

BIND: The Patient Experience

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Introductions

Christy Huff, MD

- Benzodiazepine Information Coalition (BIC), Director
- American College of Cardiology, Fellow
- Colorado Consortium's Benzodiazepine Action Work Group, Steering Committee



D E Foster

- Easing Anxiety (The Benzo Free Podcast), Founder & Host
- Colorado Consortium's Benzodiazepine Action Work Group, Co-Chair
- Book: "Benzo Free: The World of Anti-Anxiety Drugs and the Reality of Withdrawal," Author



Presentation objectives

1. Benzo Stories
2. Benzodiazepine Experience Survey
3. BIND Description
4. Life Effects
5. Lack of Support
6. Management of Symptoms
7. Resources



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Benzo Stories

- Christy's Story
- D's Story



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Christy's Story

- History
 - Xanax (0.25 mg), taken as prescribed for sleep during health crisis
 - Physical dependence, tolerance, and inter-dose withdrawal within 3 weeks
 - Used Ashton method to taper (Valium), then later micro-taper, took 3+ years
 - 3 years BZ free, still have protracted symptoms
- Effects
 - Experienced 80 distinct symptoms.
 - **Including:** Chemical terror, POTS/tachycardia, severe fatigue, memory loss, cognitive impairment, muscle spasm and pain, akathisia, suicidal ideation, severe nausea, GERD, sensitivity to light and sound, internal tremor, intrusive thoughts, heat and cold intolerance, chills
 - Lifestyle Effects
 - Inability to work, drive, care for my child, manage my household, cook, complete basic self care (shower), sometimes bedbound



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D's Story

- History
 - 12 years on clonazepam (1-2 mg daily)
 - Taken as prescribed by primary care physician for gastric distress — No warnings
 - Direct Taper / 18 Months
- Effects
 - Now 7 ½ Years Off — Protracted Condition — Daily symptoms and limitations of BIND
 - Over 50 distinct symptoms, many severe
 - **Including:** Extreme anxiety, panic attacks, depression, cognitive dysfunction, memory loss, anger/irritability, emotional blunting, suicidal thoughts, akathisia, facial paresthesia, pelvic floor dysfunction, gastric distress, urinary difficulties, abdominal distension, muscle aches and tears, heart palpitations, air hunger, gasping, flushing, personality changes, vertigo, sensory hypersensitivity, throat tightening, tinnitus, slurred speech, etc.
 - **Misdiagnosis:** Prostatitis / Prescribed fluoroquinolone (neuropathy)¹ / Increase in symptoms
 - Lifestyle Effects — Loss of Career / Loss of Freedom / Loss of Confidence / Loss of Self
 - New Life / Different Life — Book / Podcast / BAWG / Research Author

¹ Ashton 2002 / FDA 2018



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Benzodiazepine Experience Survey

- Introduction
- Demographics
- Patient Quotes



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Benzodiazepine Experience Survey

Introduction

- Online Survey
 - Internet survey
 - October 2018 - January 2019
 - Presenters Involvement
 - Christy Huff (Co-Creator, Author)
 - D E Foster (Statistician, Author)
- Publication
 - First paper published, others planned and in development
 - **Experiences with benzodiazepine use, tapering, and discontinuation: an Internet survey.** *Therapeutic Advances in Psychopharmacology*. Published April 25, 2022.

