the AM agent that was the target of the withdrawal attempt. This is distinguished from resuming maintenance treatment with AMs, which was considered an outcome statement about success and was not coded as a coping attempt. A few participants described intermittent Benzodiazepine Use (n=3/105; 2.9%) and Pain Relief (n=3/105; 2.9%). One participant noted using Antihistamines for itches (1%), two people reported the use of Sleeping Pills (1.9%), and two described using low-dose AMs on an as-needed basis (1.9%).

Environmental strategies involved the use of environmental-modification or stimulus control as a method for managing the effects of withdrawal. Participants described Creating a Safe, Low-Stress Environment (n=5/105; 4.8%), and Avoiding Stressful Environments (n=4/105; 3.8%), for example:

"[I] made sure I was in a safe place with people who loved me"

"*Avoided going into public places*"

Support strategies referred to using support from Therapists and Counsellors (n=6/105; 5.7%), Psychiatrists or Doctors (n=3/105; 2.9%), Family or Spouse (n=3/105; 2.9%) and Other Supports (n=2/105; 1.9%) including one reference to Support Groups and one nonspecific report of 'others'. Family or Spouse support strategies referred to talking and communication, staying with family and having a sense of connection with loved ones. Substance-Use Strategies comprised

Drinking Alcohol (n=3/105; 2.9%), Smoking Cigarettes (n=3/105; 2.9%) and Taking Drugs (n=3/105; 2.9%), for example:

"*Whatever I felt was needed, smoked a bit of weed*".

Within the 'other' category two participants reported coping with AM withdrawal effects via self-harm and/or suicidal behaviour.

As seen in Table 3, grouping personal, environmental, support, and medication strategies together to reflect the use of any coping strategies, and excluding those who reported coping via substance-use, failed to show statistically significant associations with success (p=.133), current use (p=.078), or relapse during withdrawal (p=.143). Only the use of personal coping strategies was individually explored for statistical associations with the chosen measures of success. There were no significant associations between the use of personal coping strategies (health behaviours and psychological strategies) and success (p=0.054), current use (p=0.330), or relapse during withdrawal (p=.291).

Discussion

This cross-sectional survey of 105 people's most recent attempts to stop taking AMs represents only the third, and largest, study to date that specifically explores the way people manage attempted discontinuation of AMs, and how those efforts affect the success of their attempts. Participants were disproportionately New Zealand European, female, educated beyond high-school, and employed, suggesting results may not be readily generalised to all who attempt to discontinue AMs.

Support and coping appear potentially relevant to people across ethnic groups, gender identities, levels of education, and employment status, but it is important to keep in mind that these groups may have different needs and approaches that are not captured by participants in this sample. A comparable study with a similar sample size and a much more even gender distribution had very similar qualitative findings [20], which lends some tentative confidence to the current results.

Success and current use

In this sample, 55% had successfully stopped AMs for varying periods of time, and 50.5% were not taking AMs at the time they completed the survey. This is similar to the only other comparable qualitative study [21], though naturalistic studies report lower rates of success between 30-40% at long-term follow-up [4]. The majority of those who stopped successfully and had no current use reported remaining off AMs for over a year, while 37.7% of those with no current use had most recently used AMs more than five years ago. A small minority among those who were successful and reported no current use (n=6) had only recently stopped within the past six months, and the literature suggests a strong likelihood that at least some of these people will relapse and resume AMs for at least a short time in the future [4,9]. The literature also suggests that among those who were unsuccessful some will likely make repeat attempts to discontinue [20] and that some of them may succeed [3].

Withdrawal experiences

Most of the group experienced unwanted withdrawal effects during the period of reduction, consistent with the literature [20], but only 27.6% described experiences that met criteria for relapse during withdrawal. This is substantially less than the 50%-77% rates reported in meta-analyses of randomised controlled trials [25,26]. This is likely because the rate reported here refers to relapse within the withdrawal period only, and does not include relapses that occurred in the initial years following discontinuation. The use of definitions requiring varying thresholds of severity may also partially explain this difference; when our definition of relapse during withdrawal was expanded to include those who reported lesser forms of symptom exacerbation during withdrawal the figure increased to an equivalent 52%. It is unknown whether the relapse events described here result from the mechanisms of withdrawal, the re-emergence of a mental-health condition or an interaction with other factors like unrelated stressful events, and it is not within the scope of this investigation to explore this debate. Regardless of their cause, in this group, descriptions of

symptom exacerbation and relapse during the withdrawal period were common difficulties that participants had to face as part of their attempt to discontinue.

Support for Attempted Discontinuation

Half of the sample reported having support for their attempt to stop. Perhaps the most important finding is a small but significant association between support and both successfully stopping AMs and maintaining discontinuation. Those who had support were more likely to describe successfully stopping, and less likely to report current use of AMs at the time they completed the survey, suggesting that having support for attempted discontinuation may improve the likelihood of successfully stopping. However, it is also possible that other unmeasured variables, of which there are many, may account for the associations observed here. The qualitative data suggests having support provides a source of encouragement and hope alongside practical assistance with daily living, employing healthy coping strategies, and managing the reduction process. A significant negative association between support and relapse during withdrawal strengthens the conclusion that having support may improve the likelihood of success and is consistent with the results of research showing social integration is a predictor of improved functional recovery outcomes following discontinuation [9].

