

Discontinuing Psychiatric Medications: A Survey of Long-Term Users

Laysha Ostrow, Ph.D., M.P.P., Lauren Jessell, L.M.S.W., Manton Hurd, M.S.N., P.M.H.N.P., Sabrina M. Darrow, Ph.D., David Cohen, Ph.D., M.S.W.

Objective: Individuals undergoing long-term psychiatric treatment frequently choose to stop taking psychiatric medications. To enhance service user choice and prevent undesirable outcomes, this first U.S. survey of a large sample of longer-term users sought to increase knowledge about users' experience of medication discontinuation.

Methods: A sample of 250 U.S. adults with a diagnosis of serious mental illness and a recent goal to stop up to two prescribed psychiatric medications, which they had taken for at least nine months, completed a web-based survey about experiences, strategies, and supports during discontinuation.

Results: About half (54%) met their goal of completely discontinuing one or more medications; 46% reported another outcome (use was reduced, use increased, or use stayed the same). Concerns about medications' effects (for example, long-term effects and side effects) prompted the decision to

discontinue for 74% of respondents. They used various strategies to cope with withdrawal symptoms, which 54% rated as severe. Self-education and contact with friends and with others who had discontinued or reduced medications were most frequently cited as helpful. Although more than half rated the initial medication decision with prescribers as largely collaborative, only 45% rated prescribers as helpful during discontinuation. Of respondents who completely discontinued, 82% were satisfied with their decision.

Conclusions: Discontinuing psychiatric medication appears to be a complicated and difficult process, although most respondents reported satisfaction with their decision. Future research should guide health care systems and providers to better support patient choice and self-determination regarding the use and discontinuation of psychiatric medication.

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Use of psychiatric medications is one of the largest drivers of mental health treatment expenditures in the United States, with over 16% of adults filling such a prescription in 2013 (1). Although use of psychiatric medications has increased in the past few decades, no clear guidelines exist about when to attempt medication discontinuation, which may lead some people to take medications longer than necessary (2). In practice, many individuals discontinue use at some point in treatment (3,4), and effective treatment decisions should include information on the risks and benefits of using or not using medications, as well as the option to discontinue.

Although most research on medication management has implicitly taken adherence to prescribed regimen as the norm, work is needed to fill the knowledge gap on how to support people when they choose to discontinue. Such information not only could limit risks associated with long-term use but also would align with principles emphasizing service user choice and self-determination (5,6), which have been associated with improved outcomes and treatment engagement (7). Because individuals frequently choose to stop taking psychiatric medication (3,4), service users, their

families, and providers must have the information they need to maximize safety during discontinuation while avoiding treatment dropout and isolation.

Previous studies of individuals who discontinue medication are generally limited to a single class of medication (3,5,6), with most participants using medication for less than six months (2). Landmark clinical trials of psychiatric drug treatments for psychosis, depression, and bipolar disorder have found discontinuation rates as high as 74% (8–10). Moreover, withdrawal symptoms can occur after abrupt or gradual discontinuation of major psychiatric drugs (6,11–13). A few studies have asked service users about experiences of discontinuation. Some service users have reported physical and emotional disturbances during discontinuation, and some have reported receiving little help from medical providers during the process. Overall, little is known about why and how users experience and cope with discontinuation, and especially about what they find helpful during the process.

This article presents findings from a survey of U.S. adults who had a goal to completely stop taking up to two

prescribed psychiatric medications that they had taken for at least nine months. The survey aimed to expand knowledge of individuals' experiences, strategies, and supports as they attempted to meet their goal, regardless of whether they achieved it, and to document effects that they judged to result from stopping psychiatric medications. Although experiences are likely to differ somewhat by medication class, we aimed in this initial study to capture the real-world context in which individuals may use or discontinue one or more medications simultaneously.

This study represents the first of its kind in the United States and was led by current and former users of psychiatric medications with professional training in research and clinical practice. Such unique expertise has the potential to enhance each stage of the research process and to open new lines of inquiry, as demonstrated by the aims of this study (14,15). Research on this topic is necessary for public health systems and private providers to improve the quality of person-centered care and promote self-determination.

