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Experiences with benzodiazepine use, tapering, and discontinuation: an Internet survey

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Abstract

Background: Over 92 million prescriptions for benzodiazepines are dispensed in the United States annually, yet little is known about the experiences of those taking and discontinuing them.

Objective: The aim of this study is to assess the experiences of those taking, tapering, or having discontinued benzodiazepines.

Methods: An online survey ($n = 1207$) elicited information about benzodiazepine use, including long-term use, tapering, discontinuation, and withdrawal symptoms.

Results: Symptoms associated with benzodiazepine use, tapering, and discontinuation were numerous and ranged from symptoms such as anxiety, insomnia, and nervousness to digestive problems, irregular heart rhythms, uncontrollable anger, photosensitivity, balance problems, and others. When asked how benzodiazepine symptoms affected their lives, 82.9% reported work problems, 86.3% had problems with social interactions and friendships, and 88.8% had problems with fun, recreation, and hobbies. Suicidal thoughts or attempted suicide was reported by 54.4%, and 46.8% said benzodiazepines caused lost employment. Most of the respondents for whom benzodiazepines were prescribed (76.2%) stated they had not been informed that benzodiazepines were indicated for short-term use only and that discontinuation might be difficult. About a third (31.5%) reported food allergies and/or seasonal allergies that occurred only after benzodiazepine use.

Conclusion: The trajectory of those who taper or discontinue benzodiazepines is unpredictable, and many patients experience a range of protracted and severe symptoms, even years after benzodiazepines were completely discontinued. Greater awareness is needed for both prescribers and patients about the potential for a difficult withdrawal from benzodiazepines.

Keywords: benzodiazepines, benzodiazepine withdrawal symptoms, neuroadaptation, protracted benzodiazepine withdrawal symptoms

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Introduction

Over 92 million benzodiazepine prescriptions were dispensed in the United States in 2019, making them one of the most prescribed medications in this country.[1] In September 2020, the US Food and Drug Administration (FDA) announced class-wide changes in the approved prescribing information for all benzodiazepines, including an updated 'boxed warning' describing serious risks associated with their use and that the continued use of benzodiazepines had the potential to lead to clinically significant physiologic dependence, and that these risks increased with longer treatment duration and/or higher daily doses.[1] Benzodiazepines belong to a class of pharmacological agents approved for treatment of generalized anxiety disorder, insomnia, seizures, panic disorders, social phobia, and certain other conditions.[2] In general, their prescribed use is recommended to be short term, no more than 2–4 weeks,[3] but they are routinely prescribed and taken for much longer

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periods, even years.[4] Over the mid- and long term, benzodiazepines may cease to be effective and/or cause adverse reactions,[5–7] which may not be properly recognized by patient or prescriber. Chronic benzodiazepine users do not usually engage in the typical patterns of illicit drug use seen with such drugs as opioids, stimulants, or alcohol. However, neuroadaptation does occur, particularly with longer exposure and increasing doses, which can make it difficult for people to stop using benzodiazepines, even when they wish to do so. These neuroplastic changes may be enduring and cause prolonged and distressing symptoms, even well after benzodiazepines are discontinued.[8]

The medical community does not fully understand the trajectory of benzodiazepine discontinuation. As is the case with most drugs for which use is associated with neuroadaptation, the early phase of withdrawal typically involves two components: first, removal of the drug from the targeted neuroreceptor(s) and second, the adaptive stress response manifested by autonomic arousal.[9] In general, this is called the acute withdrawal syndrome. However, for benzodiazepines, there is emerging evidence for longer term consequences, which could be either a protracted withdrawal syndrome or evidence of enduring neurotoxicity, and which remain to be well described or fully elucidated. Tolerance due to neuroadaptation can allow for benzodiazepine-related symptoms to emerge even while a patient is still taking the full prescribed dose of medication. Tolerance may result in emergence of inter-dose symptoms despite taking the full dose. When a patient tapers off benzodiazepines, the same or other symptoms may emerge and wax or wane over the course of the taper. When the patient completely ceases to take benzodiazepines, symptoms may persist for an undetermined time period, although it is not clear whether these are based on protracted withdrawal phenomena or enduring neurotoxicity.[9]

While a slow taper is recommended for ceasing benzodiazepine use,[8] there is little clinical understanding of what this may involve and a paucity of guidance to navigate the process. The aim of this online survey was to document the personal experiences of a convenience sample of individuals who had used benzodiazepines, including those currently taking a full prescription, those in the process of tapering, and those who had completely discontinued benzodiazepines.

