

**How do individuals in the UK experience recovery from  
prescribed benzodiazepine dependence and what helped?**

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## ABSTRACT

**Background:** Benzodiazepines are a class of drug prescribed mainly for anxiety and insomnia. Since 1988, UK guidelines have warned not to prescribe benzodiazepines for longer than 2-4 weeks, because they cause dependence and withdrawal symptoms that can last months to years. Despite this, an estimated 72% of prescriptions between 2015-18 in England exceeded 4 weeks. There is a lack of services available in the UK to support individuals struggling with dependence and withdrawal, and limited scientific literature available on the experience of, and how to support individuals with, recovery from benzodiazepine dependence.

**Aims:** This study aims to explore the experience of recovery from prescribed benzodiazepine dependence, what individuals found helpful during the recovery process, and their views on what future services should look like.

**Methods:** Qualitative data was collected through semi-structured interviews with seven participants who were prescribed benzodiazepines for at least 4 weeks, struggled with stopping or withdrawal symptoms, and stopped taking benzodiazepines at least one year ago. Interview transcripts were analysed using Reflexive Thematic Analysis within a phenomenological framework.

**Results:** Four themes were developed, which cover: (1) facing disbelief and failures in the healthcare system and consequent calls for improved education; (2) receiving and providing peer support; (3) the changing relationship to withdrawal symptoms during recovery, strategies used to cope with symptoms, and the persistence of post-withdrawal symptoms long after stopping; (4) severe suffering that can impact many different areas of life, can lead to enduring trauma, and requires holistic support.

**Conclusion:** This study demonstrates how some benzodiazepine patients endure severe suffering that can be unnecessarily exacerbated by disbelief and failures in the healthcare system, resulting in trauma and distrust of healthcare professionals. This situation could be improved by believing and validating patient experiences, so appropriate care can be received and further harm avoided. Counselling Psychologists may particularly need to focus on establishing trust, providing validation, and advocating for this client group. The findings further point to a need for improved education, commissioning of specialist services and a national helpline, updated NICE guidance, and improved monitoring of prescribing behaviour.

## INTRODUCTION

1.1 million adults in England were prescribed benzodiazepines in the year 2020-2021 (NHS England, 2023). Long-term use can cause severe adverse effects (Ashton, 2002) and dependence can occur after only 2 weeks (Higgitt et al. 1988). Therefore, national guidelines state that benzodiazepines should not be prescribed beyond 2-4 weeks (British National Formulary [BNF], 2022). Despite this, approximately 72% of prescriptions between 2015-18 exceeded 4 weeks (Davies et al., 2022). Withdrawal symptoms can last months to years (BNF, 2022; Lader, 1987) and the physical and psychological impact of withdrawal can be severe enough for some patients to lose their families, friends, livelihoods, or lives through suicide (Guy et al., 2018; Finlayson et al., 2022).

When seeking support, some patients report being disbelieved that they were experiencing withdrawal, receiving inaccurate information, or unhelpful responses from doctors (Guy et al., 2018). In terms of other avenues for support, there are no specialist national services for prescribed drug dependence in the UK and local services cover only 3% of the population (Guy et al., 2019b). Out of 1,200 psychological therapists surveyed, only 7.3% felt adequately trained to support clients with withdrawal or stopping prescribed drugs, despite almost all having discussed this with clients (Blair et al., 2021; Guy et al., 2019b). According to the Health and Care Professions Council (HCPC, 2015), Counselling Psychologists should “be able to critically evaluate psychopharmacology and its effects from research and practice” and “understand the impact of psychopharmacology and other interventions on psychological work with service users”. This does not seem to currently be possible due to limited research on how therapists can support recovery (Guy et al., 2019a; Taylor et al., 2019).

Research on recovery from benzodiazepine dependence is dominated by randomised control trials (RCTs), where the main outcome measure is often stopping benzodiazepines (Darker et al., 2015; Parr et al., 2009). Thus, most research appears to view stopping the drug as the endpoint and marker of successful treatment, despite the potential for distressing withdrawal symptoms to continue for months or years afterward (BNF, 2022; Lader, 1987). Recovery from benzodiazepine dependence can be complex and enduring, requiring longer term support addressing ongoing physical and psychological difficulties (Hamlin & Hammersley, 2004).

Some researchers have called to move research away from RCTs with limited useful impact on clinical practice, toward drawing on patient experiences (Groot & van Os, 2020). There is limited qualitative research on subjective recovery experiences beyond stopping benzodiazepines, what patients found helpful while and after stopping, and their views on what support services should look like. This research seeks to explore these questions, which are timely as Public Health England recommended further research in this area and commissioning of specialist services (Taylor et al., 2019). A phenomenological approach was chosen to explore benzodiazepine patients' ongoing recovery experiences, to attempt to amplify the voices of a group whose experiences are sometimes ignored or invalidated in the healthcare system thereby often causing them more harm (Guy et al., 2018).

## LITERATURE REVIEW

This chapter provides a critical review of the literature on withdrawal and recovery from prescribed benzodiazepine dependence, what might help during this process, and what support is available or should be available in the future. Due to limited qualitative research exploring ongoing subjective recovery experiences from benzodiazepine dependence, literature on antidepressants and recovery from mental health problems and addiction is included to provide background on relevant advancements in other fields.

### History and Background

Sedatives, now known as ‘anxiolytics’, for reducing anxiety, and hypnotics, for inducing sleep, have been used throughout history. These include opium preparations between the 16<sup>th</sup>-19<sup>th</sup> centuries, bromides and chloral hydrate in the late 19<sup>th</sup> century, barbiturates in the early 20<sup>th</sup> century, and benzodiazepines from the 1960s (Gabe, 1991). While each seemed initially well received, reports of adverse effects and dependence soon followed (Gabe, 1991; Lader, 2011). Critics describe this as “the ‘predictable cycles of opinion’ in which new psychiatric drug ‘treatments’ pass from accidental discovery, to glowing descriptions of safe and effective action for a range of previously problematic conditions, to reluctant acknowledgement of drawbacks, to tacit admission that the drug is ‘either useless, of very limited use, or even positively harmful’, at which point ‘the treatment is abandoned and the whole cycle starts again with something else’” (Johnstone, 2021, p. xix). Pharmaceutical companies can market drugs without no obligation to research whether patients experience problems while or after stopping them, or developing solutions for supporting patients if they do (Groot & van Os 2020).

By the 1970s, benzodiazepines became the most prescribed drug worldwide (Ashton, 2005), with the majority (70% in the UK (Taylor, 1987)) prescribed to women, often long-term (Ashton, 1991). Benzodiazepines were introduced as a ‘safer alternative’ to barbiturates, with low dependence risk (Ashton, 2005), but soon found to pose similar risks. Adverse effects of long-term use include: emotional blunting, anxiety, panic attacks, agoraphobia, insomnia, depression, paradoxical excitement (including aggression), impaired cognitive/psychomotor function, cognitive decline, accidents/injuries, suicidality (Ashton, 2002; Dodds, 2017; Ford et al., 2014; Lader, 2011; Neutel & Patten, 1997; O’Brien, 2005). Long-term use can exacerbate



symptoms benzodiazepines are meant to treat (Rickels, 1999). One study of 4,425 long-term patients taking benzodiazepines found that 61.2% met diagnostic criteria for generalised anxiety disorder and 22.5% for panic disorder, often with ‘marked severity and disability’, despite these being difficulties benzodiazepines purportedly treat (Pelissolo et al., 2007). By the 1980s, patients began coming forward noting tolerance, adverse effects, dependence, and withdrawal (Ashton, 1984, 1987). The Committee for the Safety of Medicines (CSM, 1988) warned that benzodiazepines can cause dependence and withdrawal, and limited prescribing to 2-4 weeks. Z-drugs, which share a mechanism of action with benzodiazepines (Peppin et al., 2020), were introduced to replace benzodiazepines for insomnia, with claims that these were not dependence-forming, but soon found to have the same drawbacks (Jones & Sullivan, 1998).

In 1982, the UK’s Medical Research Council agreed to conduct large scale research on long-term benzodiazepine use when research revealed brain shrinkage in patients (Lakhani, 2010). They never did and the documents were marked ‘closed until 2014’, perhaps because the Medicines and Healthcare Products Regulatory Agency overseeing drug safety is funded by pharmaceutical companies. From 1988-1993, 13,000 UK patients took legal action against pharmaceutical companies for failing to warn of benzodiazepine harms, but the case collapsed when legal aid was withdrawn (Davies, 1996). However, individual patients have successfully sued prescribers for mis-/long-term prescribing and excessively rapid withdrawal (a list can be found at <https://benzo.org.uk/legal/index.htm>).

## **Current Uses**

Benzodiazepines are predominantly prescribed for anxiety and insomnia, but also as muscle relaxants, anti-convulsants, pre-anaesthesia in surgery, and supporting alcohol withdrawal (BNF, 2022). Used appropriately and short-term, benzodiazepines can be beneficial: for example, controlling prolonged seizures, anxiety relief, or sleep induction. Benzodiazepines are, however, prescribed in care homes to dementia patients, often with no reason recorded or for behavioural and psychological dementia symptoms, contravening national guidance (La Frenais, 2021). Benzodiazepines are used in prisons, including for alcohol withdrawal or agitation during psychosis (Royal College of General Practitioners [RCGP], 2019). They are frequently prescribed to people considered to have severe psychiatric illnesses for sedation and ‘rapid tranquillisation’ for perceived aggression (Moncrieff, 2020). Psychiatric inpatients are

often prescribed benzodiazepines, including for vaguer perceived problems like general distress and ‘challenging behaviour’ (Moncrieff, 2020). Benzodiazepines are prescribed to children, but prescribing reasons data seem less readily available. Benzodiazepines are not recommended for anxiety disorders or insomnia in children and only indicated for anxiety or insomnia caused by fear (e.g., before surgery) or sedation during procedures (BNF for Children, 2023). However, some studies show that benzodiazepines are prescribed to children diagnosed with anxiety disorders in general practice and are the drug most commonly co-prescribed with antidepressants (Cybulski, 2022; Dai Cao, 2021). Evidence and national guidance supporting both is lacking.

### **Tolerance, Dependence, and Withdrawal**

Benzodiazepines increase activity of the inhibitory neurotransmitter gamma-aminobutyric acid (GABA), depressing the central nervous system (Ashton, 2002). Tolerance, where benzodiazepines stop creating the desired effect and a higher dose is required to do so, and physical dependence can develop after 2 weeks of continuous use (Higgitt et al., 1988), evidenced by withdrawal symptoms emerging when stopping (Hallstrom and Lader, 1981; Petursson, 1994). Withdrawal symptoms can last months to years after stopping (Ashton, 2002; Lader, 1987). Symptoms when reducing or after stopping can include: anxiety, panic attacks, insomnia, depression, suicidality, depersonalisation, derealisation, nausea, muscle pain/weakness, tremors, tinnitus, perceptual hypersensitivity, tachycardia, seizures, psychosis (Ashton, 2002; Busto et al., 1986; Lader, 2012; Olajide & Lader, 1984; Petursson & Lader, 1981; WHO Review Group, 1983). Most of these have been recorded at therapeutic doses (WHO Review Group, 1983) and due to tolerance are often experienced by long-term patients remaining on the same dose (Ashton, 2002). Those taking shorter-acting benzodiazepines can experience withdrawal symptoms *between* doses (Ashton, 2002). National guidelines state that prescribing should be limited to 2-4 weeks (BNF, 2022). Benzodiazepines should be withdrawn slowly at the patient’s own pace, as stopping abruptly can cause severe withdrawal symptoms, seizures, and death (Ashton, 2002; Ashton, 2005; Hu, 2011). In a survey of 1,207 patients, 97.2% of those who had tapered or stopped reported withdrawal symptoms, 36% reported some symptoms lasting months, while over 50% reported some symptoms lasting 1 year or longer (Huff et al., 2023).

## Definitions and Language

This thesis uses Public Health England's definition of dependence: "an adaptation to repeated exposure to some drugs and medicines usually characterised by tolerance and withdrawal [...]. Dependence is an inevitable [...] consequence of long-term use of some medicines and distinguished here from addiction" (Taylor et al., 2009). This definition is interchangeable with physical dependence (O'Brien et al., 2006). Addiction is defined as physical dependence alongside compulsory drug seeking and taking a drug despite negative consequences (Taylor et al., 2019; O'Brien et al., 2006). The ICD-11 (World Health Organization, 2019) and DSM-5 (American Psychiatric Association, 2013) differentiate patients taking benzodiazepines as prescribed from illicit use and misuse of prescribed benzodiazepines. However, the ICD-11 uses 'substance dependence' as an umbrella term for what is here defined as addiction/misuse, while the DSM-5 uses 'substance use disorder'. Both exclude those experiencing only tolerance and withdrawal, while the DSM-5 further excludes those who became dependent under medical supervision.

The position taken here is not that there is always a black-and-white distinction between these definitions of dependence and addiction. For example, individuals may become physically dependent through a prescription but need to acquire illicit benzodiazepines if prescribing is stopped abruptly or take more than they were prescribed due to suffering tolerance withdrawal from long-term prescribing and thus seek early repeat prescriptions (Taylor et al., 2019). The intention is to focus on patients whose suffering is primarily a consequence of prescribing. Inadequate diagnosis of these patients with addiction can lead to suboptimal care provision (Gleeson, 2019) and many are a poor fit for substance misuse services (Guy & Davies, 2018; Coombes & Cooper, 2019).

Prescribed benzodiazepine patients have long advocated to be distinguished from those using illicit substances or misusing benzodiazepines, to avoid deflecting blame from prescribers who caused the problem onto benzodiazepines patients (Downes-Grainger, 2009) and avoid the stigma of being viewed as a 'drug addict' (British Medical Association [BMA], 2015). The intention is not to stigmatise people who use illicit drugs but highlight the discrimination and inadequate support benzodiazepine patients often face (BMA, 2015). Benzodiazepine patients are often stigmatised as misusing drugs despite simply complying with medical advice, and

support groups and charities describe frustration toward doctors for blaming their patients for dependence (BMA, 2015). Pharmaceutical companies tried to deflect blame onto patients in the 1960s-1970s: dependence warnings claimed prescribing only posed a risk to those already ‘addiction-prone’ (Herzberg, 2009).