METHODS

Recruitment and Sample

People who had taken psychiatric medication for more than nine months and had discontinued or attempted to discontinue were the target population (16). Most researchers on the team, who identified as members of the target population, pooled their networks and sent recruitment flyers and social media announcements to electronic mailing lists, mental health agencies, university-based counseling and wellness centers, advocacy organizations, former and current service users, and service providers across the United States. Data were collected in June 2016 by using an anonymous Qualtrics (17) online survey.

In all, 742 individuals accessed the survey. Of these, 250 met all inclusion criteria prespecified for the study: over age 18; received a lifetime psychiatric diagnosis of schizophrenia, schizoaffective disorder, schizophreniform disorder, psychosis not otherwise specified (NOS), bipolar disorder I, bipolar disorder II, bipolar disorder NOS, or major depressive disorder; took prescribed psychiatric medications in one of five classes (antidepressants, anti-anxiety medications, antipsychotics, mood stabilizers, and stimulants) for more than nine months in the past five years; and had a goal to completely discontinue one or two of these medications and had attempted to do so. Taking three or more drugs simultaneously was seen as a complicating factor, potentially increasing recall bias and complicating attribution of discontinuation reasons and of withdrawal effects, as well as lengthening the questionnaire. Thus it was decided in advance to exclude respondents who indicated that they had attempted to discontinue more than two medications. Among those who accessed the survey, this was the most common exclusion criterion, affecting 248 individuals. [A CONSORT diagram of participant recruitment is included in an online supplement to this article.]

Survey Instrument

Our survey instrument was designed on the basis of previous research (6,18,19), clinical tools (20–24), and the study collaborators' expertise as clinicians, researchers, and service users. After pilot testing with 15 members of the target population (six of whom met inclusion criteria), 105 closed-ended questions (with skip patterns) were retained in the instrument, including an obligatory six-question inclusion screen that determined whether a respondent could proceed to the remaining sections pertaining to current medication status, motivations and strategies for discontinuation, withdrawal effects, social supports, relationships with providers, psychiatric treatment history, health status, and sociodemographic factors. Approximately ten open-ended questions were also included to complement various sections, but those answers are not reported in this article.

Analyses

Stata 13 was used to conduct descriptive statistical analyses (25). Numbers and percentages of valid (nonmissing) responses are reported for key variables, along with the number of item nonresponses.

RESULTS

Sociodemographic and Clinical Characteristics

Table 1 presents data on characteristics of the 250 adults who participated. The sample was largely female and middle-aged, with a large majority identifying as white and non-Hispanic. Respondents were highly educated—only 27% had less than a bachelor's degree. However, over half reported a current annual household income under \$40,000, and only 40% were employed full-time.

Of the eight lifetime diagnoses that determined eligibility, nearly 80% of respondents (N=197) selected only one. In all, 64% selected major depressive disorder, 41% bipolar disorder, and 20% schizophrenia or another psychotic disorder (Table 2). Respondents had a substantial history of involvement in psychiatric treatment, as was intended by the inclusion criteria. Nearly two-thirds (65%) had been hospitalized in a psychiatric inpatient unit, including 59 (29%) admitted under a court or doctor's order.

Previous Experience With Medication

Respondents reported extensive exposure to psychiatric medication, with most (71%) respondents taking psychiatric medication for more than nine years. Approximately half (N=123, 49%) reported first taking psychiatric medication in young adulthood and about a fifth before age 18 (N=42, 17%). When asked to rate the helpfulness of their most recent medication or medications prior to attempting discontinuation, 95 (38%) indicated that the medication had been helpful, 106 (43%) that medication had been somewhat helpful, and 48 (19%) that medication had not been helpful.