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

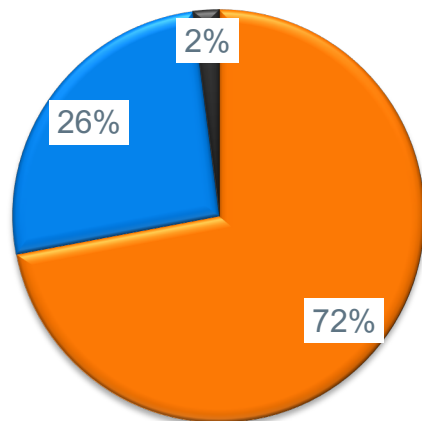
Finlayson 2022

Benzodiazepine Experience Survey

Respondents

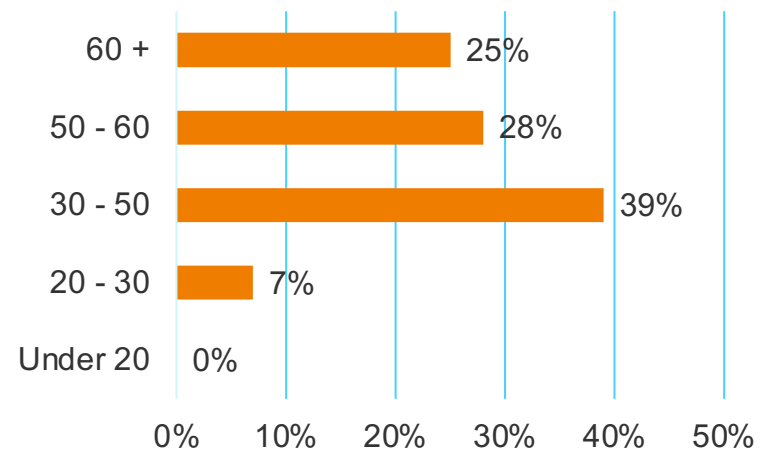
- **1,207** Qualified Respondents
- **77%** were from the United States

Gender



Female Male Other

Age



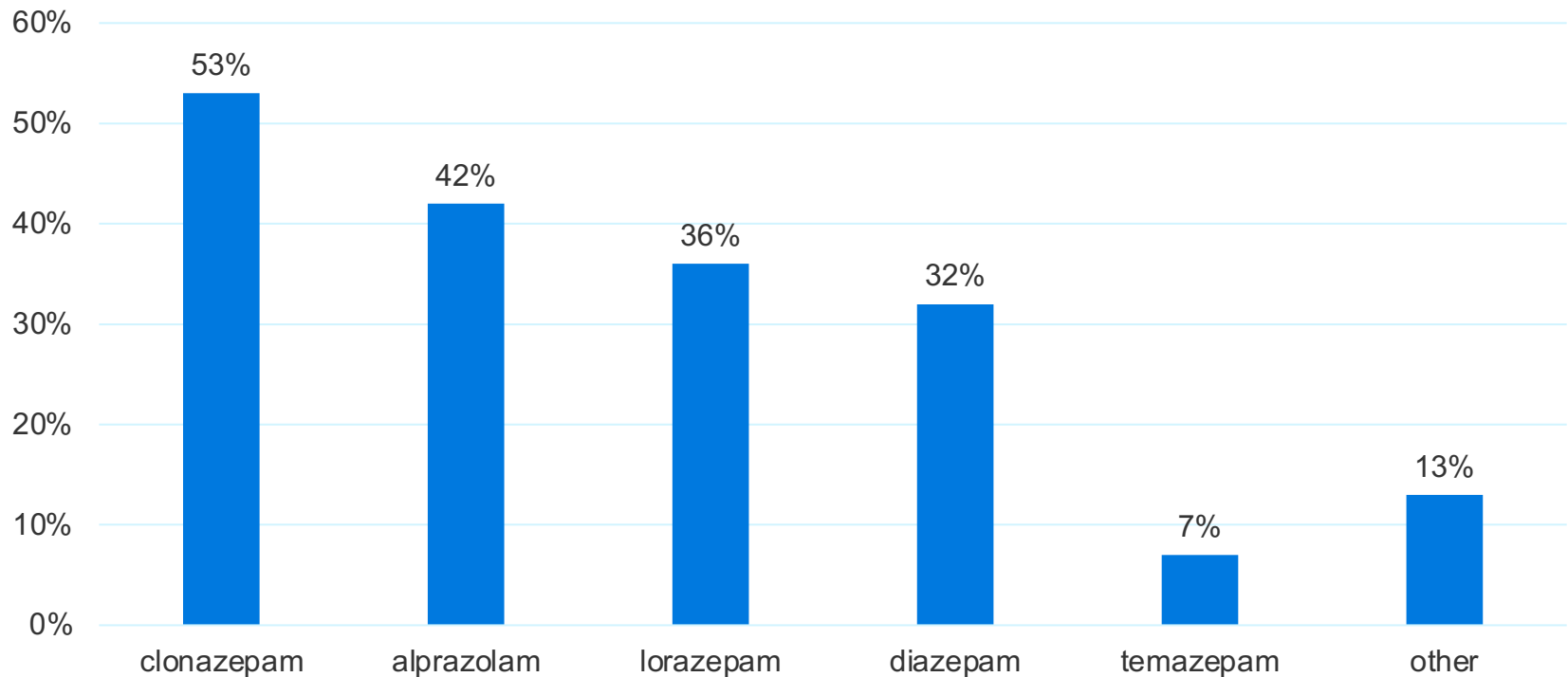
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Benzodiazepine Experience Survey