### **The Medicalisation of Distress**

Medicalisation has been defined as the social creation of illness, categorising ordinary life experiences as medical illnesses or ‘disorders’ that can only or primarily be understood and resolved through medical treatment (Illich, 1976). Medicalisation situates problems within the individual, rather than acknowledging and addressing contextual and systemic issues that may be causing distress (Moncrieff et al., 2005). Patient care can overemphasise medical treatment to the detriment of alternative approaches, while downplaying adverse drug effects. From the mid-2000s, the biomedical model and interventions underpinned by it, positing that distress is “rooted in an underlying disease mechanism or organic pathology” (Guy et al., 2019b, p. 9), have come under increasing criticism (Johnstone, 2021). Medicalisation is argued to have promoted harmful and unnecessary over- and long-term prescribing (Healy, 2012). United Nations Special Rapporteur psychiatrist Dainius Puras wrote in his report: “the field of mental health continues to be over-medicalised and the reductionist biomedical model, with support from psychiatry and the pharmaceutical industry, dominates clinical practice, policy, research agendas, medical education and investment in mental health around the world [...] There is also a bias towards first-line treatment with psychotropic medications, in spite of accumulating evidence that they are not as effective as previously thought, that they produce harmful side effects [...]. Despite those risks, psychotropic medications are increasingly being used [...].” (UN General Assembly, 2017, p. 6).

### **Benzodiazepine Prescribing**

1.1 million adults in England were prescribed benzodiazepines between 2020-2021 (NHS England, 2023). In 2019, Public Health England completed a comprehensive review investigating dependence and withdrawal from prescribed drugs, including benzodiazepines, in adults (Taylor, 2019). They found that prescription rates increase significantly with age, despite benzodiazepines posing a greater risk to older adults due to increased risk of falls,

fractures, and cognitive impairment (Izza et al., 2020; Ng et al., 2018). National guidelines state that prescribing to this population should be avoided (BNF, 2022). Women are over 1.7 times likelier to receive a prescription than men (Marsden et al., 2019). Scotland has higher prescribing rates, but the same rate of overprescribing to women (Scottish Government, 2021). No recent reports from Wales and Northern Ireland were found. Data on children is less readily available. Figures provided in response to a House of Lords question indicate anxiolytic and hypnotic prescribing, including benzodiazepines, increased by 57% from 2017/18 to 2021/22 with 122,181 under-18s prescribed these in England in 2021-22 (Johnston & Buckland, 2022; UK Parliament, 2022). Prescribing duration data was not found.

The majority of patients surveyed report never having been warned about adverse effects, dependence, or withdrawal by prescribers, with 0% in a UK study (Guy et al., 2018) and 6.1% in an international study including UK patients (Finlayson et al., 2022) reporting being warned. This contravenes national guidelines, requiring giving patients sufficient information about the risks of proposed treatment to consider consent valid (Department of Health, 2009; General Medical Council, 2020), known as informed consent. In England, an estimated 69.6% of individuals prescribed benzodiazepines in March 2018 were prescribed them continuously for at least 3 months, 50.4% for at least 12 months, and 31.5% for at least 3 years (Marsden et al., 2019; Taylor et al., 2019), despite these not being indicated for use beyond 4 weeks (BNF, 2022) since 1988 (CSM, 1988). Between 2015-2018, 67-72% of benzodiazepine prescriptions were unnecessary, contravening national guidelines by being prescribed beyond 4 weeks (Davies et al., 2022). This was described as low-value care: “interventions that provide little or no benefit to patients” and “have the potential to cause harm” (Davies et al., 2022, p. 1). An estimated £38.5-43 million was spent in 1 year on unnecessary benzodiazepine prescriptions in England.

When GPs were interviewed, needing to restrict prescribing was acknowledged, but many said that prescribing and long-term prescribing were legitimate for particularly ‘needy’, ‘deserving’ patients, including those experiencing ongoing difficult life circumstances and perceived as poorly equipped to deal with them, including being unemployed, from ‘dysfunctional’ families, unhappy marriages, having a partner who drinks, and domestic violence (Rogers et al., 2007). These are invalid reasons for prescribing, contravening national guidance (BNF, 2022). Some GPs disclosed that prescribing was not just about wanting to ease patients’ difficulties but

easing their own pain and putting off having to confront patients' real issues (Rogers et al., 2007).

### **Support Available**

UK guidelines for stopping benzodiazepines recommend a gradual reduction plan (tapering) to lessen severity of withdrawal symptoms or switching to an equivalent dose of longer-acting diazepam from short-acting benzodiazepines first, and state that counselling can help during and after tapering (BNF, 2022). However, even following a slow taper, severe withdrawal symptoms can continue for months or years (Lader, 1987). The guidelines advise that Cognitive Behavioural Therapy (CBT) may be offered if “available” and “considered necessary and appropriate” to ameliorate withdrawal symptoms. However, they claim that it may not be a suitable time to taper if patients are not psychologically and physically stable and present with depression or anxiety (Clinical Knowledge Summaries [CKS], 2022). This is problematic, because physiological and psychological problems, including depression and anxiety, are known adverse effects of long-term use (Ashton, 2002). Furthermore, despite reports documenting the harms of long-term use and lack of specialist support available (Reay, G., 2009; RCGP, 2013; BMA, 2015; Taylor et al., 2019), there are limited specialist services actually providing this type of support.

There are no specialist national services for prescribed drug dependence in the UK; local services cover under 3% of the population (Guy et al., 2019a). A 2018 search revealed only four UK specialist services for benzodiazepine patients, all NHS-funded, but three provided by charities and only one by the NHS (Guy & Davies, 2018). These had some commonalities, including GP/primary care service involvement, a helpline combined with counselling and/or support groups, and individually tailored support plans (Taylor et al., 2019). No information was provided on which interventions helped or how many patients reinstated after stopping beyond 12 months (Guy & Davies, 2018; Taylor et al., 2019). A recent study identified seven UK services for benzodiazepine patients, four with NHS providers, and surveyed providers to inform future service development (Cooper et al., 2023). Common practices included gradual, hyperbolic tapering using a patient-led, individualised approach, ongoing support and reassurance (including via helplines), psychosocial support including therapy, and embedding

lived experience throughout, from service founders, to hiring, peer support, and information sources used to support tapering.

Benzodiazepine dependence is theoretically managed in primary care (Lader et al., 2009), with patients given a tapering schedule to withdraw at home (Ashton, 2005). However, in a call for UK patient experiences on prescribed drugs including benzodiazepines, 69% of 158 respondents said doctors denied they were in withdrawal, were unhelpful, or gave inaccurate information, leading over half to distrust them and seek help elsewhere (Guy et al., 2018). Information sources patients found helpful were websites (35%), Facebook groups (18%) and prescribed drug charities (8%); only 1% found the NHS helpful. Due to doctors denying they were in withdrawal, “patients are finding themselves with vague diagnoses e.g. ‘medically unexplained symptoms’ or ‘functional/somatic system disorders’, which are essentially psychiatric diagnoses attributing various debilitating and disabling physical symptoms to patients’ own anxiety, beliefs, etc. This has the effect of discounting, disempowering and demoralising these patients still further” (Guy et al., 2018, p. 11). Doctors attributing withdrawal symptoms to a problem with the patient rather than the drug, lead to an additional diagnosis (25%), prescriptions for further drugs (17%), hospitalisation (15%), and at least one A&E visit (7%). This is also problematic, because stopping benzodiazepines is likelier to be successful if doctors recognise withdrawal symptoms, the first step toward supporting patients with managing them (Moncrieff, 2020). Patients reported that there was no pathway for feedback on their experience, for their voices to be heard (Guy et al., 2018). Patient experiences are “currently systemically not acknowledged, and so patients find themselves caught in a loop whereby the system designed to help them not only fails to do so but in many cases repeatedly compounds the problem” (Guy et al., 2018, p. 13). Montagu (2017, p. 119) states: “I was diagnosed with illnesses I did not have, treated with drugs which did not work and which ultimately caused me great harm. After being harmed, I suffered the double injustice of having that harm denied”.

In a 2015 call for evidence, the most cited example of suboptimal care was rapid tapering or sudden stopping of benzodiazepines (which can be fatal) by GPs, often without patient consultation or consent (BMA, 2015). In response, patients turned to support groups or withdrawal charities. Submissions from the RCGP, Royal College of Psychiatrists, support groups, and charities agreed that the barrier to GPs devising appropriate tapering plans was

lacking knowledge and training, meaning GPs can underestimate withdrawal severity, not recognise the difference between prescribed and illicit drug dependence, and devise rapid tapers potentially more appropriate for the latter. The report resulted in recommendations for a 24-hour national helpline, specialist services, and tapering and withdrawal guidance (Kmietowicz, 2016).

Public Health England's review called for a national helpline and website developed with experts-by-experience; commissioning specialist services; improved clinical guidance; training doctors; patient information about drug benefits, risks, alternatives, and informed choice; and research into withdrawal and treatment (Taylor et al., 2019). The then Secretary of State for Health committed to considering implementing a 24-hour national helpline and a working group was established to decide the scope and type of services needed (Davies et al., 2022). To date, nationwide specialist services have not materialised. The government were reportedly still 'assessing the evidence' for a helpline 2 years later (Robinson, 2021), despite this having already been recommended in 2015 (Kmietowicz, 2016). Meanwhile, the Bristol Tranquilliser Project, one of only two specialist services offering a limited helpline (20 hours a week) accepting calls throughout England and Wales, is closing as the NHS stopped the charity's funding (Nash, 2022; Bristol Tranquilliser Project, 2023). NHS England's (2023) implementation plan for Public Health England's review, recommends specialist services, training, education, and medication reviews encouraging deprescribing, with no mention of a national helpline.

The National Institute for Health and Care Excellence [NICE] guidelines were updated but appear to have failed to consider recent evidence, including patient experiences documented in the academic literature (Montagu, 2021). For example, the guidance states that when tapering, "stopping the last few milligrams is often seen as being particularly difficult", clinicians should reassure patients that "this is usually an unfounded fear derived from long-term psychological dependence", and to warn patients not to taper at an "extremely slow rate towards the end" (CKS, 2022). This guidance, based on Ashton (2002), is outdated, appearing to tell doctors that patients are merely imagining the final steps of the taper are particularly difficult and discouraging tapering as safely as possible. Up-to-date evidence suggests a 'hyperbolic' relationship between drug dosage and effects, meaning the same reduction at lower drug doses has a greater impact due these being a significantly larger reduction percentagewise, observed



in PET scans and patient symptom scores (Horowitz, 2022). Withdrawal symptoms likely become more severe with each dose reduction. Horowitz (2022, p. 6) recommends reducing the “dose by an amount that reduces the effect on target receptors in a linear fashion [...] making smaller and smaller dose reductions as the total dosage gets lower. [...] the final dose required before completely stopping will be very small, much smaller than commonly used doses, and in many cases much smaller than available tablet formulations. (Horowitz, 2022, p. 6).” This approach is recommended in the *Maudsley Prescribing Guidelines in Psychiatry* (Taylor et al, 2021) and used in specialist withdrawal services (Cooper et al., 2023).

### **Psychological Practice**

If there are limited specialist services and patients feel unsupported by doctors, are psychological therapists in a position to provide some support? It has been argued that benzodiazepine withdrawal requires integrated support addressing both physical and psychological difficulties (Hamlin & Hammersley, 2004). In a UK survey of 1,200 practising psychological therapists, 96.7% said they are working with at least one client taking prescribed drugs, including anxiolytics; for 50%, this applied to over half of their clients (Guy et al., 2019b). 92.7% had had clients discuss withdrawing from or stopping their prescribed drugs with them (Blair et al., 2021). However, 42.5% lacked confidence about knowing where to find useful information on working with them most therapeutically, only 7.3% reported having adequate training to do this very well, and 93.1% wanted professional guidance (Guy et al., 2019b).

In 2019, professional bodies, academics, professionals, and experts-by-experience created the *Guidance for psychological therapists: Enabling conversations with clients taking or withdrawing from prescribed psychiatric drugs* (Guy et al., 2019b), to enable therapists to speak to clients and prescribers and recognise and work with the impact of prescribed drugs on the therapy process. The guidance states: “it will be helpful if therapists are aware of [...] the process and possible experiences of withdrawing from prescribed psychiatric drugs” (Rizq et al., 2019, p. 30). It emphasises the importance of planning withdrawal, understanding withdrawal effects, and the impact on clients’ support networks. It highlights the broader impact on individuals’ lives, including when withdrawal is not understood by family members or perceived to be an ‘over-reaction’ (Read et al., 2019), and that withdrawal can be severe

enough to lead to loss of family/friends/jobs/home, bankruptcy, and suicide (Guy et al., 2018; Finlayson et al., 2022). They proposed a ‘combined wisdom’ approach for supporting withdrawal, summarising experiential, theoretical and anecdotal sources (Guy et al., 2019a). They emphasise the importance of accessible, accurate information, involving an informed prescriber in the taper, access to client-centred support, information and support around coping strategies, and client and therapist both suspending their usual assumptions about the sources of distress during withdrawal. Suggested coping tools include acceptance/non-resistance, mindfulness, positive self-support/-talk, breathing exercises, Emotional Freedom Technique, exercise, faith, grounding, healthy distractions, hobbies, meditation, self-compassion, sleep, diary-keeping, visualisation, and de-catastrophising. However, this combined wisdom approach was adopted due to a lack of formal research on what therapeutic strategies effectively support withdrawal (Guy et al., 2019a).

## **Treatment Research**

The recovery from benzodiazepine dependence field is dominated by positivist, quantitative research involving RCTs. A meta-analysis of RCTs using pharmacotherapies, including flumazenil, antidepressants, pregabalin, or valproate, to support benzodiazepine withdrawal concluded that there appears to be insufficient quality evidence supporting their use, due to lack of reporting on adverse effects and patient-centred and long-term outcomes (Baandrup et al., 2018). Meta-analyses of RCTs on psychosocial interventions, such as CBT or sending psychoeducational letters, found that most studies had low participant numbers and followed up for less than 12 months post-intervention (Darker et al., 2015; Parr et al., 2009), despite the potential for withdrawal symptoms to continue for months to years (BNF, 2022; Lader, 1987). Many benzodiazepine patients attempt to withdraw more than once and reinstate the drug again after stopping; longer term follow-up studies show substantial reinstatement rates post-treatment (Golombok et al., 1987; Morin et al., 2005). There has also been difficulty achieving high stopping rates in RCTs (Parr et al., 2009).