Materials and methods

An anonymous online survey was developed (see Supplemental Appendix I) that recruited respondents from 16 Internet sites as a convenience sample (see Supplemental Appendix II). The survey consisted of 19 questions, split into the following sections: demographics, history of benzodiazepine use, symptoms, and outcomes (see Supplemental Appendix I). To avoid duplication, the Qualtrics Internet survey tool was employed so that only one response could be submitted per IP address. The survey was designed collaboratively by two of the authors (J.M. and C.H.) and hosted on the University of Southern California's secure server.

The survey link was posted for a month three different times (October 2018, November 2018, and January 2019). Among the sites that offered the survey were several large benzodiazepine-related websites and 10 Facebook groups related to benzodiazepine use. A link to the survey was also offered on some Facebook pages and Reddit threads related to general health and mental health. This allowed 48 collections (16 sites, three times each), comprising 66.5% of the sample. The remaining 33.5% of the sample originated from organic Internet searches and referrals. It was the intention of the authors to collect the largest sample size possible.

Survey results were analyzed in SAS software by a medical statistician and subsequently confirmed by an experienced data scientist using the Microsoft SQL server platform. The authors can make available to interested readers a full report on the steps taken and data included for each point of analysis. This article complies with Consensus-Based Checklist for Reporting of Survey Studies (CROSS) CROSS methodology.[10]

Results

A total of 1682 individuals started the survey, of whom 1207 respondents were identified by the source system as having finished the survey, although some of these 'finishers' did not answer every question. In this article, 'respondents' is the term used to describe these identified finishers. Respondents were 71% female, 26% male, and 2% who preferred not to state their gender identity or had other gender identity. Many respondents took several different related drugs. Of the finished respondents, 1190 had taken benzodiazepines, 247 had taken a Z-drug, 167 had taken antipsychotics, 222 had taken gamma-aminobutyric acid (GABA)

analogues (such as the anticonvulsants gabapentin and pregabalin), and 558 had taken antidepressants. Many respondents took more than one class of drug. In fact, 55.9% took a benzodiazepine and at least one other of these drugs. Nearly all respondents had a prescription for benzodiazepines (98.6%) and most (68.4%) said they 'definitely' took their benzodiazepines as prescribed, 22.0% said they 'mostly' took them as prescribed, while 8.7% said they did not take them as prescribed.

Respondents were grouped into five age categories: those <20 years (0.2%), 20–30 years (7.3%), >30 but <50 years (38.8%), >50 but <60 years (27.9%), and >60 years (24.8%). Most respondents lived in the United States (76.6%), but respondents came from several countries, including Canada, the United Kingdom, Australia, Japan, Germany, France, Denmark, Ireland, and other countries. About two-thirds of respondents (66.5%) found out about the survey from a benzodiazepine support group and 23.0% discovered it by Internet search.

Many respondents had taken more than one type of benzodiazepine, whether concurrently or sequentially. The most frequently taken benzodiazepines were clonazepam (52.9%), alprazolam (41.7%), lorazepam (36.1%), and diazepam (32.1%). Patients were prescribed benzodiazepines for a wide range of conditions (see Table 1).

Table 1. Main reason for which the benzodiazepine(s) was originally prescribed.

Main reason for prescription(s) $n = 1207$	Number of patients (%)
Situational anxiety	528 (43.7)
Insomnia, sleep	487 (40.3)
Panic attacks	481 (39.9)
Depression	398 (33.0)
Generalized anxiety disorder	286 (23.7)
Pain or nerve spasms	132 (10.9)
Muscle spasms or clenched muscles	106 (8.8)
Restless leg	53 (4.4)
Part of treatment assistance for cancer, major illness, or accident	34 (2.8)
Seizures	20 (1.7)
Hallucinations or schizophrenia	17 (1.4)
Premenstrual syndrome	15 (1.2)
Other	195 (16.2)

Respondents could give more than one answer.