Benzo Usage

Type of Benzodiazepine

(some individuals took multiple benzos)



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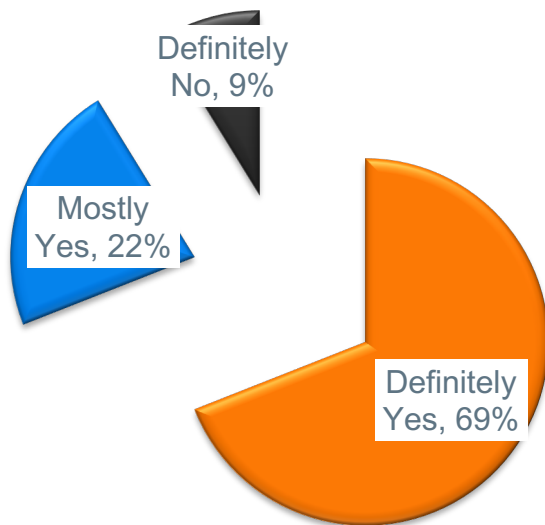
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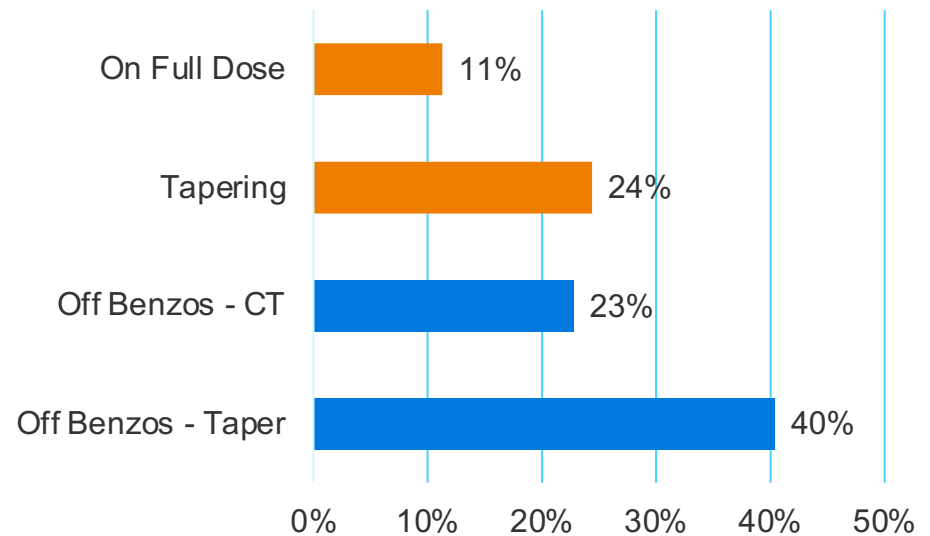
Benzodiazepine Experience Survey

Benzo Usage

Taken as Prescribed?



Taper Status



91% of respondents took their benzodiazepine (definitely or mostly) as prescribed

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BZ Experience Survey

Patient Quotes

"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."

"Benzos have completely destroyed my life, existence is beyond torture, I do not believe I will survive."

"I was constantly coming down with mystery illnesses from the drug and these illnesses required additional medications to cover up the problems. Doctors never once acknowledged the pills could be the reason behind my issues."

After 30 months of not taking BZ, one 10-year user said, "I'm still so violently ill. I'm bedridden most days with symptoms."

"It is important that we be believed when we report how horrific the symptoms are that we have experienced and they can go on for many, many years. One of the most brutal aspects to my withdrawal experience is that I was not believed and even laughed at."