While there was evidence for the effectiveness of CBT and taper vs taper alone at 1-3 months, no difference was found from 6-24 months (Darker et al., 2015; see also Takaesu et al., 2019). There was also insufficient evidence for the effectiveness of motivational interviewing (Darker et al., 2015). The few studies identified as successful in one meta-analysis (Darker et al., 2015)

either excluded a wide range of patients or were effective only for a highly motivated subgroup, giving little indication of *how* people withdrew, coped with withdrawal, or the experience of the ongoing recovery process. For example, Ten Wolde et al. (2008) found that sending a tailored vs generic letter to long-term benzodiazepine patients significantly led to stopping, 51.7% and 35.6% respectively. However, this effect only held for individuals who rated their intention to stop as high beforehand, with no indication given of why their motivation was high or how they withdrew in comparison to those who were unable to. The only outcome measure used was “Are you using benzodiazepines? yes/no” at 12 months. Providing basic information could be a promising avenue demonstrating that low-cost, easily deliverable interventions explaining benzodiazepine harms and gradual tapering as a blanket intervention across long-term patients identified in primary care records could reduce long-term use for patients without comorbidities who can withdraw with *minimal to no support* (Lynch et al., 2020; Ten Wolde et al., 2008) but does little to advance practice and research on supporting those that struggle.

Vicens et al. (2006) found that significantly more people had stopped at 12 months with standardised advice and biweekly GP follow-ups vs routine care but did not indicate whether routine care patients visited the GP with the same frequency or what routine care entailed. As with Ten Wolde et al. (2008), the study seems to simply indicate that routine care currently does not involve informed consent and basic patient care. ‘Standardised advice’ included providing information on adverse effects, dependence, tolerance, withdrawal, and a safe tapering plan. The only outcome measure used was whether patients reduced or stopped. They also excluded so many different groups, rendering this intervention helpful for the ‘perfect patient’ only. Among the exclusion criteria were known adverse effects of long-term use (Ashton, 2002; Barker et al., 2004): severe anxiety/depression, cognitive impairment, increased anxiety and insomnia. Furthermore, most patients included were on a low dose of 10mg diazepam or less. Another study on the effectiveness of group therapy alongside tapering found that nobody taking over 10mg of diazepam or who drank more than 2 alcohol units a day stopped benzodiazepines long term (Oude Voshaar et al., 2006). A recent meta-analysis of brief primary care interventions, face-to-face consultations or written information advocating gradual tapering, concluded that these were likelier to lead to patients stopping than routine care (Lynch et al., 2020). However, only two out of eight studies included followed up beyond 6 months and these employed the stringent exclusion criteria outlined above (Vicens et al., 2006; Vicens et al., 2014).

Effective interventions identified in Lynch et al.'s (2020) meta-analysis were 'information about health consequences' and a 'credible source' (Lynch et al., 2020). However, this again points to a lack of informed consent at the prescribing stage, given that information about health consequences of benzodiazepine use is part of the 'essential requirements of care' in national guidelines, and thus should have been given *prior* to prescribing anyhow (NICE, 2021). Providing this information to someone already on long-term benzodiazepines is also standard practice (NICE, 2022b). Perhaps the more useful question is not whether current guidance works, but *whether it is*, or *why it is not*, being followed, and the impact on patient experiences. Indeed, an international study, including UK patients, found that 76.2% said prescribers 'definitely did not' inform them that benzodiazepines should only be used short-term, with only 6.1% saying they were 'clearly warned' or 'warned' (Finlayson et al., 2022).

Overall, reviews of the literature seem to indicate that doing something works better than doing nothing, with little indication of whether these effects hold long term (Darker et al., 2015; Parr et al., 2008; Lynch et al., 2020). Some interventions identified as successful involved providing information that patients should already be routinely provided with (Ten Wolde et al., 2008; Lynch et al., 2020; Vicens et al., 2006) but may not be. Many also appear to target patients likeliest to stop with little or no difficulty or support as they use minimal/brief interventions only. Exclusion criteria in RCTs, while often necessary, can compromise external validity as they are not representative of the population they serve (Humphreys & Weisner, 2000); comorbidity is the rule not the exception (Westen et al., 2004). Furthermore, withdrawal experiences vary both *between* and *within* individuals. Thus, an RCT 'evidence-based' treatment may never be found and trying to impose one may be harmful to patients who fall outside of what is deemed to help the majority of participants in a non-representative sample (Groot and van Os, 2020). Groot and van Os (2020, p. 6) state: "the 'evidence-based-model' of medical science has led to a culture of substantially ignoring patient experiences". Due to substantial variance in experiences throughout the population, even with a more representative sample RCT "outcomes are not meaningful for the most vulnerable patients at the end of skewed distributions" (Groot & van Os, 2020, p.8). They reference the harm done when RCT evidence was used in the Netherlands to set faster tapering rates than were tolerable for some patients. They argue that accepting and working with the uncertainty involved may be more meaningful than unrealistically expecting RCTs to improve models predicting outcomes.

Instead of asking the black-and-white question ‘what’, we can ask ‘how’ and ‘why’, allowing for exploration of subjective experiences (Simpkin & Schwartzstein, 2016). RCTs focus on *whether* change occurred but not *how*, which is sometimes of more interest to Counselling Psychologists (Bury & Strauss, 2007). RCTs operate on a positivist, realist paradigm, assuming that treatment is like a cause-and-effect medical intervention administered, like a ‘drug’ to an ‘ill’ patient, that can quickly change longstanding problems (Orford, 2008; McLeod, 2001). RCTs assume that stopping benzodiazepines is all there is to recovery, measuring this as the main desired outcome, which ignores variable subjective experiences, the potential for post-/protracted withdrawal symptoms, and the substantive ongoing physical and psychological healing process some patients need to undertake (Hammersley, 2001; Fixsen, 2015; Fixsen & Ridge, 2017). Online support forum *BenzoBuddies* (2013) has a dedicated ‘Post-Withdrawal Recovery Support’ section, while research exploring persisting post-withdrawal problems (LaCorte, 2018) and strategies to support individuals with these is ‘hardly existent’ (Cosci & Chouinard, 2020).

As previously outlined, patient experiences appear to have also been neglected when drafting the new NICE guidelines, in favour of RCTs that provide little new or useful information (Montagu, 2021). NICE guidelines are created using a hierarchy of evidence that considers RCTs the gold standard but are meant to allow for using qualitative and quantitative evidence submitted by stakeholders, observational data, and expert-by-experience testimonies. However, patient experiences and academic research based on these were neglected, meaning that evidence and thus clear instructions on how to taper safely were excluded, as RCTs have not yet covered this area (Montagu, 2021).

## **Recovery**

There have been calls from the prescribed harm community and allied researchers to move the prescribed drug dependence field from focusing on RCTs which have yielded limited clinically useful results (Groot & van Os, 2020) to drawing on patient experiences and knowledge (Fixsen & Ridge, 2017; Hengartner et al., 2020; White et al., 2021). There have been similar movements in other fields such as mental health and addiction. While prescribed drug dependence is iatrogenic and *not* addiction or a mental health problem, these fields are used as

reference points below as this shift is arguably still in its infancy in the prescribed drug dependence literature.

Paradigm shifts in mental health and addiction treatment and research have been proposed for moving from a disease-centred model looking at testing formal evidence-based interventions to a long-term recovery model prioritising individual experience and meaning (Davidson, 2003; Slade, 2009; Spaniol et al., 2004; White, 2004). In the former, medicalised approach, recovery is an objectively measurable clinical outcome defined by clinicians, pathology measures, and diagnostic manuals, which does not vary between individuals (Slade, 2009). In RCTs, ‘recovery’ seems to be conceptualised as a stable, objectively observable phenomenon, generally measured as stopping benzodiazepines. RCTs also often assume a linear cause-and-effect relationship between treatment and stopping (Orford, 2008). In contrast, a long-term recovery approach conceptualises recovery as a *non-linear, ongoing process* and *personal experience*, defined subjectively with different meanings for different people, although there are shared aspects to the experience (Leamy et al., 2011; Slade & Longden, 2015, White et al., 2005). The non-linear nature of recovery from benzodiazepine dependence is highlighted in patient accounts of often unpredictable ‘waves’ (exacerbation of symptoms) and ‘windows’ (relieve from symptoms) (Fixsen, 2015; Fixsen & Ridge, 2017; Frederick, 2014). Patients describe long, ongoing recovery journeys continuing well beyond when they stopped benzodiazepines (Fixsen 2014; Fixsen & Ridge, 2017). Finally, recovery is about subjective quality of life rather than just being drug or symptom-free, and achievable without professional support (Anthony, 2000; Leamy et al., 2011; White et al., 2005; White, 2007). A survey of specialist prescribed drug services, where lived experience is embedded throughout their practices, found that these prioritise quality of life, with successful outcomes seen as “subjective to each patient” (Cooper et al., 2023, p. 17).

Prescribed drug dependence seems unique in that unlike mental health or addiction, few specialist services are available; many, if not most, patients will *have to* try to recover without formal treatment. Treatment is only one of many factors that can support recovery and many recover without formal treatment (Anthony, 2000; Slade & Longden, 2015; White et al., 2005). Even when treatment helps, it is only a time-limited piece of a longer recovery journey (Perkins, 2012; White, 2004). It has been argued that treated recovery and recovery without formal treatment may not be as distinct as believed and bringing both research streams together

may shed light on common change processes underlying all recovery (Orford, 2008; DiClemente, 2006) allowing psychologists to aim to reinforce these (Moos, 1994). For example, patient experiences of mental health recovery emphasise factors including connectedness with others, meaning in life, identity, hope for the future, and empowerment (Leamy et al., 2011) which can occur outside of treatment. Unfortunately, most of the aforementioned literature is from the mental health and addiction fields, as there is limited prescribed drug dependence literature available on personal recovery experiences. This may be because patients are still fighting for recognition and services. The partial and gradual shift to a recovery model in mental health and addiction began in the 2000s (White, 2005), while academic and public interest in prescribed benzodiazepine dependence peaked in the 1980s-90s (Gabe, 1991), but appears to have been comparatively underresearched until recently.

A personal recovery approach highlights and aims to change the balance of power (Perkins, 2012). While the dominant approach is arguably one where clinicians “define the patient’s reality in terms that their profession has invented, then try to persuade the patient of the veracity of [their] explanation”, personal recovery emphasises that “each person is the expert in their own recovery and has a right to define their own reality” (Perkins, 2012, p.17). This approach places experts-by-experience at centre stage, with clinicians in supporting roles as and if needed. Power issues need highlighting in recovery from prescribed benzodiazepine dependence, because many patients reporting being disbelieved about their experience and harmed with additional diagnoses and prescriptions, when they themselves knew what was happening (Guy et al., 2018). Many patients experience harm from doctor-led, ‘evidence-based’, one-size-fits-all tapers, leading to calls for shared decision-making, as patients often know their own needs better than their doctors (Groot & van Os, 2020).

### **Patient Experiences and Knowledge**

Due to a lack of formal support and scientific literature, patient experiences and initiatives, predominantly online, have become the main guide to recovery from prescribed drug dependence (Groot & van Os, 2020; Guy et al., 2018; White et al., 2021). However, patient knowledge and experiences have mostly been ignored in the scientific literature, clinical guidance, and psychiatry (Groot & van Os, 2020). The *Guidance for Psychological Therapists*

(Guy et al., 2019b) is a notable exception, because it is co-authored with experts-by-experience and draws on experiential accounts and studies using a range of methodologies.

Limited attention has been paid to benzodiazepine patient experiences shared and support provided within online support groups (notable exceptions being Fixsen, 2015; Fixsen & Ridge, 2017), despite these potentially providing most UK withdrawal support (Guy et al., 2018). Many patients share their experiences online; for example, 14,000 personal YouTube videos were found on “benzo withdrawal” (Witt-Doerring et al., 2018). Peer support websites have tens of thousands of members. In December 2021, [www.benzobuddies.org](http://www.benzobuddies.org) had over 89,000 members and the 23 benzodiazepine support groups found on Facebook had over 44,900 members between them. Thus, benzodiazepine patients clearly want to share their experiences and learn from others’ experiences. Online support groups facilitate information sharing, instilling hope, and taking control of and sharing experiences, which may be especially important as benzodiazepine patients’ experiences are often invalidated or stigmatised (Fixsen, 2015).

### **Antidepressant Patient Perspectives**

While research into benzodiazepine patients’ experiences is limited, studies exploring the experiences of patients on antidepressants, which cause dependence and similar withdrawal phenomena (Nielsen et al., 2012), demonstrate the value of such research. In international surveys of over 1,000 antidepressant patients each, less than 5% reported being informed about adverse effects (Read & Williams, 2018), less than 1% reported being told about withdrawal (Read et al., 2018), 82% reported prescribers were unfamiliar with withdrawal symptoms, 71% found doctors’ advice on stopping unhelpful, and 60% reported GPs denied that stopping could cause withdrawal symptoms (Read et al., 2023). In a call for UK patient experiences, respondents reported doctors not informing them about the risk of withdrawal, not recognising withdrawal symptoms, lacking knowledge on safe tapering, and misdiagnosing with relapse of their underlying condition/a different illness (rather than withdrawal); patients thus sought support outside of mainstream healthcare, including online (Guy et al., 2020). Support groups have proliferated on Facebook (White et al., 2021) and researchers have drawn on user experiences and data to inform scientific literature and clinical practice. In a study examining Facebook support groups, 80-90% in one group stated that they sought support online due to a



failed clinician-led taper (White et al., 2021). Patients reported that what they need most from services is appropriate tapering support: access to smaller doses, flexible, personalised reduction schedules, regular follow-up monitoring (Read et al., 2023). Patient experiences online have also been explored to highlight heretofore minimised or neglected withdrawal, post-withdrawal, and protracted withdrawal symptoms, and inform clinical practice (Belaise et al., 2012; Hengartner et al., 2020; Stockmann et al., 2018). Experts-by-experience have also authored academic literature imparting experiential knowledge from providing support to thousands online (Framer, 2021) to individual testimonies (Stockmann, 2019). Research indicates that patients are often misdiagnosed by doctors as experiencing ‘relapse’ of their original condition (e.g., depression, anxiety) but patients themselves can differentiate between withdrawal and symptoms of their original difficulties because symptoms are unprecedented, qualitatively different, severe, and irregular rather than consistent (Framer, 2021; Hengartner et al., 2020). Hengartner et al. (2020) argued that this demonstrates the importance of including subjective patient experiences in clinical assessment, diagnosis, and research. These studies also highlight the heterogeneity of withdrawal phenomena in antidepressants (Hengartner et al., 2020), which appears to apply to all psychotropic drugs including benzodiazepines (Lerner & Klein, 2019).