TABLE 1. Sociodemographic characteristics of 250 individuals with a goal of discontinuing psychiatric medication

Characteristic	N	%
Age (M±SD)	46.2±13.1	
Item nonresponse	46	
Gender		
Female	158	76
Male	41	20
Transgender	5	2
Self-identify	3	1
Item nonresponse	43	—
Annual income		
<\$12,000	35	17
\$12,000–\$24,999	38	19
\$25,000–\$39,999	38	19
\$40,000–\$69,999	44	21
\$70,000–\$149,000	33	16
\$150,000–\$349,999	13	6
≥\$350,000	2	1
Item nonresponse	47	—
Education		
High school diploma or GED, some college	55	27
College degree	67	33
Graduate degree	84	41
Item nonresponse	44	—
Employment		
Full-time	81	40
Part-time	34	17
Unemployed, looking	13	6
Unemployed, not looking	33	16
Volunteering	9	4
Retired	19	9
Student	15	7
Item nonresponse	46	—
Race		
White	181	87
Black	8	4
American Indian	2	1
Asian	1	1
Pacific Islander	1	1
Other	15	7
Item nonresponse	42	—
Ethnicity		
Hispanic	13	6
Non-Hispanic	194	94
Item nonresponse	43	—
Receiving public assistance		
Yes	131	66
No	69	35
Item nonresponse	50	—
Recruitment source		
Social media site	139	56
E-mail list	46	18
Professional Web site	33	13
Friend or family	15	6
Personal Web site	11	5
Provider	5	2

Time Since Discontinuation

In this sample, 76% reported on discontinuation of an antidepressant, 56% of an anxiolytic, and 47% of an

TABLE 2. Clinical characteristics of 250 individuals with a goal of discontinuing psychiatric medication

Characteristic	N	%
Diagnosis		
Psychotic disorder	50	20
Bipolar disorder	102	41
Depressive disorder	161	64
Item nonresponse	0	—
Discontinuation status		
Complete discontinuation	135	54
Another status ^a	115	46
Item nonresponse	0	—
Medication class		
Antidepressants	189	76
Anxiolytics	139	56
Antipsychotics	118	47
Mood stabilizers	95	38
Stimulants	33	13
Item nonresponse	0	—
Total lifetime exposure		
<5 years	26	13
5–9 years	35	17
>9 years	146	71
Item nonresponse	43	—
Lifetime psychiatric inpatient stay		
Yes	135	65
No	72	35
Item nonresponse	43	—
Lifetime psychiatric inpatient stay under a doctor’s order or court order		
Yes	59	29
No	148	72
Item nonresponse	43	—

^a Discontinued one medication but not the other, reduced but did not discontinue one or more medications, or remained on the same dose or higher

antipsychotic medication (Table 2). Among those who completely discontinued their medication, 67 (52%) reported having been off medications a year or more, 43 (33%) reported less than one year, and 19 (15%) had been off one medication for a year or more but off the other medication for less than one year.

Reasons for Discontinuation

The survey listed 13 possible reasons for discontinuing medication; participants could select more than one reason and add others (Table 3). Respondents most commonly selected concerns about the medications’ effects, such as long-term effects, side effects, and impact on reproductive health) (N=205, 85%); reasons related to personal development, such as wanting to know oneself without medication, learning new approaches, or following advice from someone in their personal life (N=147, 61%); and those related to current “medication utility,” such as feeling better and medication not being useful anymore) (N=150, 63%). The least common reasons were related to a health care encounter: advice from the prescriber or other health care

TABLE 3. Reasons for discontinuing psychiatric medication among 250 individuals with a goal of discontinuing psychiatric medication

Reason	N	%
Long-term effects	177	74
Adverse effects	175	73
Wanted to know who I am	115	48
Learned about alternative approach	82	34
Felt better	81	34
Drug not useful	70	29
Drug did not work anymore	54	23
Short-term use intended	31	13
Concerned about reproductive health	30	13
Advised to discontinue by prescriber	19	8
Advised to discontinue by health care provider	13	5
No access to medications	10	4
Advised by someone in personal life	10	4
Other	71	29
Item nonresponse	10	—

provider, not having access to medication, or intending only short-term use of medication.