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BIND Description

- Confusion / Terminologies
- BIND Definition
- Symptoms



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BIND Description

BIND: It's not withdrawal

- Doctors often trained to look for symptoms of w/d only

Other Terminology for BIND

- Protracted Withdrawal (PW)
- Post-Acute Withdrawal Syndrome (PAWS)
- Persistent / Prolonged Withdrawal Syndrome (PWS)
- Benzodiazepine Withdrawal Syndrome (BWS)
- Benzodiazepine Injury Syndrome
- Benzo Brain Injury
- Others



BIND Description

Definition

Benzodiazepine-Induced Neurological Dysfunction (BIND)

BIND is a constellation of functionally limiting neurologic symptoms (both physical and psychological) that are the consequence of neuroadaptation and/or neurotoxicity to benzodiazepine exposure. These symptoms may begin while taking or tapering benzodiazepines, and can persist for weeks, months, or even years after discontinuation.¹

14 Categories of Symptoms

- 7 Psychological
- 7 Physical

¹ Alliance for Benzodiazepine Best Practices 2022

BIND Description

Psychological Symptoms

Anxiety	Behavioral	Cognitive	Excitability	Perception	Sleeping	Social
General Anxiety (GAD)	Anger	Cognitive Dysfunction	Akathisia	Depersonalization	Insomnia	Agoraphobia
Hypochondria	Irritability	Memory Loss	Agitation	Derealization	Intrusive Nightmares	Anthropophobia
Panic Attacks	Rage	Intrusive Memories	Jumpiness	Hallucinations	Return of Dreaming	Haphephobia
Paranoid Thoughts	Aggression	Hypersensitivity	Restlessness	Misperceptions	Toxic Naps	Social Phobias
Phobias	Depression	Lack of Concentration	Restless Legs	Perceptual Distortions	Sleep Apnea	Isolationism
	Obsessions	Easily Overwhelmed				Emotional Distancing
	Apathy					
	Suicidal Thoughts					
	Personality Change					
	Psychosis					

BIND Description

Physical Symptoms

Abdominal / Gastrointestinal	Eyes, Ears, Nose & Mouth	Head & Neck	Heart & Lungs	Muscular	Nerve Sensations	Immune & Endocrine
Abdominal pain	Blurred Vision	Balance Issues	Heart Palpitations	Aches and Pains	Altered Sensations	Increased Infections
Appetite Change	Double Vision	Dizziness	Over-breathing	Electric Shocks	Hypersensitivity	Lowered Immune System
Benzo Belly	Difficulty Swallowing	Light Headedness	Chest Pain	Fatigue	Numbness	Breast Swelling
Constipation	Dry Mouth	Headache	Air Hunger	Sprains	Paresthesia	Breast Pain
Diarrhea	Strange Smells	Migraines	Gasping	Pulls & Tears	Formication	Menstrual Difficulties
Distention	Metallic Taste	Neck Pain	Flushing	Stiffness	Skin Rashes	Sexual Dysfunction
Inflammation	Oral Thrush	Slurred Speech	Sweating	Tremors	Itching	Loss of Libido
Nausea	Sore Eyes	Throat Tightening		Twitches	Tingling	
Groin Pain	Sound & Light Sensitivity			Jerks & Tics	Burning Skin	
Pelvic Floor Dysfunction	Tinnitus			Weakness		
Urinary Difficulties				Convulsions		
Weight Change				Paralysis		
				Seizures		

BIND Description

Benzodiazepine Experience Survey

Percentage of respondents who experienced top 12 symptoms

Symptom	Percent
Nervousness, anxiety, fear	88%
Sleep disturbances	87%
Low energy	86%
Difficulty focusing, distracted	85%
Sensitivity to light, noise, talk, smell, triggering symptoms	79%
Memory loss	77%
Digestion, nausea, diarrhea, other stomach/gut issue	75%
Head pain, pressure	72%
Trembling or tingling in limbs, skin	72%
Balance problems	71%
Uncontrollable crying or anger	71%
Muscle weakness	70%

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Life Effects

- Life Altering Condition
- Suicidality



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Life Effects

Life Altering Condition

- Career (financial hardship)
 - Loss of income
 - Loss of insurance
- Healthcare costs
- Relationships / family
- Judicial System
- Disability / mobility
 - Driving / transportation
 - Loss of independence
- Confidence / self-esteem



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Life Effects

Life Altering Condition

Benzodiazepine Experience Survey

Have your discontinuation symptoms affected...