Symptoms

Most respondents had discontinued benzodiazepines (63.2%), while 24.4% stated they were in the process of tapering and 11.3% reported continuing on a full dose. The symptoms experienced by patients in the latter group are likely due to tolerance to the prescribed dose of benzodiazepine, among those who had not yet initiated a tapering dose reduction. Of those who had discontinued benzodiazepines, 10.4% took a year or longer to taper, although symptoms often persisted beyond discontinuation. Of those who had tapered, 4.4% took >2 years to taper and 6.0% tapered for more than 1 but less than 2 years. Of those who discontinued benzodiazepines, 5.2% reported they 'withdrew just fine without taper' and 17.6% said they 'did not taper, quit abruptly but with consequences'.

Respondents were asked about symptoms that occurred while they were taking full-dose benzodiazepine therapy, during a taper, or after benzodiazepine discontinuation. Note that many patients reported multiple symptoms and many patients had tapered more than once. Symptoms occurred in the majority of patients, with certain symptoms persisting for a year or more (see Table 2).

Benzodiazepine information

Most respondents (76.2%) said their health care providers 'definitely did not' tell them that benzodiazepines were intended for short-term use and discontinuation might be difficult, and 5.6% said they were 'probably not' given this information. A minority of respondents (6.1%) stated they had been 'clearly warned' or 'warned, but not sufficiently' (7.9%). A small number of respondents (3.1%) had no recollection of whether or not they were told about benzodiazepine risks.

Life effects

Respondents reported that in some cases, the symptoms associated with benzodiazepine discontinuation had affected various aspects of their personal lives (see Table 3). Adverse life consequences were attributed to benzodiazepine use and/or withdrawal by some respondents (see Table 4). Notably, more than half of respondents to this question (54.4%) reported experiencing suicidal thoughts or had attempted suicide.

Table 2. Symptoms during or after benzodiazepine use or during a taper. Respondents could give more than one answer.

Symptom (n=1,207)	Duration of Symptom				Did not experience this
	Days	Weeks	Months	Years	
Low energy	7.0%	6.1%	21.5%	51.6%	12.9%
Nervousness, anxiety, fear	6.4%	7.8%	23.7%	50.2%	11.0%
Difficulty focusing, feeling distracted	7.0%	7.0%	21.5%	49.7%	13.8%
Sleep disturbances	6.8%	7.1%	23.9%	49.0%	12.2%
Memory loss	6.8%	5.4%	20.5%	44.2%	22.1%
Sensitivity to light, noise, talk, smell, triggering symptoms	6.1%	8.1%	21.7%	42.8%	20.4%
Muscle weakness	5.7%	8.2%	20.4%	36.0%	28.7%
Digestion, nausea, diarrhea, other stomach/gut issues	8.0%	8.3%	19.3%	38.9%	24.6%
Trembling or tingling in limbs, skin	8.4%	7.2%	21.0%	35.1%	27.4%
Symptoms triggered or worsened by foods, alcohol, or caffeine	6.7%	6.0%	19.6%	35.0%	31.7%
Stabbing pain, burning, aching sensation, or joint pain	6.6%	6.5%	20.6%	34.7%	30.6%
Head pain, pressure	8.6%	7.5%	21.6%	34.2%	27.2%
Difficulty driving or walking	7.6%	8.0%	20.2%	33.1%	30.2%
Balance problems	10.2%	8.0%	21.8%	31.0%	28.1%
Heart rhythm irregularities or high blood pressure	7.5%	7.7%	19.6%	30.7%	33.6%
Muscle spasms in back or limbs	9.8%	8.0%	16.8%	29.2%	35.3%
Uncontrollable crying or anger	9.6%	10.3%	22.4%	28.3%	28.6%
Difficulty breathing or swallowing	8.6%	8.0%	16.0%	20.6%	45.9%
No appetite, disinterest in food	9.6%	12.5%	21.4%	19.5%	36.1%
Akathisia, need to move or pace constantly	8.6%	8.4%	18.1%	19.1%	44.9%
Whole body trembling uncontrollably	12.4%	8.6%	14.8%	12.8%	50.4%
Hallucinations	9.7%	6.3%	9.4%	6.1%	67.6%
Whole or partial body seizures	8.7%	2.9%	4.2%	4.6%	78.7%