Discontinuation Status

In terms of the ultimate status of the discontinuation process, 54% of respondents met their goal of completely discontinuing all psychiatric medications (Table 2). The remaining 46% either discontinued one medication but not the other, reduced but did not discontinue one or more medications, or remained on the same dose or higher. Most respondents who completely discontinued indicated feeling satisfied with their decision. Of those who completely discontinued, most (N=105, 82%) were satisfied or very satisfied with their decision to discontinue. Half (N=52, N=50%) of those who did not achieve their goal to completely discontinue were satisfied or very satisfied.

Withdrawal Experiences

About one-third (36%) chose to discontinue over a period of more than six months, another third (31%) did so in one to six months, and a third (33%) in less than one month, with half of this group (16% of the sample) choosing to do so “cold turkey” (Table 4).

Despite the extended discontinuation period for most respondents, 54% reported severe withdrawal symptoms. From a list of 13 potential withdrawal reactions (plus options to list others), respondents picked a mean±SD of 7.0±3.6 (range 0–12). Most frequently selected were changes in sleep (N=181, 80%), and psychological effects, including increased anxiety (76%), difficulty with emotions (73%), and sadness or tearfulness (70%). Respondents also reported physical withdrawal effects, including fatigue (69%), memory and concentration problems (61%), flu-like symptoms (62%), and

TABLE 4. Withdrawal effects endorsed by 250 individuals with a goal of discontinuing psychiatric medication

Variable	N	%
Time period for discontinuation		
Immediately, “cold turkey”	39	16
≤1 month	42	17
1–6 months	77	31
>6 months	89	36
Item nonresponse	3	—
Effects		
Changes in sleep	181	80
Item nonresponse	23	—
Increased anxiety	171	76
Item nonresponse	24	—
Difficulty with emotions	162	73
Item nonresponse	29	—
Sadness, tearfulness	155	70
Item nonresponse	27	—
Fatigue	153	69
Item nonresponse	29	—
Difficulty with thinking	145	64
Item nonresponse	24	—
Flu-like symptoms	138	62
Item nonresponse	27	—
Difficulty with memory or concentration	135	61
Item nonresponse	28	—
Neurological symptoms (for example, “brain zaps”)	133	61
Item nonresponse	29	—
Diarrhea or constipation	102	47
Item nonresponse	33	—
Thoughts of suicide	97	44
Item nonresponse	31	—
Thoughts of self-harm	78	36
Item nonresponse	31	—
Psychosis	48	22
Item nonresponse	34	—
Other (optional)	85	34
Severity of effects		
Low	45	20
Medium	59	26
Severe	124	54
Item nonresponse	22	—

diarrhea or constipation (47%). Asked to rate the overall impact of withdrawal effects on daily activities (from 1, no impact, to 10, severe impact), 54% of respondents reported severe impact (mean=7.1±3.1, range 1–10).

Coping With Discontinuation

Respondents were asked about the self-care strategies, social support, and provider support they used to cope with discontinuation and work toward their medication goals.

Self-care. From a list of 15 self-care practices used during discontinuation, respondents selected a mean of 8.0±3.6 (range 0–15). Self-education (such as reading books on the topic, Internet research) was rated the most helpful by 174 respondents (76%). The practices rated next most helpful were being outdoors (N=173, 74%), getting sleep

(N=156, 67%), expressing feelings (N=154, 67%), being with pets or animals (N=153, 67%), and physical exercise (N=155, 66%). [A table in the online supplement presents data on responses to self-care items.]

Social support. In response to questions about the size of their trusted social network, about half of those who responded (N=99, 54%) counted between one and five trustworthy people, and 24% (N=47) reported more than ten people. Only 4% (N=7) reported having no one they could count on in their network. It appeared that social support was helpful during discontinuation. Among those who responded, 91 (42%) reported that friends and others who had discontinued or reduced medications were helpful. Internet support groups for people discontinuing medication were also a common source of helpful support (N=86, 41%), as was family (N=83, 39%).