Lifestyle Effect	Percent
Fun, recreation, hobbies	89%
Social interaction, friendships	86%
Ability to take care of home, others	85%
Relationships with spouse, family	85%
Work life	83%
Ability to drive or walk	76%

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Life Effects

Life Altering Condition

Benzodiazepine Experience Survey

Have you experienced any of the following consequences of withdrawal?

Lifestyle Effect	Percent
Significantly affected marriage, other relationships	57%
Suicidal thoughts or attempted suicide	54%
Lost a job, fired, became unable to work	47%
Experienced significant increase in medical costs	41%
Loss of wages or lower wages in a reduced job capacity	33%
Lost savings or retirement funds	27%
Violent thoughts or actual violence against others	24%
Lost a home	13%
Lost a business, if a business owner	8%
Lost child custody	3%

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Life Effects

Suicidality

- Statistics
 - **54% of survey respondents** reported suicidal ideation and/or attempted suicide ¹
 - A **review of 17 studies** found that benzodiazepines can be associated with increased suicide risk ²
- Causes
 - **Suicidal ideation can be a side effect or withdrawal symptom**, in the form of random, intrusive thoughts that encourage self harm
 - With BIND, there is also **weariness from severity/persistence of symptoms** and despair from not knowing if symptoms will improve

¹ Finlayson 2022

² Dodds 2017

Lack of Support

- Sources of Support
- Medical Community
- Family / Relationships
- Turning to the Internet



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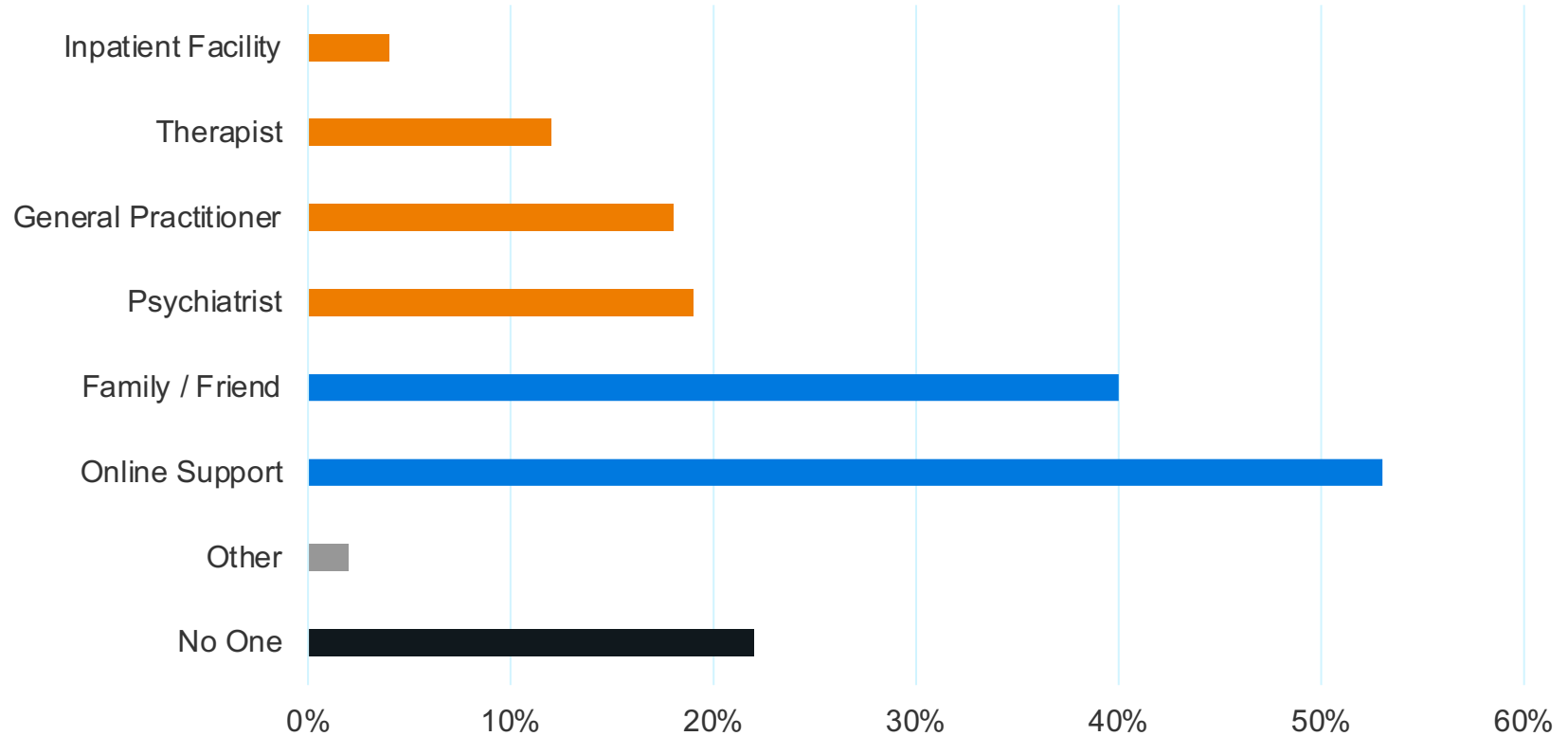