### **Benzodiazepine Patient Perspectives and What Helps**

Research from the benzodiazepine patient’s perspective has mainly focused on areas such as prescribing reasons, use patterns, perceptions of dependence, views on doctors and support available, reasons for stopping, and strategies that helped with withdrawal up to the point of stopping, mainly in treatment studies, or using questionnaire data and brief structured interviews (Allary et al., 2020; Canham et al., 2014; Cook et al., 2007; Cormack, 1989; Mokhar et al., 2019; Parr et al., 2006; Sirdifield, 2017). However, there is limited research exploring ongoing recovery experiences *after* stopping or what helps at this stage. Extra-treatment factors cited for stopping benzodiazepines in some treatment studies were good social support (Allary et al., 2020), alternative consumption (e.g., drinking more tea), and alternative therapies (Cormack, 1989). Reasons for stopping in one study were realising benzodiazepines were interfering with their lives and relationships, and strategies used to stop involved changing how they thought (believing in themselves and their abilities to cope without benzodiazepines), tailored tapering plans, stopping abruptly (which can be fatal), and lifestyle change (Parr et al., 2006). Barriers were inability to cope with withdrawal symptoms, lack of support from

doctors/peers/specialists, and experiencing anxiety/depression. When asked what would help them to cope with the difficulties the drug was originally prescribed for in the future, they said activities (tai chi, strenuous exercise, yoga, work, creative arts), lifestyle/diet changes, alternative drugs/therapies (valerian, acupuncture, antidepressants), avoiding activities that exacerbate their medical conditions, more sleep, and realising there are other ways of dealing with problems (Parr et al., 2006). Benzodiazepine patients in another study only identified abrupt cessation of prescription (which can be fatal) or being urged to stop as a lever for change (Mokhar et al., 2019).

An Irish study using semi-structured interviews with patients on and off benzodiazepines, about barriers and facilitators to stopping, concluded that each participant has a unique experience, and thus interventions may need to be tailored individually (Lynch et al., 2021). Questions were structured around strategies/skills more than experience, with stopping the end goal rather than achieving subjective wellbeing in long-term recovery beyond stopping or exploring post-/protracted withdrawal phenomena. There was some exploration relevant to coping beyond stopping. However, the authors echoed Parr et al.'s (2006) questioning style, asking how patients coped/would cope with re-emergence of the symptoms of the condition the drug was prescribed for originally. This is a potentially harmful message to communicate, as it could perpetuate the belief that an original 'condition' emerges upon stopping that they may be unable to cope with, legitimising the medicalisation of distress and diagnostic explanations, disregarding that this could be withdrawal (often mistaken for 'relapse' of the original condition). An alternative way of addressing this could be asking about coping with withdrawal symptoms, as well as acknowledging that benzodiazepines suppress normal emotional reactions so long-term patients often need to relearn how to cope with normal emotions again (Moncrieff, 2020), and asking how they might cope/coped with these. In response to this question, participants who had stopped identified sleep hygiene, exercise, mindfulness, meditation, counselling and CBT, positive self-talk, and breathing techniques. Barriers to stopping included doctors not supporting their request to stop, not reviewing their medication, or not discouraging long-term use. The most commonly reported stopping strategy was gradual tapering, but all participants withdrew at different rates, with some withdrawing dangerously fast or stopping abruptly and at least one reporting a seizure as a consequence. While participants used online support sites, some reported that this was a 'double-edged sword': negative information on these could be triggering and provoke fear. The researchers

did not record how long it had been since participants stopped benzodiazepines and excluded participants experiencing cognitive impairment. Cognitive impairment is a known adverse effect of long-term use and while cognition improves after stopping, patients may still experience significant impairment 6 months after stopping (Barker et al., 2004). Thus, the experiences of those who experienced significant harm from benzodiazepines may have unintentionally been omitted.

In a continuation of this work, Lynch et al. (2022) developed an intervention toolkit for primary care clinicians of recommendations that can be selected for an individually tailored approach. This was codesigned with experts-by-experience, which seems apparent in the study's sensitivity to language. For example, 'commitment' was excluded as a behaviour change technique, as this may imply that people unable to stop benzodiazepines lack commitment (the NICE guidelines, in contrast, suggest people who are not "willing, committed, and compliant" may not be suitable to have withdrawal managed in primary care (BNF, 2022) despite there being no real alternative across most of the UK). One recommendation under 'habit reversal', is avoiding "any connotation between this [technique] and drug addiction or abuse" (Lynch et al., 2022, p. 9), a point rarely addressed in the academic literature. Another benefit is that the toolkit is meant to be a 'living resource', welcoming feedback from user experience, regular reviews, and updates. However, they do not address how they intend to get primary care clinicians to *use* this toolkit, in a climate where the majority do not appear to be following even the most basic duty of care by obtaining informed consent before prescribing benzodiazepines (Guy et al., 2018; Finlayson et al., 2022). Furthermore, the toolkit focuses on stopping benzodiazepines but not how to support recovery beyond this.

Finlayson et al.'s (2022) quantitative, international survey is a notable exception in research from the benzodiazepine patient's perspective, taking a holistic view and looking beyond stopping as a marker for a successful 'outcome'. They asked respondents about the adverse consequences dependence and withdrawal had on their lives, including a significant impact on marriage/relationships (56.8%), suicidal thoughts/attempted suicide (54%), job loss/being fired/unable to work (46.8%), and new medical conditions. 31.5% reported new allergies and 18.1% an autoimmune disorder diagnosis after starting benzodiazepines; it is unclear whether these continued after stopping. The researchers allowed for free-form comments but did not qualitatively analyse these. They show fruitful areas for future research, including experiences

and impact of mistreatment and misrepresentation of benzodiazepine risks by doctors, limited tapering options due to difficulty finding knowledgeable support, personal/professional losses due to benzodiazepine use/tapering/withdrawal, and suicidality after stopping. This highlights how much more complex dependence and withdrawal are than simply stopping benzodiazepines, and how much more there may be to ongoing recovery.

### **Therapist Perspectives on Ongoing Recovery**

In contrast to the research focused on stopping benzodiazepines that dominates the field, Counselling Psychologist Hammersley's (2001) thesis exploring 26 therapists' perspectives on the process of therapy with benzodiazepine patients is one of the only pieces of qualitative research providing clues to the complex nature of recovery experiences beyond stopping. While the focus is benzodiazepine patients in therapy, more nuance is revealed than in positivist, quantitative treatment studies or qualitative accounts that focus mainly on stopping or brief responses in structured interviews. For example, therapists said that underlying problems, including loss or abuse, previously suppressed by benzodiazepines sometimes emerged as clients withdrew. Some clients grieved for years of their life lost to benzodiazepines, bringing up anger (e.g., at prescribers) and shame at having been deceived into taking them. Many said the issue clients brought to therapy was no longer present upon withdrawal, signifying it may have been caused or exacerbated by benzodiazepines. They noted psychological dependence, where clients felt unable to cope and that only something external had the power to change them, with change requiring a shift toward self-reliance. They said that support initially needed to focus on withdrawal (Hammersley, 2001). This is not aligned with national guidance, which says comorbid conditions should be treated first (CKS, 2022), but makes sense in light of problems such as anxiety and depression being known adverse effects and withdrawal symptoms (Ashton, 2002). Hammersley's (2001) choice of questions demonstrates an insider's insight (having undertaken specialist work) into patient experiences and dedication to improving understanding of and alleviating suffering. This sets this study apart from some arguably more superficial research focusing solely on stopping and neglecting wider experiences. These accounts highlight there is a lot more to recovery than withdrawal, which itself may bring complex issues to the surface that require ongoing support. This remains to be explored from the benzodiazepine patient's perspective in future research.

Hammersley (2001) considered interviewing benzodiazepine patients, because hearing their views is a social justice issue. However, the focus on the therapeutic process meant that participants would likely need to be recruited via their therapist, making recruitment difficult and posing ethical issues. As previously argued, recovery with and without formal treatment may not be as distinct as believed and bringing both areas of research together may shed light on change experiences across all recovery (Orford, 2008; DiClemente, 2006) allowing psychologists to aim to facilitate these (Moos, 1994). Thus, generating knowledge with implications for therapeutic practice does not necessarily have to be conducted with patients accessing therapy and patient perspectives could be sought without requiring access via a third party. Hammersley (2001) reflects that a lived experience researcher, such as myself, may be better placed to interview patients, who may have negative experiences and viewpoints that they may feel more comfortable sharing with a lived experience researcher.

### **Benzodiazepine Patients' Experiences of Ongoing Recovery**

#### ***Fixsen & Ridge (2017)***

Only two formal qualitative studies were found on ongoing personal recovery experiences, including the period after stopping, from the benzodiazepine patient's perspective. Fixsen and Ridge (2017) employed a narrative approach analysing experiences of withdrawal and distress from 832 pre-existing accounts from online peer support groups, blogs, and YouTube videos. They emphasise that people seek out accounts that resonate with their own experiences and many stories are intended to reassure others that they are not alone. Withdrawal is sometimes described as 'hell' and isolation, including accounts of distressing and protracted withdrawal, particularly exacerbated in those withdrawn too rapidly. They describe severe anxiety, panic, or fear, for some the greatest fear being associated with the final dose reduction before stopping. Many describe severe and protracted depression, including suicidal thoughts, hopelessness, and despair about ever being themselves again. They describe a sense of alienation, derealisation, dissociation, cognitive impairment, and perceptual and sensory distortions. They feel trapped inside themselves or a different world, where suffering and existential distress play on a loop, described in one account as an 'ongoing trauma'. Physical symptoms involve torturous pain and perceptual hypersensitivity. Individuals found it helpful to remain aware that their experience was a chemically induced one shared by others. Many

expressed regret at having ever taken benzodiazepines, anger toward prescribers, and a sense of injustice that prescribers suffer no consequences. Individuals describe waves and windows occurring seemingly at random, mimicking/exaggerating difficulties they struggled with before starting benzodiazepines, resulting in a rollercoaster of hope and hopelessness. Many question whether they will ever heal or be themselves again (others provide reassurance that they will). Individuals offer each other tips on what might help, such as learning non-pharmacological techniques to cope with underlying issues (e.g., yoga, meditation) and accepting the ongoing suffering with faith that you will heal.

The researchers chose not to discriminate between illicit and prescribed use, which may be more feasible for research not involving recruiting participants. Prescribed harm community members communicated to me that they would not promote research outside of the prescribed patient experience. The prescribed patient experience is also unique with regard to a potential breach of trust and anger toward prescribers, which are only partially captured here. Furthermore, the researchers did not seek consent, because data was openly available. In previous research, Fixsen (2015) discusses awareness of potential consent issues and how even anonymous posters may not want private experiences discussed publicly. Fixsen and Ridge (2017) share only brief anonymous quotes, unlikely to be recognised or breach authors' privacy, appropriate for the breadth and scope of their work. However, British Psychological Society (BPS, 2017) guidelines argue that publicly accessible internet data may nonetheless be considered private by individuals posting accounts and suggest contacting site moderators/owners for advice. *BenzoBuddies* (2014), one site used for their study, states that members should not be used in research without permission of the website and author of each post. While reasonable and understandable, this poses a barrier for carrying out such research in the future.

The researchers are clear that “stopping benzodiazepines is rarely the end of the story”; one account states: “the real healing comes after you jump [stop]” (Fixsen & Ridge, 2017, p. 19-20). While they include accounts of ‘renewal’, recovery beyond withdrawal, these mostly focus on instilling hope but do not expand on these experiences. While using pre-existing online accounts allowed them access to more participants than might be feasible in interviews (Given, 2008), a potential disadvantage is being unable to explore ongoing recovery in detail as many who achieve substantial recovery stop posting (Fixsen & Ridge, 2017). This leaves a fruitful

area for exploration in future research. They conclude that patient experiences can help researchers and clinicians understand distress and recovery, leading to the development of new support strategies and treatments that align better with patient needs and experiences. They recommend further research into recovery. As this is an international study, there would be value in exploring UK-specific experiences to capture how these may vary based on local support and prescribing practices and provide local perspectives on service development and support provision.

### ***Fixsen (2015)***

The only other qualitative study found capturing ongoing personal recovery experiences from the benzodiazepine patient's perspective beyond stopping is Fixsen (2015), a UK-based lived experience researcher. She provides an autoethnographical analysis of her diaries and online accounts, from dependence, to initiating withdrawal and ongoing recovery. She describes biographical disruption experienced during dependence, identity reconstruction, and healing from the trauma of withdrawal. She transitions from a sense of drowning and being locked in, to initiating a lonely struggle, searching for support and kinship, resurfacing, oscillating between 'waves' of depression, hypersensitivity, and pain, and 'windows' of improvement, and finally rebirth and reconstruction. She describes this as an ongoing process that, at the time of writing, she was still in the midst of. She describes experiencing severe distress and dulled senses while on benzodiazepines, alongside an inability to express emotions or cry, with 'normal emotions' and tears returning in 'buckets' during withdrawal and grieving for lost time. The only other research that appears to capture this grief is Hammersley (2001). She describes how her doctor doubted the severity and duration of withdrawal, and she tapered by trial-and-error without knowledge or medical guidance. She also describes the frustration that friends and family show at her lack of improvement.