Discontinuation outcomes are often conceptualised as simple by-products of medication-factors, diagnostic prognosis, and the withdrawal method used to manage the taper. In this group, discontinuation outcomes are also associated with having support for the attempt from other people. This suggests that overtly providing support to people who would like to stop AMs may improve their chances of success. It has been said that people seeking to recover from severe mental-health problems like psychosis “need the encouragement and support of an ally and an advocate, rather than the distanced and dispassionate insights of a neutral observer” [27, p 108]. This also appears to be true for people who take AMs and would prefer to stop. The associations observed here were statistically small in magnitude, but qualitatively important. Of course the effectiveness of any support relationship rests on interactions between environmental

opportunities, and multiple people, who each may be more or less able to give or receive support as it is needed during withdrawal or in the event of relapse.

In line with other studies [19-21,28], the current investigation suggests people may frequently make their attempts with little to no support, and may deliberately withholding information about their attempt from prescribers and family members in fear of receiving discouraging responses, similar to the results of other studies [19,20,29]. The current results suggest this may hinder their chances of successfully discontinuing. Having support was associated with reduced relapse during withdrawal, and may help reduce the risks associated with attempting discontinuation. Given that it was possible for many to stop long-term (51% of the sample stopped for over one year) and maintain wellbeing without AMs, the current results strongly support the arguments made by other researchers [16,30-32], consumer rights legislation [33], and the service-user movement [34-37], that people should have the choice to take AMs or not take them, the choice to change their minds later, and all the information and resources required to make choices that are safe and have the best possible outcome for their recovery.

Efforts to Manage Withdrawal Effects

Efforts to manage withdrawal began well before the withdrawal process for many people, with half consulting a doctor and most making other advanced preparations for their attempt. Around a third of the sample reported brief intermittent use of AMs during withdrawal and some described intermittent use as one of the ways they coped after successful discontinuation when their other efforts were proving ineffective. Intermittent use of AMs to cope with the effects of withdrawal was significantly associated with relapse during withdrawal and resuming maintenance treatment with AMs. It seems unlikely that intermittent use caused greater rates of relapse. Those who intermittently returned to previous doses during withdrawal potentially did so because they were already experiencing relapse. Other authors have suggested briefly returning to a previous dose may help prevent relapse from resulting in hospitalisation [16,19]. Intermittent use during

withdrawal may help curb the negative consequences of an unsuccessful attempt, but in this group did not prevent relapse or improve the likelihood of successful discontinuation.

Results did not support statistically significant relationships between successful discontinuation or current use and consulting a doctor, making other advanced preparations, or use of coping strategies during withdrawal. Though they do not here share direct associations with success and relapse, these efforts to manage may yet be associated with other unmeasured outcomes like the degree of distress experienced. In addition, the nature of the coping strategies people used, the preparations they made, and the guidance they received as a result of efforts to consult a doctor may be more influential than whether any effort was made at all. For instance, avoidant and active or approach-focused coping strategies have been shown to have different effects on a range of measures of wellbeing when they are used habitually [38], and to bear divergent predictive relationships with QOL, both among those who take AMs and those who have stopped taking them [23]. People in this study described using a range of active, or approach-focused, coping strategies involved in self-care, self-soothing, expression, physical health, and help-seeking, as well as a range of avoidant coping strategies such as distraction, and isolation, which would conceivably have quite different effects on their internal experiences and the consequences of the withdrawal effects they face. There is a pressing need for further research in this area.

Limitations

The survey involved a relatively small sample, with demographic characteristics that differ from the general NZ population and other existing studies [9,19,20]. People residing within inpatient units and those without internet access were unable to participate. The sample was predominantly educated and employed. An over-representation of women and people of NZ-European ethnicity means results may neglect areas of specific relevance to men, people with other gender identities, and those from other ethnic groups. We have attempted to explore whether there are any differences in the attempts of those who successfully stopped and those who resumed. However, the results may be affected by the small sample size and sub-groups within it.

Interpretation of the results of statistical tests based on results obtained via content analysis is made fraught by the strong possibility that people neglected to mention topics of relevance when responding to open-ended questions, particularly with regard to relapse during withdrawal, which was not queried directly, and coping behaviours which are often carried out automatically without awareness of the decision to act in one way or another. Tests of statistical association were based on simple two-by-two cross-tabulations and other variables may account for the associations observed here. More research is needed to explore whether associations between support and successful AM discontinuation hold when other variables like withdrawal method and medication factors are taken into consideration.

Those who reported successfully stopping and no current use had remained AM-free for variable periods of time, including those who had last used AMs more than five years ago, and those who had last used them less than a year ago. Associations reported here do not speak to how long people were able to remain AM free.

This study lacked measures for symptom severity, diagnostic factors, AM dose, duration of continuous treatment, continuing use of other medications during or after AM withdrawal, and contextual stressors, which may also affect the success of attempted discontinuation. Polypharmacy was common in this group, but it is unknown whether people continued to take additional psychiatric medications during withdrawal from AMs.

Further research with larger samples, standardised measures, and control variables are required to more systematically explore how people cope during withdrawal, and what forms of support, consultation, advanced preparations and coping methods variously help and hinder people's chances of success. There is a need to extend the research to consider the impact of contextual stressors and internal resources known to affect mental health. This study suggests AM discontinuation outcomes may be affected by people's support networks and highlights the important role that connection with encouraging others can play in the safety and success of efforts to discontinue AMs. Improving support for AM discontinuation may enable people to attempt

withdrawal more safely and with a greater likelihood of success. Individual outcomes and efforts to manage may vary, but they do not appear to rest entirely on the individual alone.

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