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Lack of Support

Sources of Support

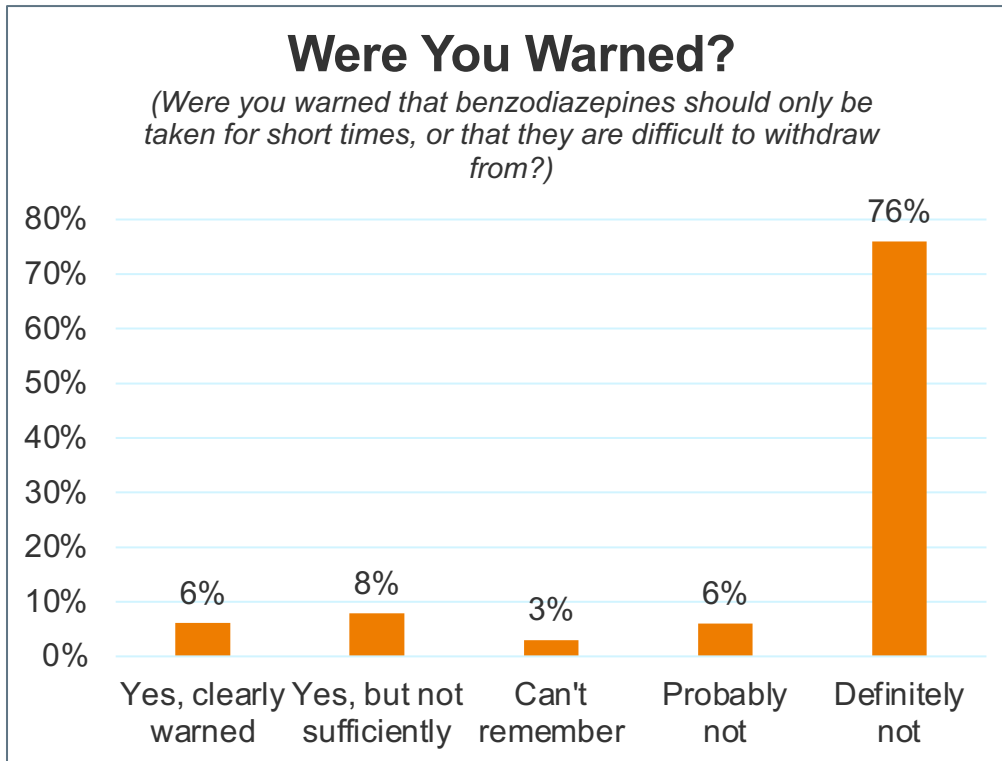
(Sources of assistance during withdrawal identified by 493 Benzo Buddies participants)



Pittman 2013

Lack of Support

Medical Community



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The FDA review that led to the updated BZ boxed warning in Sept. 2020 States that there is a *“lack of awareness or misconceptions among prescribers about appropriate management of patients taking benzodiazepines.”*



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US FDA 2020

Lack of Support

Medical Community



FDA Review

- 104 adverse event reports were reviewed.
- Common themes were:
 - **Misdiagnosis of BZ withdrawal** leading to increased dose of BZ
 - Can also lead to unnecessary medical testing and poly-pharmacy
 - Patients told they could **stop BZ abruptly** since it was a “low dose.”
 - Patients told to **taper too quickly** (e.g., halve the dose), resulting in withdrawal symptoms

US FDA 2020

Lack of Support

Medical Community

“While it might initially seem that these communities and video blogs are simply artifacts of the internet culture, a closer look at the stories told on these forums suggests a different message. The message is that physicians have been unprepared for these withdrawal disorders and are unable to treat or even guide patients through complicated withdrawal from these substances.”