She writes about strategies and experiences that helped during withdrawal. She describes the importance of finally having her experience validated by a medical professional following initial disbelief. She seeks support from a specialist charity run by lived experience volunteers whose trustworthiness, understanding, and advice provide relief. It helps to be told to take her time, use distraction, and be reassured that she will get through it. She benefits from reading survivors' memoirs which encourage her to seek support from the online community, which

she feels provides a shared voice and helps individuals to make sense of their experiences. What helps differs at different stages during recovery. For example, TV, music, seeing friends, or CBT are initially too stimulating, painful, or impossible and she focuses on meditation, cooking, walking and Emotional Freedom Technique. At later stages, spending time with others becomes more possible. She gains strength from small improvements, experiencing empowerment in pushing forward despite hardship toward a new self: “After such an ordeal, going back to “old me” was never an option” (Fixsen, 2015, p. 9.)

She omits parts of her recovery process, such as spirituality, for personal reasons, which could merit exploration in future research. Her research demonstrates the value of an experiential account capturing the richness of phases, influences, and experiences during ongoing recovery. While hers is a single account going up to 3 months after stopping, future research would benefit from an exploration of the ongoing process of recovery. Indeed, she explains that while she is feeling better, there is still a lot of trauma to overcome. Both studies highlight dependence and withdrawal being experienced as traumatic and the *Guidance for Therapists* states that this may need to be considered in therapeutic work (Rizq et al., 2019). However, no other research was found drawing attention to this and further research into ongoing recovery would be beneficial in gaining an understanding of experiences of trauma during recovery. Fixsen (2015) also emphasises the value of rich experiential accounts in research, countering how such experiences are often medicalised and assigned diagnostic labels.

### **Relevance to Counselling Psychology**

A long-term recovery approach prioritising lived experience is aligned with Counselling Psychology values, “concerned with the individual’s subjective experience, appreciating the complexity of difference and focusing on wellbeing rather than just cure” (Rafalin, 2010, p. 41). Furthermore, ensuring that the voices of benzodiazepine patients are heard is a social justice issue (Hammersley, 2001). Benzodiazepine dependence disproportionately impacts women and older adults (Marsden et al., 2019), patient voices are not heard in the healthcare system (Guy et al., 2018), patients have been described as a muted social group without influence or voice, and dependence and withdrawal often take place in social isolation (Fixsen, 2015). Researching an underresearched area can be a form of social justice if Counselling Psychologists aim to amplify the voices of marginalised communities (DeBlaere, 2019) via



qualitative research, which is better suited to finding out what matters to individuals than RCTs (Hanley et al., 2016). Participants' individual voices are often not heard in RCTs, nor their views on the treatment they received, as they are viewed as passive recipients of treatment (McLeod, 2001). Individual perspectives of those who are experts on their experience is an equally valid approach to understanding recovery experiences (Fixsen & Ridge, 2017), particularly given a lack of progress in treatment studies (Orford, 2008). Counselling Psychologists can provide leadership in social justice through publication, changing policies, psychological practices and societal values, and including community members in shaping services, with the aim of addressing social inequalities affecting marginalised groups (DeBlaere, 2019; Goodman et al., 2004; Tribe & Bell, 2018). Indeed, Public Health England's review recommended that service design involve consultation with experts-by-experience (Taylor et al., 2019). As online accounts of ongoing recovery after withdrawal may be limited (Fixsen & Ridge, 2017), interviews may elicit more detailed accounts of these experiences, as well as allow for asking what patients think services should look like. As a lived experience researcher, I may be in a favourable position to elicit benzodiazepine patients' experiences (Hammersley, 2001). Finally, the research process itself may benefit participants, as recounting one's story can sometimes be a part of the recovery process (Fixsen, 2015; Herman, 2015).

### **The Current Study**

Due to a lack of formal support and scientific literature, patient experiences and initiatives online have become the main guide to recovery from benzodiazepine dependence (Groot & van Os, 2020; Guy et al., 2018). However, there has been limited research attempting to tap the vast experiential knowledge accrued by benzodiazepine patients in ongoing recovery. Subjective recovery-focused research has impacted policy and services by leading to the implementation of recovery-oriented systems of care in other fields such as mental health and addiction (White et al., 2005). However, there is little such research on benzodiazepine dependence and prescribed drug dependence overall. Exploring subjective experiences not only during but *after* stopping may help highlight the need for continuity of care for this population, generate ideas about what that might look like, and provide a foundation for future research. Furthermore, there is limited research available on what people find helpful during recovery. As Public Health England have recommended training and commissioning of services (Taylor et al., 2019; NHS England, 2023), this is a critical moment to ask

benzodiazepine patients what they would recommend such services should look like so that their voices can be included. This research focuses on those who found it difficult to stop benzodiazepines or struggled with post-withdrawal symptoms, and would have thus benefited from support, as the overarching aim is improving support provision and awareness.

This study aims to take a qualitative approach to explore the following questions:

1. How do individuals experience ongoing recovery from prescribed benzodiazepine dependence in the UK?
2. What do they think helped?
3. What do they recommend future services should look like?

## METHODOLOGY

### Research Paradigm

#### *Taking a Qualitative Approach*

Research on recovery from prescribed benzodiazepine dependence is somewhat dominated by positivist, realist, quantitative research focusing on stopping benzodiazepines as the outcome in RCTs. This approach tends to neglect patient experiences and may be less than ideal for identifying what helps, due to high levels of variability in withdrawal and recovery experiences between and within patients (Groot & van Os, 2020). Counselling Psychologists are often faced with the medical model's dominance in practice and research settings (Blair, 2010). The medical model is rooted in a realist, positivist paradigm, asserting a 'hierarchy of validity' of scientific methods, with RCTs considered the gold standard and qualitative studies at the bottom (Blair, 2010). There is a tension between Counselling Psychology values, which posit that research cannot be conducted neutrally and emphasise the importance of meaning and subjectivity in the research process, and the positivist paradigm underpinning the medical model, which proposes that scientific inquiry must be conducted value-free and asserts that such objectivity is possible (Blair, 2010; Prilleltensky & Nelson, 2017). Thus, quantitative methods rooted in positivism are often not appropriate for exploring phenomena that interest Counselling Psychologists (Blair, 2010). Quantitative and qualitative research also differ in terms of their emphasis on power and control: quantitative research exercises a high level of control on what participants can say and how this is evaluated whereas qualitative research is by its nature more collaborative, open, and dialogic (McLeod, 2001). Finally, there has been a call in the prescribed drug dependence field to shift research efforts away from using RCTs as the gold standard toward listening to patient experiences (Fixsen & Ridge, 2017), because RCT "outcomes are not meaningful for the most vulnerable patients at the end of skewed distributions" (Groot & van Os, 2020, p. 8).

#### *Reflexive Thematic Analysis*

My research questions are concerned with exploring the lived experience of participants classed as hard-to-reach (Reay et al., 2009), which is most suited to a qualitative approach (Willig, 2012; Brooks & King, 2017). Braun and Clarke's (2022) Reflexive Thematic Analysis

(RTA) was chosen, because my aim was to look for patterns across data to make sense of shared experiences. RTA is accessible to beginner qualitative researchers such as myself, the educated general public when used within a phenomenological framework, and policymakers (Braun & Clarke, 2022). RTA findings can be foundational for further research (Braun & Clarke, 2006), which is important as I am taking a qualitative approach to recovery beyond withdrawal in a field where such research is sparse. Some have argued that Thematic Analysis is not a distinct method or is an unsophisticated or basic method (Braun & Clarke, 2022). However, different versions of Thematic Analysis, such as RTA, are widely used distinct methods outlining a coherent analysis method. The sophistication of analysis depends on *how* the method is used, not the method itself, as with all analytic approaches (Braun & Clarke, 2022). Willig (2013, p. 199) states that “the researcher needs to do a lot of conceptual work before they can embark upon the research itself”. This is because RTA is epistemologically flexible; thus, it is important to be clear about one’s stance as this impacts data analysis (Braun & Clarke, 2006). Research questions, aims, philosophical assumptions, and method need to be aligned (Willig, 2013).

### ***Epistemological Position***

Epistemologically, a phenomenological approach was chosen as this aligns with the aim to explore subjective recovery experiences (Willig, 2013). Phenomenological approaches aim to produce knowledge about the quality and meaning of participants’ subjective experiences (Willig, 2013), aligning with Counselling Psychology values, which prioritise unique subjective experiences above standardised treatments (Bury & Strauss, 2007). The researcher’s role is similar to a ‘person-centred counsellor’, rather than trying to get participants to accurately describe an objective reality or discover what causes particular phenomena (Willig, 2013). A phenomenological approach proposes that the same phenomena “can be experienced in many different ways, so that there are potentially as many (experiential) worlds as there are individuals” (Willig, 2013, p.72).

My ontological position is contextualist, lying between realism and relativism, accepting that external reality exists without assuming a single reality (Braun & Clarke, 2022). Reality is accessible via language, but as knowledge is context-dependent it will always be incomplete as context, and thus reality itself, is dynamic (Terry et al., 2017; Jaeger & Rosnow, 1988).

Context is part of, and inseparable from phenomena, hence all interactions impact reality and what knowledge can be obtained (Jaeger & Rosnow, 1988). Knowledge is therefore “local, provisional, and situation dependent” and findings depend on the context in which data was collected and analysed (Madill et al., 2000). Contextualism rejects the notion that we passively observe a stable reality, positing that we actively alter our world through our interactions and thus the researcher, by creating a particular social context, alters reality and potential knowledge (Jaeger & Rosnow, 1988). As reality is viewed as constantly changing, meaning made by participants needs to be considered by taking into account the cultural and sociohistorical context they occur in (Jaeger & Rosnow, 1988). Contextualism does not reject the notion of ‘truth’ but proposes that all knowledge will to some extent be true within particular contexts and not in others. It accepts the existence of order and patterns, while acknowledging that these “occur within a ‘sea of complex phenomena’” (Jaeger & Rosnow, 1988, p.11). The phenomenological approach, with its emphasis on uniqueness and individuality that allows for details embedded in context, can be seen as reflecting a contextualist ontology (Lyddon, 1998). Contextualism differs from its neighbouring ontology critical realism, which instead posits that there is a single, relatively unchanging reality, and it is rather our knowledge of it which is transitive (Pilgrim, 2014).

A contextualist ontology was adopted as this aligns with my own worldview, phenomenological approach (Lyddon, 1998), and research questions focusing on the phenomenon of recovery. In studies operating on a realist, positivist paradigm, such as RCTs, ‘recovery’ seems to be conceptualised as a stable, universal phenomenon, objectively observable and typically defined as having stopped benzodiazepines. A linear cause-and-effect relationship is often assumed between treatment and stopping (Orford, 2008). RCTs ask *if* change occurred but now *how*, a question that is often of more interest to Counselling Psychologists (Bury & Strauss, 2007). My stance, aligned with how recovery is conceptualised by some in the mental health and addiction fields, is that recovery is an *individual experience*, defined subjectively with different meanings for different people, although there are also shared aspects to the experience, and change is a *non-linear* and *dynamic* process (Leamy et al., 2011; Slade & Longden, 2015, White et al., 2005). In line with a contextualist worldview, the withdrawal experience varies both between and within individuals (Groot & van Os, 2020), and thus cannot be viewed as a stable, universal phenomenon (Lyddon, 1998). Thus, “*how does change occur*” and “*do individuals feel they are recovering, according to their own definition*”

thereof” are more suitable questions. Contextualism is compatible with the underlying aim of searching for patterns, as it accepts that order and patterns exist while respecting that these occur within a rich, diverse, and dynamic reality (Jaeger & Rosnow, 1988) of lived experience embedded in context (Lyddon, 1998).

My epistemological stance informed how analysis was conducted in RTA. It is possible to provide a meaningful description of the entire dataset or a comprehensive look at one area within it (Braun & Clarke, 2022). I looked for themes across the entire dataset as this is suitable when there is little research on the topic and participants’ views are unknown. RTA can be inductive or deductive. My analysis was inductive, due to my phenomenological stance, focusing on units of experience (Braun & Clarke, 2022). I was not attempting to test existing hypotheses or replicate themes identified in the literature, rather themes were developed via a bottom-up approach grounded in the data (Terry et al., 2017). I coded primarily for patterns relating to the experience of recovery, what participants experienced as helpful, and their views on service recommendations. However, Braun & Clarke (2022, p. 56) state that “the subjective and embedded process makes pure induction impossible: we bring with us all sorts of perspectives, theoretical and otherwise, to our meaning-making, so our engagement with data is never purely inductive”.

Interpretation is viewed as being on a continuum from more descriptive to more interpretative; purely objective description is not possible because “coding and theme development are assumed to be subjective and interpretative processes [...] the analysis is seen as something created by the researcher, at the intersection of the data, their theoretical and conceptual frameworks, disciplinary knowledge and research skills and experience; it is not seen as something waiting ‘in’ the data to be found” (Terry et al., 2017, p. 20). Due to my phenomenological stance and research question, I aimed to take participants’ experiences at face value, with interpretation more descriptively grounded. However, as analysis cannot be purely, objectively descriptive, I reflected on my use of subjectivity during the research process (see Reflexivity chapter).

Themes in RTA are identified on the basis that they relate meaningfully to the research questions, rather than because they are more prevalent in the data (Braun & Clarke, 2006). Themes can be identified on a semantic or latent level. I coded semantically as this is aligned

with my research question and phenomenological stance, trying to remain close to participants' experiences, rather than looking beyond the data for underlying ideas or assumptions.

### ***Other Approaches Considered***

I considered other qualitative approaches that focus on looking for patterns of meaning across a dataset but rejected these as they aligned less closely with my personal position, epistemological stance, and research questions. Interpretative Phenomenological Analysis (IPA) was considered as it is also a phenomenological approach. However, IPA focuses on language use and is further toward the interpretative end of the continuum in terms of the extent to which meaning is derived from the researcher's interpretation (Smith et al., 2009). In IPA, the researcher engages interpretatively on two levels, empathically *and* suspiciously (Eatough & Smith, 2017), whereas the level of interpretation is chosen by the researcher in RTA (Braun & Clarke, 2022). As benzodiazepine patients' voices remain mostly unheard or their experiences contested (Fixsen, 2015; Guy et al., 2018), I wanted to remain as true to participants' experiences as possible. Using a hermeneutics of suspicion "does not seek to capture participant perspectives as such. Such 'critical' analysis might not only be unrecognisable to participants; it might even upset, offend, or anger them, if it does not resonate with their experience" (Braun & Clarke, 2022, p. 277). Furthermore, my research question is more suited to RTA as it is broad and in an underresearched area where participants' views are unknown (Braun & Clarke, 2006), thus focusing on looking for themes across participants rather than unique features of each participant (Braun & Clarke, 2021). The latter may become more suitable once more broad, foundational research is available.