Provider support. Most respondents were engaged in treatment at the time they decided to discontinue. Most (N=162, 73%) were working with a prescriber, and many (N=112, 52%) were working with a psychotherapist (for example, a social worker or a psychologist). Of those working with a prescriber, only 45% (N=73) described the prescriber as helpful during the process of discontinuation. Most respondents in treatment had been engaged for some time, with 61% (N=97) of respondents having a relationship with their prescriber for over a year before beginning the discontinuation process.

Respondents were also asked to describe the extent of the prescriber's involvement in their decision to discontinue medication. More than half (N=90, 57%) described the decision-making process as collaborative (for example, "I decided and my prescriber accepted," "My provider decided and I agreed," or "It was a joint decision"), 16% (N=25) began the process against their prescriber's advice, and the remaining 27% (N=43) didn't tell their prescriber, stopped seeing the prescriber, or saw a new prescriber. Four respondents who reported having a relationship with a prescriber at the time of deciding to discontinue did not indicate the nature of the decision-making process.

DISCUSSION

This is the first U.S. survey of a large sample of longer-term users to document experiences of psychiatric medication discontinuation. Although most respondents possessed certain socioeconomic privileges (including race, education, and people to count on), many had considerable experiences in treatment, received public benefits, and were involuntarily hospitalized. These individuals took psychiatric medications for years before choosing to stop them for reasons already well documented in the literature: adverse effects, potential long-term risks, and the availability of beneficial alternatives (26–29).

The findings extend and complement those from the few previous surveys, in which fairly similar proportions of

participants found medications helpful. The sample in this study reported a longer period of medication use but a similar period without medication since discontinuation and somewhat lower overall rates of withdrawal effects. The lower rates of effects may be related to how long respondents took to discontinue. Compared with the one previous survey that addressed this topic (6), a larger proportion of respondents in this study took more than six months to discontinue (33% versus 7%), and a smaller proportion discontinued all at once (16% versus 41%).

The experience of discontinuation itself was reported to be physically and emotionally challenging, with respondents reporting several undesirable withdrawal effects that have been noted in previous research (6,19). Nonetheless, 82% of respondents who achieved their medication goals reported being satisfied or very satisfied with their decision.

This study may be the first to report detailed findings on helpfulness of various supports to discontinuation. Respondents' ratings of the helpfulness of self-care and interpersonal support, compared with ratings of the helpfulness of providers, are notable. Although many respondents described collaboration in the initial decision-making process about discontinuation, most did not indicate that providers were helpful during the ensuing experience of discontinuation. Many who were discontinuing medications did not feel supported by providers, which is problematic, particularly because many respondents reported severe withdrawal effects.

Much work has demonstrated that the therapeutic alliance—the relationship between a provider and a client that enables them to work together—predicts positive treatment outcomes (30). This alliance may be affected by how providers communicate about discontinuation. The limited support respondents reported may be due partly to inadequately validated information to guide prescribers and psychotherapists (31). Communication about discontinuation faces a challenge similar to that faced by research on discontinuation: it can be difficult to define and distinguish between withdrawal effects and psychiatric symptoms (11). Individuals undergoing discontinuation have described experiencing the resurfacing of difficult emotions and withdrawal effects simultaneously (32). In practice, prioritizing patient goals for medication use and well-being may help maintain open communication while the field awaits further research (31). Many individuals must find support through friends, family, peers, and online support groups. In this study, respondents found these sources of support particularly helpful, along with self-care. Resources and interventions employing these supports may be especially promising, along with tapering options that guide providers to reduce the risk of severe withdrawal effects. Future research should investigate barriers, including providers' perspectives and training, as well as implementation of shared decision making in which safe and effective discontinuation of medication is included in the range of treatment alternatives.

As with most currently available surveys on discontinuation, this study relied on retrospective self-reports, which are subject to significant recall bias. In addition, individuals may have responded because of especially positive or negative experiences (self-selection bias). Individuals were recruited by nonprobability sampling. This study's limited budget dictated sampling from the researchers' networks in order to reach long-term users with diagnoses of serious mental disorders who attempted to discontinue.