— Psychiatric Times, 2018

Witt-Doerring 2018



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Lack of Support

Medical Community

- Symptom Identification / Confusion
 - Withdrawal vs. BIND
 - Misconception that symptoms would resolve within 10-28 days
 - BIND Symptom vs. Relapsing / New Medical Condition
- Distrust
 - Turn to alternative medicine
- Lack of Informed Consent
 - BAWG / BIC Informed Consent — benzoinfo.com/informed-consent



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Lack of Support

Family / Relationships

- 85% of survey respondents claim negative effects on family and home ¹
- Factors that can affect familial / friend support
 - Misunderstanding / Disbelief
 - Caretaker Fatigue
 - Severity & Duration of Illness
 - Loss of Income
 - Loss of Libido / Intimacy
 - Anger / Irritability
- Family / Relationship therapy can be beneficial

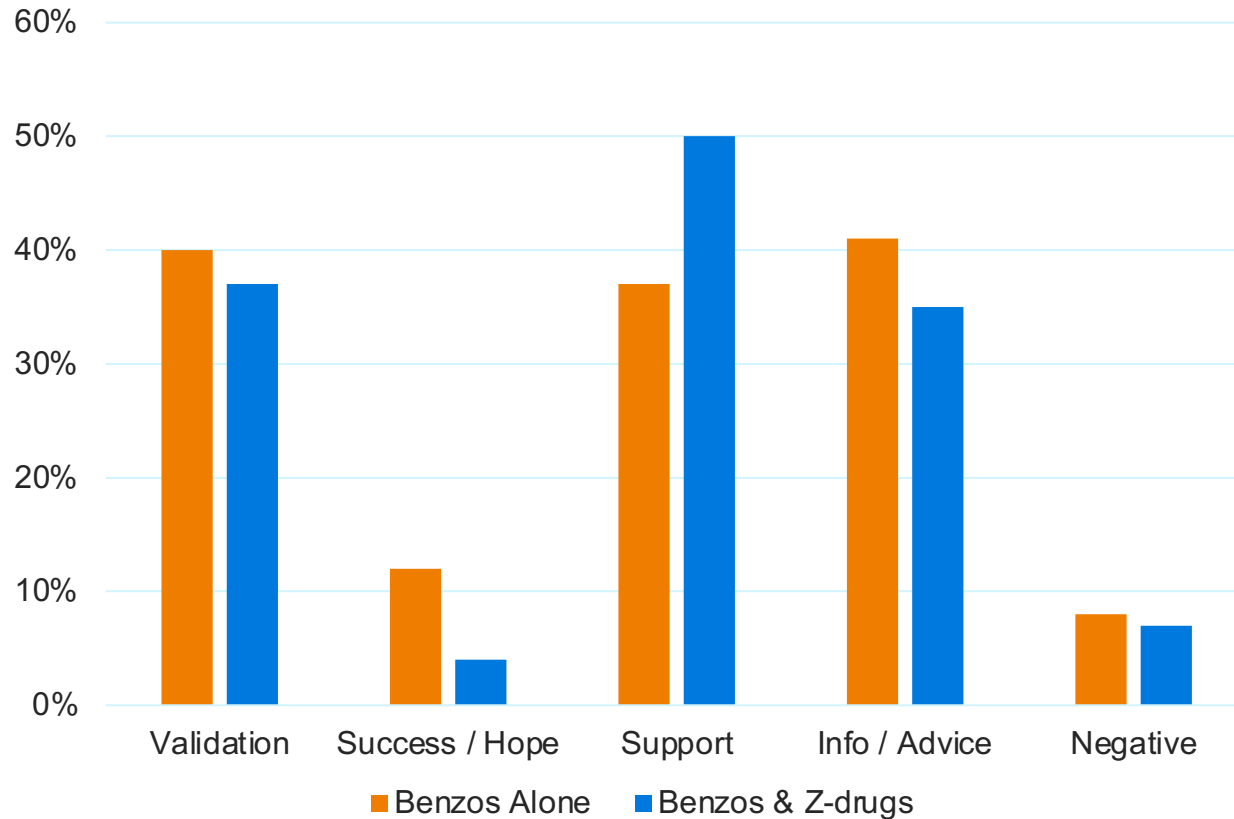


¹ Finlayson 2022

Lack of Support

Online Support

Benefits of Online Support (reported by Benzo Buddies members)