I considered Grounded Theory, which aims to create conceptual explanations of a phenomenon (Charmaz, 2014). My research question has a stronger focus on the *experience* of the phenomenon of recovery itself, including participants' unique experiences and views, rather than aiming to look for structures or mechanisms underpinning recovery. Furthermore, while there is value in exploring factors underpinning recovery, Grounded Theory requires a larger sample size than might be realistic within the timescale of a professional doctorate (Braun & Clarke, 2021).

### **Peer Consultation**

Prior to recruitment, I contacted the *Benzodiazepine Information Coalition*, a patient-founded, non-profit raising awareness of benzodiazepine risks when taken as prescribed, with a draft participant advert for feedback. They had previously expressed the importance of using non-stigmatising language (Lamberson, 2018), not misrepresenting prescribed benzodiazepine patients as ‘addicts’/addicted to a drug when they are harmed and physically dependent. We discussed my use of the word ‘recovery’, which they felt was associated with addiction or being symptom-free and asked for my definition. They recommended I change this to ‘healing’. Having explained how I defined recovery, why I chose this term, and referencing my knowledge of its use in the prescribed patient community (e.g., Fixsen & Ridge, 2017; Frederick, 2014; Facebook group ‘Benzo Recovery & Existence’ with 5,4000 members), they expressed they would support my research, whichever term I chose. I compromised, using ‘healing’ in the advert and keeping ‘recovery’ in the title and consent form. I chose this, because though I outline my definition of recovery in this thesis, without this explanation one might assume that recovery means recruiting participants who are no longer experiencing harm. Thus, for a brief advert where this cannot be fully explained, their language was clearer, while keeping the title on documents meant not misleading participants about language used in the thesis.

## **Recruitment**

I recruited online via Facebook groups and blogs associated with prescribed drug (*Let’s Talk Withdrawal Podcast*, *Mad in the UK*) and benzodiazepine withdrawal and recovery (*Benzo Recovery & Existence*, *Positives While Healing From Benzodiazepines*, *Beating Benzos*, *Beating Benzos Protracted Withdrawal*, *Benzodiazepine Withdrawal Support Group (BWSG) 1.0*, *Benzo Warrior Community*, *Benzo Success and Support*, *Benzodiazepine Information Coalition*). I sought administrators’ permission where possible, providing background by sending my website link (<https://benzodiazepineresearch.weebly.com/>). Where I was unable to get in contact with an administrator, I wrote “admins please delete if you feel this is not appropriate” in the post’s header (which some then did and some did not). See Appendix A for examples of adverts and the website. I tried to seek permission from *BenzoBuddies* but received no response.

## **Participants**



I aimed to recruit up to 10 participants. Braun and Clarke (2013) recommend 6-10 for professional doctorate research.

Inclusion criteria:

- Age 18 and over
- Living in the UK
- Took prescribed benzodiazepines continuously for at least 1 month
- Found it difficult to stop/come off benzodiazepines or struggled with withdrawal/post-withdrawal symptoms
- Stopped taking benzodiazepines at least 1 year ago (did not need to be symptom-free or no longer experiencing harm from benzodiazepines)
- Withdrew from benzodiazepines only at the time (not tapering/stopping multiple prescribed drugs at the same time as the benzodiazepine)
- Did not feel that they were currently struggling with other prescribed drugs
- Did not feel they were struggling with misuse of recreational drugs or alcohol
- Did not feel they would find it too upsetting to talk about their experience in an interview
- Able to participate in semi-structured interviews via Microsoft Teams

The criteria of having been off benzodiazepines for at least one year corresponds to the Betty Ford Institute's (2007) definition of 'sustained recovery' sometimes used as a research parameter, and chosen here in the absence of similar benchmarks in prescribed drug dependence research.

Nine participants completed consent forms, eight were interviewed, and seven included in the analysis. One participant was unable to attend for personal reasons. Another participant's interview, while valuable, was deemed a poor fit with the research aims and other interviews. While they experienced difficulties stopping benzodiazepines (this is where my participant advert could perhaps have been more explicit) these appeared more around the role prescribed and non-prescribed benzodiazepines, alcohol, and other drugs played in their life and struggles

overall than difficulties encountered with physical dependence, prescribed harm, and withdrawal phenomena.

## **Data Collection**

Semi-structured interviews were used. These are suited to phenomenological inquiry and consistent enough to ensure research questions are explored as fully as possible, yet flexible enough to follow up on unexpected topics (Langdridge, 2007). The interview schedule (Appendix B) involved open questions and prompts about how people were prescribed and came off benzodiazepines, whether they still experience difficulties, what helped/helps now, and what they think future services should look like. The interview schedule was piloted in a role-play with my supervisor acting as a participant to receive feedback from an experienced interviewer (Brinkmann & Kvale, 2018). My supervisor also listened back to the first interview recording and provided feedback. This feedback mainly related to me at times not asking follow-up questions to yield thicker description. Interviews were online and recorded via Microsoft Teams. Online interviews are an effective alternative to face-to-face interviews in qualitative research (Lo Iacono, 2016), with the advantage of being able to access hard-to-reach groups, convenience, minimising travel and time costs, ensuring safety during the pandemic, and enabling UK-wide recruitment. Interviews took place between July and October 2021 and lasted between 49-120 minutes. Simone sent an overview of her experience by email beforehand and consented to its inclusion in the analysis. The second and third participants spoke at length about issues relevant to the research questions after I had stopped recording. In supervision, we agreed I would stop recording later, meaning some later interviews include the debriefing as well. Participants were always informed when recording began and stopped and could also verify this on Microsoft Teams. A confidential transcription service carried out verbatim transcription. I listened back to recordings while reading transcripts to check for accuracy (Braun & Clarke, 2022).

## **Analysis**

RTA is both progressive, because it involves following specific steps, and recursive, because the process is not linear but involves going back and forth through the steps as necessary (Braun & Clarke, 2022). Examples of my coding process which not only went back and forth between

the steps but also between a handwritten and digital process are documented in Appendix I. Data was analysed by following Braun & Clarke's (2006, 2022) steps:

**Step 1** is familiarisation with the data. I printed and read each transcript while listening to the recordings to familiarise myself with the data. I tried to actively read with a 'phenomenological attitude', attempting to set aside presuppositions to step into participants' shoes (Finlay, 2009). I made notes about initial ideas relating to each transcript and the whole dataset.

**Step 2** is coding. I reread the transcripts repeatedly, systematically coding for semantic content line by line by hand paying even attention to each data unit. I refined the codes and/or added new ones with each rereading. I wrote out codes that I found meaningfully repeated across the dataset onto post-it notes.

**Step 3** is generating initial themes. I brainstormed by organising the post-it note codes into potential themes and subthemes and also drew initial mind maps. I realised that I had initially generated topic summaries based on my research and interview schedule questions, rather than generating themes, which in RTA are a shared meaning or idea (Braun & Clarke, 2022). Thus, I went back and forth between steps 2 and 3 repeatedly, reorganising the codes into potential themes based on shared meaning and ideas. I transferred this process from paper onto my computer, refining the coding again and transferring extracts and codes directly into Microsoft Excel, where I input 520 coded extracts from 7 transcripts and all potential theme ideas. I then separated out the extracts into potential themes and subthemes in separate tabs.

**Step 4** is developing and reviewing themes. I wrote a description of each theme and subtheme and went back through the dataset, which helped me to get a sense of whether they were internally coherent and distinct. This led me to collapse some subthemes into a single subtheme. I tried to make sense of the relationship between the themes by drawing mind maps. I then discussed my themes, subthemes, extracts, and brief descriptions with my supervisor. We agreed that the themes were internally coherent and distinct, but some extracts needed to be shortened or given context so they could stand alone.

**Step 5** involves naming, defining and refining themes to capture what they are about and why this is interesting, and **Step 6** involves writing up the analysis. I went back and forth between

these steps. I refined theme descriptions and begun writing the results chapter, which in turn helped me further refine the theme descriptions and gave me a clearer idea of the connections between them. I returned to previous steps too, creating a refined mind map of the connections and describing these, as well as further reviewing the extracts in each theme. See Appendix J for the final table of illustrative extracts for each theme.

I used Braun & Clarke's (2022) checklist on what constitutes good RTA to guide the analysis and determine when steps were completed satisfactorily. I kept a reflexive journal during the research process to ensure quality (Braun & Clarke, 2022). Yardley's (2000) criteria for good quality qualitative research were also used to evaluate the research process.

### **Transferability**

While statistical-probability generalisability is an ideal sought in most quantitative research, this aim does not apply to qualitative research because it is generally informed by different epistemological underpinnings (Smith, 2018). Qualitative research can instead aim for transferability, meaning the findings can have relevance beyond the current study's context and setting by being "richly contextualised in a way that allows the reader to make a judgement about whether, and to what extent, they can safely transfer the analysis to their own context or setting" (Braun & Clarke, 2022, p. 143). Whether findings are transferable is thus ultimately decided by the reader, but the current study aimed to maximise the transferability potential of the findings by showing 'sensitivity to context' (Yardley, 2000) in the written report (Smith, 2018). Transferability was further aimed for by "gathering direct testimony, providing rich description and writing accessibly and invitationally" (Tracy, 2010, p. 845) to facilitate the reader's task of determining the degree of resonance with their own situation and thus whether the current research may be applicable (Smith, 2018).

### **Ethics**

My research process adhered to the principles outlined in the BPS Code of Ethics and Conduct (2018), BPS Code of Human Research Ethics (2014), and University of East London (UEL, 2015) Code of Practice for Research Ethics. UEL granted ethical approval in May 2021

(Appendix C). Pseudonyms are used and identifying details removed in interview transcripts and this thesis to preserve anonymity (HCPC, 2012).

Participants were told the process could take up to 2 hours, to allow for breaks and a debrief to ensure they were not left with difficult feelings (Liamputtong, 2007). I minimised risk through a risk assessment (Appendix E) and providing an information sheet (Appendix F) before obtaining informed consent (Appendix G). The information sheet stated the interview portion would take 30-90 minutes, so no one felt pressured to speak for longer than they felt comfortable. Participants were debriefed verbally after the interview and by email (Appendix H).

I considered that “the process of interpretation poses significant challenges because it involves a process of transformation” (Willig, 2017, p. 280). How we represent participants, particularly from marginalised populations, has been described as “the most significant ethical dilemma we face” (Swauger, 2011, p. 500). Thus, it is important to consider the greater implications of our interpretations (Swauger, 2011). Counselling Psychologists have a social responsibility “to be alert to the possible consequences of unexpected as well as predicted outcomes of their work” (BPS, 2014). Care has been taken to avoid using stigmatising language, such as addiction language or language placing blame on patients for their difficulties, to respect the dignity of the prescribed benzodiazepine patient community and their shared values in line with the BPS Code of Ethics and Conduct (2018). However, where participants used such language, their original words were preserved.

Counselling Psychologists need to be sensitive to power in relationships with community members and power differences between researcher and participant (BPS, 2018; Goodman et al., 2004). I considered that being interviewed by a trainee Counselling Psychologist may increase the inherent power imbalance due to my perceived status as a ‘professional’ and the community’s negative experiences with healthcare professionals with which I may be associated. Hammersley (2001) argued that a researcher with lived experience would be better placed to interview this group. Disclosing personal experience to participants can promote a non-hierarchical relationship and enhance rapport, but it can also make researchers feel vulnerable (Dickson-Swift et al., 2008). I considered the consequences and did not feel comfortable disclosing my lived experience in participant adverts, though this may have

improved recruitment. However, six out of eight participants asked after the interview schedule was complete and I chose to disclose at this point. I think this enhanced rapport; participants reported feeling comfortable, kinship, and trust that I understood and believed them. I authentically shared details if asked but took care not to overshare or burden participants.

## **Reflexivity**

The process of conducting qualitative research on sensitive topics can raise important issues for the researcher to consider such as developing rapport, self-disclosure, feeling guilty and vulnerable, difficulties with ending the research relationship, and exhaustion (Dickson-Swift et al., 2008). I believe these issues were impacted and often amplified in interconnected ways by my status as an insider researcher, which thus had advantages and disadvantages throughout the data collection process. An advantage might have been that I felt that I was perhaps better able to enter into participants' worlds and build rapport as I came to the topic with lived experience. However, this may have also led to the interviews and the debriefing being more intense and longer in duration, including due to feelings of guilt around abruptly ending the relationship at the end of the interview, thus increasing my levels of vulnerability and exhaustion during the period I conducted the interviews.

At the time I conducted the interviews, I believed I had taken steps to safeguard myself from some of the risks inherent in exploring emotionally charged private experiences (Liamputtong, 2007). The intensity and time required for qualitative research can be draining and researchers need to be attuned to their own limits (Ponterotto et al., 2017). I chose to do my research interviews over the summer, as I anticipated that I would have found the time commitment and emotional impact harder to manage alongside full-time study and my placement. However, in hindsight the intensity of the interviews and my commitment to reciprocity meant that I gave a lot of myself both personally and in terms of time which led to high levels of exhaustion and neglecting to consider that while I had more time in the summer, this was perhaps time I needed to recuperate from the demands of the doctorate. Thus, while passion for one's research topic, in my case fueled by personal experience, can drive social justice work, it can also interfere with self-care (Toporek et al., 2006).