Another limitation was marked homogeneity in race-ethnicity and gender. Data on nationwide trends in medication use show that fewer people of color and fewer men are exposed to psychiatric drugs (1). It is not known whether individuals who choose, or are able to choose, to discontinue medications share these demographic characteristics. In addition, rates of missing data for some sociodemographic variables ranged up to 16%, although this was not unexpected for such a survey (33). Finally, a strength of the design was its focus on persons who discontinued more than one medication class, which reflects real life better than focusing on only one medication; however, exclusion of respondents who had attempted to discontinue more than two medications greatly reduced the sample size. Many potential participants were excluded for this reason, which may indicate that many individuals take—and desire to discontinue—several medications at once, and this may be a neglected research area. Furthermore, our findings describe the experiences of individuals discontinuing various classes of psychiatric medication; thus these experiences cannot be generalized across drug classes. Initial studies have documented the withdrawal effects of various classes of drugs (5,6,13,34). We plan to address this problem in a more complete exploration of withdrawal effects in this sample.

CONCLUSIONS

These preliminary results contribute to the limited research on discontinuation experiences and helpful coping strategies. As the results highlight, discontinuing psychiatric medication is a complicated and often difficult process. Clearly, future research should guide health care systems and providers to better support patient choice and self-determination (35,36), provide information on the risks and benefits of discontinuation, and assist individuals through the process. In the Netherlands, programs have been implemented to help long-term users discontinue benzodiazepines, and the Norway Ministry of Health has recently instituted a medication-free psychiatric treatment ward in a public facility, which also helps patients taper medications if they wish to do so (37). Opportunities for support from friends, family, and peers, along with improved provider education, would help individuals during discontinuation.

Although the Food and Drug Administration mandates research to establish efficacy and safety of short-term medication use, little federal support exists for research on long-term use or optimal discontinuation strategies. Most

medication users report finding psychiatric medication helpful; however, medication appears most effective when combined with other psychosocial supports, and many individuals may require only temporary use (38,39). Increasingly, medication management is conceptualized not only as employing strategies to increase adherence but also as supporting patient goals for medication use (40). Research on adherence emphasizes collaboration and engagement, although its main focus is on supporting individuals to voluntarily take medications (41). When they choose to stop taking medication, even after adhering to a regimen for many years, their current option may be to expect little assistance from the health care system, and they may drop out of treatment, which is unfortunate. Clinicians may point to data indicating that relapse or recurrence of distress is likely to result from medication discontinuation, but the fact that individuals make choices with which clinicians disagree should not preclude clinicians from providing support once these individuals have made a decision. For respondents who are comfortable in treatment, a stronger therapeutic alliance and more options (such as holistic health care) might improve engagement and lead to less arduous discontinuation experiences. With increased knowledge of what helps individuals through discontinuation, more opportunities will arise to implement shared decision-making models (42) and decision aids (43) to enhance the judicious use of psychiatric medications and provide alternatives to those who choose not to use them.

This study recruited more long-term users than some previous studies, but future research would benefit from better representation of underserved populations. Longitudinal studies would aid treatment planning by better characterizing treatment trajectories, beginning with the experience of medication initiation, and would help identify individuals who could benefit from specific discontinuation strategies. Research should continue to explore ways to support individuals who choose to discontinue medication in order to inform practice and policy efforts to achieve more effective person-centered care.

AUTHOR AND ARTICLE INFORMATION

Dr. Ostrow is with Live & Learn, Inc., Morro Bay, California. Ms. Jessell is with the Silver School of Social Work, New York University, New York. Mr. Hurd is with Bonita House, Inc., Oakland, California. Dr. Darrow is with the Department of Psychiatry, University of California, San Francisco. Dr. Cohen is with the Department of Social Welfare, Luskin School of Public Affairs, University of California, Los Angeles. Send correspondence to Dr. Ostrow (e-mail: laysha@livelearninc.net).

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