New medical conditions not previously experienced

Respondents were asked about current symptoms they never experienced prior to benzodiazepine use. About a third (31.5%) reported food allergies and/or seasonal allergies that occurred only after benzodiazepine use. Highly sensitive airways were reported by 30.1% only after benzodiazepine use. Sensitivity to food additives or other chemicals that occurred only after benzodiazepine use was reported by 41.2% of respondents, including monosodium glutamate and soy (31.6%). While most respondents denied any previous autoimmune diagnosis, 18.1% reported being diagnosed with an autoimmune disorder following benzodiazepine initiation, whereas 11.5% indicated having received an autoimmune diagnosis prior to starting benzodiazepines. Falls and fractures were reported to be a problem in about one-third of respondents, with 5.9% saying such events had occurred before they started benzodiazepines while 21.0% said these problems began after starting benzodiazepines.

Patient comments

Respondents were allowed to make free-form comments at the conclusion of the survey and hundreds of comments were entered. In fact, the write-in comments provided profound insights into benzodiazepine-related adverse effects and how patients

Table 3. Respondents were asked how severely benzodiazepine discontinuation symptoms affected their professional and private lives.

Domain	Not at all	Mild problem	Moderate problem	Severe problem	Quite severe problem	Enormous problem
Work life	16.2%	4.5%	9.9%	9.9%	9.4%	49.1%
Fun, recreation, hobbies	10.3%	5.9%	9.4%	12.3%	13.3%	48.0%
Social interaction, friendships	12.8%	7.5%	11.2%	11.4%	14.5%	41.7%
Ability to take care of home, others	13.7%	7.8%	13.6%	12.3%	13.3%	38.4%
Relationship with spouse, family	14.3%	8.4%	14.7%	11.2%	12.8%	37.7%
Ability to drive or walk	22.8%	13.8%	15.2%	9.1%	9.0%	29.2%

Note that not all respondents answered this question ($n = 1207$).

deal with them. Several particularly relevant comments have been selected and are offered here. These comments have not been qualitatively analyzed. The authors identified nine broad themes and selected relevant comments to represent each.

Comments reported on the difficulties of benzodiazepine withdrawal

Many respondents described withdrawal as the worst experience they ever had.

- 'If I could think of the one worst possible thing you could do to a person, it would be benzo withdrawal. Beats cancer and Alzheimer's combined. If I could make it go away by chopping my arms and legs off, I would!'
- 'This is by far the worst thing to ever happen to me. I have just recently begun to have hope that I will make it off this poison'.

Health care professionals did not treat them well

There was a great deal of criticism about clinicians, and little praise for doctors or caregivers. A few said that their physicians 'abandoned' them as they struggled to discontinue benzodiazepines.

- 'I'm treated like I did something wrong for taking the prescription as prescribed and never told what it was and when I looked at medical information years ago, she [my doctor] told me not to because I was making up symptoms by reading medical information'.
- 'My doctor cut me off without warning. I believe doctors who do this should lose their license … I went to the emergency room within days of being discontinued and was "locked down" in mental health unit for 9 days with no treatment except coloring in a room full of dangerous patients'.

Table 4. The use or withdrawal from benzodiazepines was associated with a number of adverse life events.

Life consequence	$n = 1207$
Significantly affected marriage, other relationships	56.8%
Suicidal thoughts or attempted suicide	54.4%
Lost a job, fired, became unable to work	46.8%
Experienced significant increase in medical costs	40.9%
Loss of wages or lower wages in reduced job capacity	32.6%
Lost savings or retirement funds	26.7%
Violent thoughts or actual violence against others	23.5%
Lost a home	12.6%
Lost a business (if business owner)	8.4%
Lost child custody	2.6%
None of these apply	18.6%

Note that not all respondents answered this question and respondents could give more than one answer.