Dickson-Swift et al (2008) argue that the advantage of one-off interviews, as opposed to multiple contacts, mean researchers may be less emotionally involved and have less trouble ending the relationship. However, I believe my insider's status increased my emotional

involvement and led to me committing to a high level of reciprocity as it felt unethical to quickly end the interview once we reached the debrief stage. Qualitative research on sensitive topics should involve a reciprocal sharing process (Dickson-Swift et al., 2008) and has even been described as an ethical responsibility (Liamputtong, 2017). I had a strong feeling that it felt wrong to just interview someone on such a personal and sensitive topic for 1-2 hours, do a quick debrief, and just leave. One researcher described this very aptly as: “It can’t be a ‘slam bam thank you ma’am situation” (Dickson-Swift et al., 2008, p. 41). Thus, if participants wanted to stay, I gave them an equal amount of time to debrief, discuss, and ask any questions they wanted to post-interview. So, for some participants who I interviewed for 2 hours, I stayed another 2 hours if they wanted to continue talking. By doing this, I wanted to show that I truly appreciated the connection we had built as two people in the encounter of the interview, how much I was truly interested in and respected their story and themselves as unique individuals, and that it wasn’t just about ‘obtaining data’. One participant asked me all of the questions I had asked them during the interview once I had stopped recording, which felt like honoring my commitment to creating as non-hierarchical an experience as possible. Thus, in many ways, the advantages of being an insider researcher that I believe enriched the interviews and improved rapport with participants at times simultaneously contributed to researcher vulnerability and exhaustion.

Another advantage to being an insider researcher, which I have also highlighted as a benefit to including experts-by-experience in the literature review (e.g. Hammersley, 2001; Lynch et al., 2022) is my sensitivity to the language used and research questions posed throughout this thesis and in the interviews. I believe this promoted a strong focus on avoiding stigmatizing language and taking care to explain the reasoning behind this and the focus of the research to the reader.

An initial disadvantage to being an insider during the analysis process is that I neglected to identify and include “Disbelief and Failures in Healthcare” as a theme, because it was such an obvious occurrence to me, in my mind such an inherent part of recovery from benzodiazepine dependence that I did not even think to include it. It is difficult to explain why this was the case, but when I went back over the data I was surprised that because this was such a commonplace experience in my mind I had not even thought to include it, particularly considering what an important role it plays across participant experiences in this study. I thus

took care to reexamine the data, codes, and themes to check for what I considered ‘obvious’ themes that I may have excluded but did not find any other such omissions.



## RESULTS

**Table I: Participant Demographics and Background**

<b>Pseudonym</b>	Simone	Melissa	Rosalie	David	Felicity	Sarah	Patricia
<b>Age</b>	74	66	58	62	28	59	58
<b>Gender</b>	Female	Female	Female	Male	Female	Female	Female
<b>Ethnicity</b>	White British	White British	White British	White English	White British	White English-Irish	White British
<b>Benzodiazepine, dosage</b>	Lorazepam 2mg (6 years); 1mg (4 years)	Clonazepam 0.5mg	Diazepam 10mg	Diazepam (3 weeks); Clonazepam 0.5mg (6 months)	Diazepam 2-3mg	Lorazepam 4-12mg (7 years); Diazepam 60mg (25 years)	Zopiclone 3.75-7mg swapped to 5 mg Diazepam for taper
<b>Diazepam equivalent</b>	20mg	10mg	10mg	10mg	2-3mg	40-120mg	5mg
<b>Duration prescribed (excluding taper)</b>	10 years	7 years	4 years	8 months	Regular use $\approx$ 1 year (PRN – 8 years)	32 years	4.5-5 weeks

<b>Prescription reason</b>	Sleep problems after husband left	Sleep problems due to then undiagnosed Lyme disease	Vertigo due to bad reaction to antidepressant and stopping abruptly on guidance of prescriber	Bad reaction to propranolol	Continuous prescription for bad reaction to birth control pill (PRN for anxiety)	Workplace bullying and controlling relationship diagnosed as stress and depression	Withdrawal symptoms from overly rapid prescriber-led antidepressant taper diagnosed as anxiety relapse
<b>Withdrawal/ Post-withdrawal symptoms</b>	<i>“Most of the [Ashton manual] symptoms to a varying degree”</i> , depersonalisation, derealisation, muscle aches/pains, joint pain in feet – couldn’t walk, insomnia, tinnitus, night sweats, shakes, seeing flashing lights, paranoia,	Feeling really hot, severe diarrhoea, a crash that <i>“can’t even [be] put it into words”</i> , felt like she could <i>“just lay down and die”</i>	<i>“Hundreds”</i> of symptoms, panic, hearing voices, adrenaline rushes, losing balance/worsened vertigo, anxiety, fear/terror, psychosis leading to overdose, akathisia,	<i>“Well over 50 per cent of the symptoms that [the Ashton manual] lists”</i> , pins and needles, restless leg syndrome, dizziness, nausea, wobbly/unbalanced leg, racing chest, empty chest, back pain,	<i>“Hundreds of symptoms”</i> , hallucinations, suicidal thoughts, fatigue, heat intolerance, tremors, vision problems, shaking, dry heaving	Derealisation, depersonalisation, severe insomnia, akathisia, loss of appetite, suicidal ideation, brain/body zaps, depression, psychosis	Psychosis, hallucinations of ways to attempt suicide, anxiety, panic attacks, trembling uncontrollably, loss of appetite, burning sensation in head

	agoraphobia, aggression, inner core vibrations, akathisia, leg cramps, burning feet/peripheral neuropathy, fear/anxiety, gastrointestinal		couldn't walk, rapid heart rate, bladder/bowel pain, bodily jerks, twitching eyes, muscle pain, fear of dying, rage	headache, panic attacks, tinnitus, cortisol rush, feeling in the eyes, tingling hands, anxiety, depression, light sensitivity, exhaustion, internal shaking, straining eyes			
<b>Alternative sources of support</b>	Online	Helpline	Online, lived experience therapist	Online	Helplines, online, lived experience therapist	Helpline, online	Helplines
<b>Length of taper</b>	5 weeks	1 year 4 months	2 years 8 months	1 month	1 year	2 years	6 months
<b>Time off benzodiazepines</b>	16 years	12 years	1 year	3 years	1 year 10 months	4 years	6 years

## Participant Characteristics

As outlined in Table I, all participants were White British/English/English-Irish, six out of seven were women, and six were between the ages of 58 and 74. Patricia was initially prescribed and became dependent on a z-drug and tapered using a benzodiazepine. Z-drugs are benzodiazepine receptor agonists, sharing a mechanism of action with benzodiazepines (Peppin et al., 2020). Thus, her account was included and deemed a good fit with the research aims and questions. The time participants were prescribed benzodiazepines (or z-drugs) ranged from 4.5 weeks to 32 years, and time off benzodiazepines ranged from 1-16 years. While no attempt was made to recruit a demographically representative sample, recruiting more women and older adults might be expected as women are 1.7 times likelier to be prescribed benzodiazepines than men and prescribing rates increase with age (Marsden et al., 2019). Some evidence suggests that prescribing rates are lower in areas of the UK with a higher proportion of ethnic minorities (Tsimtsiou et al., 2009). Public Health England's review does not provide prescribing data by ethnicity (Taylor et al., 2019).

Four participants were prescribed benzodiazepines in response to a bad reaction to or withdrawal symptoms from another prescribed drug. Two participants were prescribed antipsychotics, with one also prescribed antidepressants and pregabalin, when benzodiazepine withdrawal went unrecognised. All participants reported experiencing debilitating withdrawal symptoms. Four participants reported experiencing so many symptoms that they used language such as "*hundreds of symptoms*" (Felicity) or "*most of the [Ashton manual] symptoms to a varying degree*" (Simone). All but one participant reported experiencing eight or more symptoms. Four participants reported experiencing psychosis or hallucinations alongside suicidal thoughts and one taking an overdose; two were admitted to hospital inpatient mental health units.

Participants reported being in a relationship both when they initiated withdrawal and at present, except one who reported living with their parents. All participants sought support outside the mainstream healthcare system. No participants lived in an area of the UK served by a specialist service for prescribed drug dependence. Simone's recovery journey took place partially outside the UK; thus, she had less opportunity to engage with the healthcare system than other participants.

She also felt talked out before I had an opportunity to ask about recommendations for future services. Thus, I only briefly asked this before ending the interview, so fewer extracts are available from her in response to this question.

**Table II: Themes and Subthemes**

*Six or seven out of seven participants contributed illustrative quotes to each theme.*

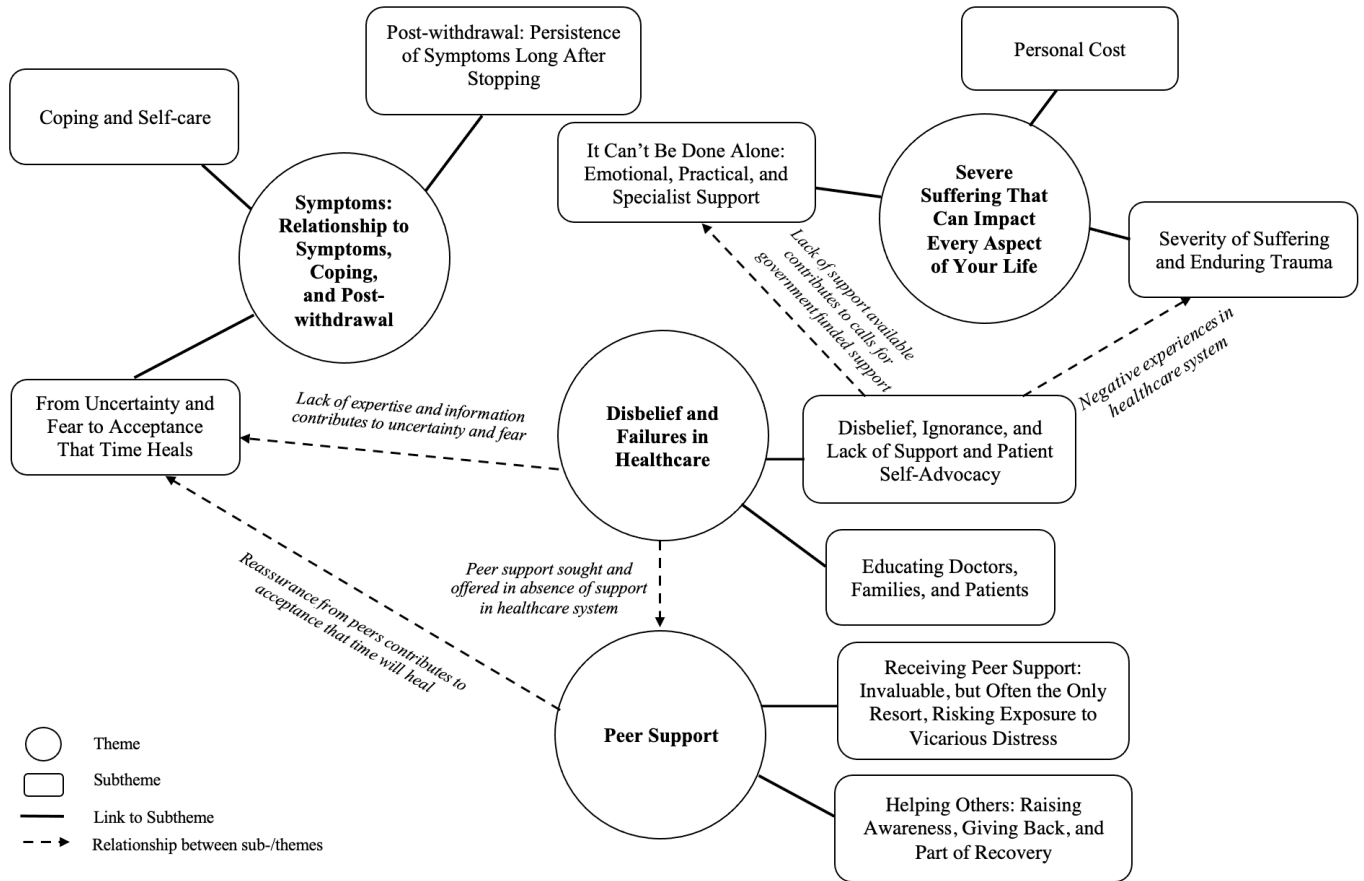
Theme	Subtheme
Disbelief and Failures in Healthcare	Disbelief, Ignorance, and Lack of Support and Patient Self-Advocacy
	Educating Doctors, Families and Patients
Peer Support	Receiving Peer Support: Invaluable, but Often the Only Resort, Risking Exposure to Vicarious Distress
	Helping Others: Raising Awareness, Giving Back, and Part of Recovery
Symptoms: Relationship to Symptoms, Coping, and Post-withdrawal	From Uncertainty and Fear to Acceptance That Time Heals
	Coping and Self-care
	Post-withdrawal: Persistence of Symptoms Long After Stopping
Severe Suffering That Can Impact Every Aspect of Your Life	Severity of Suffering and Enduring Trauma
	Personal Cost
	It Can't Be Done Alone: Emotional, Practical, and Specialist Support

**Final Themes and Connections**

This brief introduction is intended to provide context to the themes (see Table II) by highlighting the connections between them (see Figure I). Themes are indicated in quotation marks below. “Disbelief and Failures in Healthcare” appeared to connect closely to all other themes. Negative experiences and lack of adequate support provided in the mainstream healthcare system played a

role in leading participants to seek alternative sources of support, including “Peer Support” predominantly sought online. Doctors’ lack of expertise and information on dependence and withdrawal provided to participants appeared to contribute to initial uncertainty and fear participants experienced around the origin and potential duration of their symptoms (“From Uncertainty and Fear to Acceptance That Time Heals”). Doctors often did not validate that participants’ symptoms were due to withdrawal, gave alternative and inaccurate explanations, or conducted further medical investigations, which while negative for other serious illnesses also did or could not positively confirm through medical testing that these were due to withdrawal. Doctors’ disbelief and ignorance often amplified participants’ suffering, for some leading to enduring trauma due to how they were treated (“Severity of Suffering and Enduring Trauma”). For many this was predominantly due to the impact of having been harmed by long-term benzodiazepine prescribing, then disbelieved and refused help. This was often by the doctor who originally prescribed them benzodiazepines, with none of the participants reporting being warned of their dependence potential, and their doctor thus seen as bearing a degree of responsibility for their suffering. For two participants, the ignorant actions of medical professionals led to further prescribing of benzodiazepines and other drugs resulting in one collapsing and one having a seizure. Lack of support received from the mainstream healthcare system contributed to many participants calling for specialist helplines and local services to be made available in the future. The reassurance that mainstream healthcare providers were unable to give participants about their symptoms, was for some provided by their peers instead (“Peer Support”), particularly those further along in their recovery, letting them know that their symptoms were ‘normal’, would fade with time, and recovery was possible (“From Uncertainty and Fear to Acceptance That Time Heals”).