Lack of Support

Online Support (The Good, the Bad, and the Ugly)

- The Good
 - Support from individuals with similar experiences
 - Emotional Support / Friendship
- The Bad
 - Horror stories, talk of suicide can be triggering
 - Emotionally draining to support other members, when ill yourself
 - Misinformation / Bad medical advice
- The Ugly
 - These groups exist because BIND is not recognized
 - No formal support, so there is no where else to go



Management of Symptoms (Non-Medication)

- Counseling / Therapy
- Peer Support
- Alternative Treatments / Supplements
- Coping Skills / Lifestyle Modifications



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Management of Symptoms

(non-medication)

Counseling / Therapy

- CBT Treatment Efficacy
 - A 2017 NEJM review article on the treatment of benzodiazepine dependence states that good evidence exists for the use of Cognitive Behavioral Therapy (CBT) to **manage BZ discontinuation**.¹
 - A 2018 evidence-based clinical practice guideline on deprescribing BZs recommends CBT as a nondrug approach for **managing insomnia**.²

¹ Soyka 2017

² Pottie 2018



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Management of Symptoms

(non-medication)

Counseling / Therapy

- CBT Treatment
 - CBT can help develop coping skills and manage psychosocial stressors
- BIND Educated Therapy
 - If possible, utilize a therapist familiar with the unique challenges of BIND
- Limitations / Cognitive Impairment
 - Cognitive impairment and other symptoms may interfere with the patient's ability to retain new skills and put them into practice.



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Management of Symptoms

(non-medication)

Alternative Treatments / Supplements

- No where else to turn
- Trial and error
- Results vary / Individual
- Treatments
 - Massage / Acupuncture
 - Functional Medicine
- Supplements
 - Natural Herbs / Vitamins / Melatonin
- CBD/THC



Management of Symptoms

(non-medication)

Coping Skills / Lifestyle Modification

- Anxiety Management
- Acceptance
- Distraction
- Exercise
- Diet
- Sleep Hygiene
- Meditation / Yoga
- Stress Reduction



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Management of Symptoms

(non-medication)

Peer Support

- Primary tool for ongoing support
 - Those with lived-experience understand the true experience of BIND
 - Connecting with the patient / Validation
- Types of Peer Support
 - Online Groups / Coaching / Social Media / In-Person Support Groups
- Peer Support Documentation
 - BAWG Peer Support — benzoaction.org
- BAWG Peer Support Training Program
 - In Development (Deployment 2022)



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Resources

Resources

Lead Organizations

- Benzodiazepine Action Work Group (BAWG) — benzoaction.org
 - Colorado Consortium for Prescription Drug Abuse Prevention
- Benzodiazepine Information Coalition (BIC) — benzoinfo.com
- The Alliance for Benzodiazepine Best Practices — benzoreform.org
- Easing Anxiety (EA) — easinganxiety.com



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Resources

Physician Resources

- BAWG Prescribing & Deprescribing Guidance / Informed Consent — benzoaction.org
- Cooperative Doctors List — benzoinfo.com/doctors
- The Ashton Manual— benzoinfo.com/ashton

Additional Patient Resources

- Benzo Buddies — benzobuddies.org
- Benzo Warrior — benzowarrior.com
- Other discussion groups / Facebook groups / support groups



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Resources

Coaching / Therapy

- Jennifer Leigh, PsyD — benzowithdrawalhelp.com
- Baylissa Frederick, BMSc, MA — baylissafrederick.com

Peer Support

- BAWG Peer Support Guidance Document — benzoaction.org
- BAWG Peer Support Training Program (in development)

Podcast

- The Benzo Free Podcast — easinganxiety.com/podcast



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Resources

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Questions?

Benzodiazepine Action Work Group

Visit our webpage for more information on...

- Prescribing / Deprescribing Guidelines
- Informed Consent Information
- Links to Organizations and Resources
- How to Join the Work Group

BenzoAction.org



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