Tapering options were limited

One problem that respondents mentioned was their difficulty in finding knowledgeable and appropriate help to manage their physiologic dependence.

- 'This is my third taper ... much better because I am going at a slow pace, but the first two were just horrible'.
- 'Very difficult to find a health provider that will taper me off these awful chemicals'.

Some reported outright misrepresentation of benzodiazepine risks

While nearly all respondents (>98%) were prescribed benzodiazepines at some point, their relationship to the medical establishment often soured as they experienced problems with adverse effects or when they reported wanting to stop taking the benzodiazepines.

- 'The doctor who prescribed the benzo said it was "medically impossible" to overdose or become addicted to benzos. That is plainly false'.
- 'I was constantly coming down with mystery illnesses from the drug and these illnesses required additional medications to cover up the problems. Doctors misled me about my health and never once acknowledged the pills could be the reason behind any of my issues'.

Symptoms were numerous, could be severe, and were long lasting

While a few respondents were able to discontinue benzodiazepines with few or no symptoms, whether abruptly or over time, many wrote in about persistent and disturbing symptoms. Some respondents had completely discontinued benzodiazepines but still had symptoms, including one whose symptoms were misdiagnosed as fibromyalgia.

- 'Benzos ruined my life. I have been benzo-free for two years and still in protracted withdrawal'.
- 'I went full blown psychosis and had seizures'.

Some reported different symptoms than the ones listed in the multiple-choice sections of the survey

The main symptoms associated with benzodiazepine withdrawal and tapering are captured in survey questions, but respondents added others.

- 'I don't have emotional responses except fear and anxiety since benzo use. I have trouble feeling empathy and love since benzo use. This to me is the worst symptom I currently have'.
- One respondent who tapered off Valium® [diazepam] after 37 years of low-dose treatment reported unusual symptoms during the withdrawal: 'Feeling bee stings, inner shakes, pressure on the chest, difficulty making sense of traffic lights'.
- 'Please add tinnitus to the withdrawal symptoms'.

There were adverse consequences in their personal and professional lives because of benzodiazepine use, tapering, and withdrawal

The adverse effects of benzodiazepines exceeded physical symptoms and sometimes involved negative events in the respondents' personal, social, psychological, and professional lives.

- 'Lost my successful PR company'.
- 'These drugs ... have robbed my child of his mum'.
- 'I lost my corporate job after 20 years with the same employer due to low-dose benzodiazepines. This drug destroyed my entire health, personality, and quality of life'.

Many reported suicidal thoughts and actions

While many respondents described despair, anguish, and hopelessness, some described specifically suicidal intentions.

- 'I tried to commit suicide by stabbing myself in the heart. Knife was too big to fit between my ribs. So, I stabbed myself three times. I felt nothing'.
- 'I attempted suicide three times after my last dose of benzos and Ambien® [zolpidem]. I have never been suicidal before benzo use'.

Some respondents reported successful tapers with minimal complaints

While most respondents who wrote in comments expressed difficulty and despair, a few had fully or partially positive experiences with benzodiazepine treatment and/or discontinuation. It would be important to identify this group as well as those for whom withdrawal is difficult; the latter need specialists to treat them, but not the former.

- 'I have recovered enormously but was disabled by benzos and Elavil® [amitriptyline] for

20 years, diagnosed as fibromyalgia. Got 80% health back when quit! But suffered bizarre symptoms like depression, akathisia, and hallucinations never before experienced'.

- 'I was prescribed diazepam for muscle spasms after spine surgery. I used it exactly as prescribed, stopped when I no longer needed it, and had zero withdrawal or other problems'.

Discussion/conclusion

This survey found that troublesome symptoms associated with benzodiazepine use could emerge while patients were still taking a full dose of medication under clinical supervision and that these symptoms persisted over the course of tapering and even long after complete discontinuation. While there is a long list of symptoms that can occur, certain predominant symptoms emerged such as low energy, anxiety, nervousness, fearfulness, distractedness, and problems with sleep and memory. However, a wide range of other symptoms, including photosensitivity, gastrointestinal problems, food allergies, cutaneous symptoms, cephalgia, problems with balance, and others, were reported. Symptoms were sometimes severe enough to significantly affect family life, career, and mental health adversely; symptoms lasted so long after benzodiazepine discontinuation that many respondents counted the duration in years. In some cases, respondents described new symptoms they had not previously experienced after benzodiazepine cessation. We do not propose to mechanistically explain these symptoms here, but they likely fall into two broad categories – those due to withdrawal-related mechanisms and those due to enduring neurotoxic changes.

One systematic review of benzodiazepine taper protocols (28 studies) suggests that for older adults, a taper should reduce the dose by 25% every 1 or 2 weeks until the patient is drug free and states, 'no serious safety events were reported'.[11] About a third (36%) of patients in this review had medication substitution, which may have reduced reported symptoms. Moreover, not all of the studies considered in this review evaluated long-term symptoms. Busto *et al.* report that benzodiazepine withdrawal symptoms 'disappeared over a four-week period'.[12] Patients were randomized to placebo or diazepam, meaning one group quit benzodiazepines abruptly while the other was tapered over 6 weeks. Patients were followed over the course of a year. As expected, placebo patients experienced a marked increase in sometimes severe symptoms as soon as the study began, but these symptoms decreased gradually over time. This study was small; data were collected for only 40 patients, none of whom experienced seizures, disorientation, or other severe symptoms and no hospitalizations were necessary. A study of 57 benzodiazepine patients who were abruptly discontinued from benzodiazepines after >1 year of treatment and a mean daily dose of 14.1 mg diazepam equivalents reported that peak severity of withdrawal effects occurred in the first 2 days for short-acting and in the fourth to seventh days for long-acting agents.[13] This study followed patients for 5 weeks after their last dose of benzodiazepines and thus could not report on long-term symptoms. The perspective of physicians has been that short-term detoxification or tapering is equally effective, but our survey results suggest that only 22.8% of respondents could abruptly discontinue benzodiazepines. Our results show that many benzodiazepine users experience severe, debilitating, and prolonged withdrawal symptoms that not only persist beyond the 'seven days' mentioned above, even lasting for months and years, after the drug is discontinued. Many of the large number of write-in comments from respondents described attempting to quit benzodiazepines with minimal to no support from the health care system. A few were harshly critical of health care professionals who minimized their distress or disbelieved their symptoms. Many articles that discuss benzodiazepine withdrawal symptoms focus on a handful of symptoms, namely, sleep problems, anxiety, irritability, and confusion,[14] although multiple symptoms have been credibly reported[8] and were found in our survey. Thus, patients who are being deprescribed or who want to stop benzodiazepines on their own are often ill-prepared and uninformed about the symptoms that may occur and how to manage them. Moreover, the physicians to whom these patients turn are equally unclear about just how variable the course of benzodiazepine discontinuation can be and may tend to falsely attribute more prolonged withdrawal symptoms to primary psychopathology.

Well-meaning clinicians may be misled into thinking that benzodiazepine withdrawal is brief and manageable, even if it is unpleasant. For example, the package insert for clonazepam says that the drug should not be discontinued abruptly, but 'treatment should be discontinued gradually, with a decrease of 0.125 mg BID every

three days, until the drug is completely withdrawn'.[15] This is probably a too-rapid tapering plan based on the experience of the respondents in this survey. However, clinicians may give more credence to package labeling and literature than the patient, to the extent that those who have prolonged or severe symptoms may be dismissed as having primary psychopathology or be accused of malingering. Accordingly, those struggling most with benzodiazepine withdrawal symptoms may be the least likely to receive adequate management and support. Should health care professionals believe that the individual is struggling with the taper, they may be more inclined to refer the patient to a psychiatrist, an addiction specialist, or to a rehabilitation program rather than decelerating the taper. Conventional programs designed for substance use disorders seem inappropriate for benzodiazepine patients, who have neuroadaptation (physiologic dependence) without the aberrant behaviors that would constitute a use disorder.[16]

Although benzodiazepine physiologic dependence was reported in the literature as early as 1961,[17] it seems that many patients start benzodiazepine treatment without clear understanding of the potential risks from these drugs. In fact, many patients prescribed benzodiazepines have not taken part in the medical decision-making process in any meaningful way.[18]

This survey is an initial step to better recognition of the risks of benzodiazepine therapy and the awareness that withdrawal symptoms may be more varied, more severe, and more prolonged than are presented in the literature or product labeling. Benzodiazepine withdrawal symptoms are more common than most clinicians realize. Rickels *et al.* found that 58–100% (criteria dependent) of benzodiazepine users experience some type of withdrawal reactions upon discontinuation.[13] Up to 44% of long-term benzodiazepine users have persistent moderate to severe withdrawal symptoms when they attempt to discontinue the drug.[3,19] This survey and other reports suggest that benzodiazepine withdrawal symptoms show considerable interindividual variability and do not follow a predictable trajectory. Protracted withdrawal symptoms are more common than previously appreciated.[8] Further research is needed to better understand how to stratify which patients might be at particular risk for either acute or protracted benzodiazepine withdrawal.

Treatment options for those discontinuing benzodiazepines are limited. A slow taper may help reduce the duration, number, and intensity of symptoms but does not necessarily prevent them. Since even a gradual taper can be a difficult life experience for the patient, collaboration between patient and prescriber is needed, including unbiased listening to and hearing their stories, plus individualized care.

This survey found that 54% of respondents expressed suicidal ideation while taking, tapering, or after discontinuing benzodiazepines. Benzodiazepines are associated with an elevated risk of suicide or attempted suicide,[20] but suicidal thoughts or attempted suicide in such a large proportion of survey respondents is alarming. In an epidemiological study in Colorado from 2015 to 2017, 20% of the 3465 suicides in that period were decedents who had a recent benzodiazepine exposure.[21] Because it has tremendous public health implications, this area is worthy of further study.

This study has several limitations. The study reported on 'suicidal thoughts', which can range from fleeting notions of self-harm to passive desperation, preparatory planning, and disinhibition. Suicidal thoughts may be underreported, even in an anonymous online survey, as respondents might hesitate or be embarrassed to report self-destructive thoughts. There was no control group. Much of the survey dealt with symptoms presented in multiple-choice lists, and it is possible that patients may have been suggestible to the list presented, may not have correctly remembered past symptoms, or may incorrectly attribute certain symptoms or feelings to benzodiazepines. We did not account for a nocebo effect. The large number of write-in comments suggests that many respondents felt the survey did not allow them to fully describe the extent of their experiences and emotions. Another limitation of our survey is that it recruited respondents from social media and online sources that deal with benzodiazepine use and withdrawal. Respondents were self-selected, forming a convenience sample that may not represent the population of benzodiazepine users as a whole because visitors may have sought sites such as these specifically because they have experienced problems. Moreover, those who use the Internet for health information tend to be younger,[22] and those who join online support groups for medical conditions tend to be in generally worse health.[23] Our results thus may not be generalizable to the population of all people taking benzodiazepines.

Patient and clinician education are needed so that patients taking benzodiazepines are aware of both their appropriate and time-limited use and the risks involved if exposure is prolonged. Further research into protracted benzodiazepine withdrawal is urgently needed.

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Author contributions

Alistair J. Reid Finlayson: Conceptualization; Project administration; Writing – review & editing.

Jane Macoubrie: Conceptualization; Methodology; Writing – review & editing.

Christy Huff: Conceptualization; Methodology; Writing – review & editing.

D.E. Foster: Formal analysis; Writing – review & editing.

Peter R. Martin: Methodology; Writing – review & editing.

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Ethics statement

The study was approved by the University of Southern California Institutional Review Board (#UP-18-07736) and the Vanderbilt University Institutional Review Board (#200521). The study was granted an exemption from requiring written informed consent from respondents.

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Data availability statement

The data that support the findings of this study are available; please contact Dr. Jane Macoubrie at janemacoubrie@zoho.com.

Supplemental material

Supplemental material for this article is available online.

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