**Figure I: Thematic Map**



**Theme 1: Disbelief and Failures in Healthcare**

The most prominent theme was difficult and unhelpful experiences of interacting with healthcare professionals when trying to obtain support. Most participants described an ongoing battle with doctors to have the reality of their experience of benzodiazepine withdrawal acknowledged, validated, or supported appropriately. For some, their doctor’s disbelief affected whether their families believed them. Many thus needed to advocate for themselves and tried to educate both their doctors and families. For some, self-advocacy meant filing a complaint or taking legal action against their prescriber. All participants sought support outside the mainstream healthcare system after receiving inadequate support from their doctors. None of the participants were warned about benzodiazepines’ dependence potential when they were prescribed, with some told by their doctor

that benzodiazepines are not dependence-forming at low doses. Based on these experiences, all participants stated that more education is required for doctors, while many also highlighted the need for more education and accessible information for patients and their families. Some participants also said that prescribers should follow NICE guidelines on not prescribing for longer than 2-4 weeks (BNF, 2022).

The purpose of this theme is to highlight how disbelief, ignorance, and inadequate support in the mainstream healthcare system meant that participants' needs could not be met, delaying recognition of and appropriate support for benzodiazepine dependence and withdrawal. Participants needed to engage in a significant amount of work amidst their suffering to try to obtain validation and support, whether through finding alternate support or having to educate and self-advocate. This appeared to add additional layers of suffering to their experience. In contrast, participants described the importance of having their experience believed and validated.

### ***Subtheme: Disbelief, Ignorance, and Lack of Support and Patient Self-Advocacy***

Participants described facing disbelief or ignorance from doctors and how this impacted them, including often thus being unable to obtain adequate support and adding to their suffering. For example, Melissa described how patients are often “*met with a war of disbelief from their GP or whoever's prescribing*”. She explained that:

*“...from my experience, if you talk to any GP about it, they'll just dismiss that there's a problem, and that's very difficult when we've, when you've been prescribed something, you haven't actively gone out and sought it.”*

Rosalie went further to describe how this disbelief compounded her suffering, adding “*layers on top of what you're already suffering*”:

*“You know if you was in that bad state, but then there was people that understood and helped you, it would give you some relief, but to be in that state with no help, no one believed me. No one would help me.”* (Rosalie)



For some, doctors' disbelief meant that they instead misinterpreted participants' symptoms as caused by an existing/new mental health problem:

*"It's 'cause you're sort of disbelieved and, especially if you've got that history of like a bit of anxiety, you're sort of then seen as everything you experience is just your anxiety and it's just not..."* (Felicity)

*"I said, 'Well, it's probably the benzos.' [The doctor said,] 'No, no, it isn't. You're just anxious at the moment. You've got GAD [Generalised Anxiety Disorder].'"* (Sarah)

Some described how doctors' disbelief in turn affected whether their families believed them, due to the doctor's professional authority:

*"But that's the thing is because [the doctors were] saying it, they spoke to my mum and dad, they spoke to my partner, and told them that I was making it up, basically. So then they were starting to think, well, you know, is it her hormones? Is it something else? You know and they sort of didn't believe me because, because they were being told by professionals..."* (Rosalie)

*"...if the doctors don't believe us, sure as hell our families don't. If the doctors say, 'You're imagining it. You know, this is GAD, treatment-resistant depression. This is not withdrawal. [...]' Why on earth would our families believe us? [...] our nearest and dearest think we're a bit mad because, you know, we're talking about things that our doctors don't validate us for. So why would our families validate us if the doctors don't?"* (Sarah)

As also described in the previous quotes, some participants reported being made to feel like they were *"imagining"* (Sarah) or *"making it up"* (Rosalie), that it's *"all in your head"* (Melissa). Some also described being *"made to feel shameful"* (Rosalie), like they were *"mad"* (Patricia, Sarah), *"crazy"* (Sarah), or an *"addict"* (Sarah), due to the disbelief and lack of understanding they received from medical professionals:

*“...we're not even believed, so we're seen as making it up, delusional conspiracy theories, scientologists, crazy” (Sarah)*

*“...you're treated like, like you did it to yourself, you know, like you was addicted to something, you know, like I'd took heroin or something, something I did to myself. I took a tablet that the doctor assured me would help my vertigo...” (Rosalie)*

Patricia went further to describe how the shame she felt due to the lack of acknowledgement of her experience by doctors endured despite being vindicated in writing after seeking legal action against her prescriber:

*“I felt so ashamed. I still felt ashamed even though I'd got it in writing [as the outcome of a negligence claim] that it wasn't my fault.”*

She explained how she felt validation and support within the healthcare system would have mitigated this:

*“...[Support should] be offered [...] so you don't feel shame around it. You realise that it's something that's acknowledged and as is any other treatment that, you know, if you've got cancer, you'll need this amount of support. Well, if you've got benzo withdrawal, you'll need this amount of support, and you don't need to feel ashamed or it's your fault...”*

While they were not directly asked this question, none of the participants described being warned about benzodiazepines' dependence potential at the prescription stage. Many stated explicitly that their doctor either did not warn them about benzodiazepines' dependence potential, was unaware, or explicitly told them that benzodiazepines were not dependence-forming at low doses:

*“...it would have been great if somebody had said to me how dependence-forming these drugs are, you know, the consent, type thing, because I feel like [doctors are] not really knowledgeable on that at all and also like adverse effects of these drugs” (Felicity)*

*“[The consultant psychiatrist] told me that the low dose I was on, I wouldn't become dependent [...] And so he actually prescribed 2 months more, which is really scary that a psychiatrist would not even warn you.” (Patricia)*

*“[I] said, 'Doctor [neurologist], my GP is telling me I shouldn't be on [benzodiazepines].’ And [the neurologist] said, 'No, you're on a low dose' - another classic - 'You're on a low dose; it's fine.' [...] He gave me another prescription - for 100 tablets this time.” (David)*

Over time, participants described advocating for themselves in the face of this disbelief and ignorance, which for many involved a significant amount of extra work during a time of already considerable suffering. As Felicity highlights: *“You have to become your own sort of advocate really. It's wrong really.”* She explained that self-advocacy is *“really difficult actually 'cause I have a lot of cognitive stuff going on with the withdrawal”*. Rosalie described these interactions with medical professionals as a *“battle”*.

Self-advocacy often involved challenging and educating their doctors:

*“[My GP] really struggled to grasp this notion that it wasn't an underlying sort of mental illness coming through and she also struggled to understand that when you came off it that you could have symptoms that carry on. [...] So, it took a lot of education and, you know, I had to write her letters and get other people to write her letters and yeah. [...] I wouldn't say she's fully on board still, but she's a lot more on board than she was.” (Felicity)*

*“I actually did mention to the GP, 'Do you wanna oppose somebody who's like the European, probably world-best, authority on benzodiazepine withdrawal? Do you think your opinion's more valid than hers?' Because sometimes you have to. You have to challenge. You don't have to do it in a hostile or aggressive way but, yeah, I put that question to my GP and said, 'You know, maybe you wanna read her [research].’” (Melissa)*

After facing disbelief, ignorance, or limited to no support from the mainstream healthcare system, all participants accessed alternate support, including online, specialist charity helplines, and private therapists:

*“I had a terrible crash of withdrawal symptoms [4 months after stopping]. It didn't happen straightaway, I spoke to the GP about it and he was like, no, that can't happen and I said, I'm afraid it is happening. [...] Anyway, I managed to find a helpline in Liverpool.”* (Melissa)

*“I received no help or sympathy from my GP and I had to plan my own escape from the hell I found myself in. The only help I could find was the Bristol Drug Project helpline and the one in Camden...”* (Patricia)

*“I didn't get any help from the NHS or there was no sort of all they could offer really was CBT, but it's not really like that. It's quite different to sort of like a normal anxiety disorder so [...] I did get in touch with [a private therapist with lived experience] who, I have spoken to her a few times.”* (Felicity)

*“...the only people that helped me were the people online. I used to ring a woman called [name of private therapist with lived experience]. Yes, I paid to speak to her because there was no one else.”* (Rosalie)

Despite all participants seeking alternate support, completely disengaging from their prescribing doctor was often not an option if they knew the participant was tapering as the doctor controlled the amount of benzodiazepine tablets they were prescribed. Thus, self-advocacy became necessary to persuade their doctor to allow them to taper safely at their own pace:

*“It didn't make me very popular because no doctor or psychiatrist or the drug and alcohol team, they didn't want to be told how to do their job, which I wasn't [...] She'd be like, 'We get people off at 2 milligrams a week.' And I'm like, 'That is not happening.' [...] I had to argue with her continuously, but in the end, she gave up and she just let me do my taper my way, you know, and they supported it...”* (Rosalie)

*“I went, ‘Look, Dr [name] is flipping well cutting me too fast. Here’s your NICE guidelines. What does it say? It says blah, blah, blah.’ I said, ‘I am not [tapering] this fast. You need to give me some more tablets.’ [The doctor said,] ‘Oh, you sound like an addict.’ I said, ‘I don’t care, it’s my body, it’s my brain. You know, I want some more tablets.’ Well then she did give them to me, reluctantly...” (Sarah)*

For some, self-advocacy involved educating their families in the face of their disbelief in order to receive their support. After initially being unable to see her parents because they did not understand, Rosalie explained: *“my parents helped in the end, you know, when they- I made them watch [educational] videos and stuff”* (Rosalie). Felicity similarly used resources from experts to educate her family:

*“I had to get my family to watch different things, you know, videos, films like Medicating Normal and Joanna Moncrieff talks, Mark Horowitz talks. Just David He[aly], you know people, doctors that knew about this sort of thing and how difficult it can be to get off psychiatric drugs and the withdrawal syndromes and how long they can last. And, it was educating them about, you know, that really, that this is the drug and that’s what’s happening, and it can cause these symptoms, and that I needed help...”*

For others self-advocacy meant taking legal action or making a formal complaint:

*“I made a complaint to the General Medical Council about [my neurologist] [...] and they decided that he would get a written warning for the way that he prescribed me the clonazepam and the way I came off of it and his response to it.” (David)*

*“A negligence claim, and it wasn’t really for the money. It was just to raise the profile that I felt I’d been given poor advice... I got £4,000. Which as I say, it wasn’t the money, but it was the validation that I was given basically another 2 months’ worth of the stuff without being given a warning.” (Patricia)*

Participants described the importance of receiving validation, particularly following initial disbelief, which for some marked a turning point in their recovery:

*“..that was the first breakthrough for me to speak to someone who could tell me that I hadn't gone completely mad and it's because of this drug. I mean, as hideous as it was to learn that it could be 'cause of a prescription drug, it was comforting to know that I hadn't actually completely lost it...”*  
(Patricia)

*“I said [to my new psychiatrist], 'You don't think any of this could be to do with me coming off the benzos, do you?' And he said, 'Yes, I think it could well be.' And that was what I needed to hear. I wasn't crazy. I wasn't treatment-resistant depression. I wasn't this, that, and the other. [...] as soon as he said that, it all made sense. And I thought, bingo, I can understand now why I'm feeling like this [...] Nothing made sense up to that. [...] And I began a long fight back, long, slow fight back from that day onwards.”* (Sarah)

Some described how they now no longer trust doctors as a consequence:

*“I can't talk to the medical profession because I don't trust them anymore. I've lost all trust in them. I literally won't go to the doctors for anything...”* (Rosalie)

*“I've been trying to get off Effexor now [...] Don't tell the doctors. I just don't tell them. [...] I've got boxes and boxes of repeat prescriptions that I've just stored in the cupboard. Why would I give [the doctor] control of anything?”* (Sarah)

For Rosalie, the experience of disbelief appeared to impact her willingness to access other professional support that she feels she will need:

*“Yeah, I do think that perhaps I will have to have counselling at some point. They keep offering it me, but I'm not ready yet. I don't feel like sharing it with anybody else yet [...] They'd be just like, 'Oh, you know, it couldn't have been that bad.’”*

### ***Subtheme: Educating Doctors, Families and Patients***

All participants stated the need for more education and information on benzodiazepine dependence and withdrawal when asked what future services should look like, despite this perhaps not being the main crux of the question. All participants spoke about improving education for doctors. The extracts below highlight how doctors recognising what patients are experiencing was seen as an important first step:

*“It's information and education and knowledge on the part of the professionals to, how to and to recognise the possibility that the symptoms that people have got are down to the cessation of benzos or the tolerance withdrawal that they're in.”* (Simone)

*“Education is key, because the first step is to get recognition for what's actually happening to you. Without that, you know, you're going round in circles spending money, seeing specialists that are telling you it's one thing or another. There needs to be more awareness that this can happen to you, that you can get tolerant to this drug, or it can make- Start making you really, really ill.”* (Rosalie)

Some participants also spoke about education for patients' families:

*“...educating GPs, family, 'cause I had to do all of that and it's very difficult when it's coming from you. When you're unwell, you know it's better coming from an outsider that can explain all of this. Definitely education...”* (Felicity)

*“...Heather Ashton, in her clinic, [...] Wouldn't have just involved the patient. She would have involved their nearest and dearest, and said to them, 'Yes, you know, they are suffering withdrawal. This is what's going to happen to them, and this is what you can do to help. [...] I'm sure there are support groups for family members that are helping somebody come off cannabis, cocaine, whatever, you know. Why don't, why on earth don't we need that support as well?’”* (Sarah)

Some also spoke about the need for education and written information for patients or listed specific resources they benefited from:

*“...a lot of people coming off, they would not have had my tenacity to go and do all this research. That's why it's got to be there for them, and it's got to be in a very user-friendly way. [...] you need proper information.”* (Sarah)

*“...[my GP] could've prescribed, if you like, BenzoBuddies and Benzofree.org. And the NHS could've provided me with the [Benzo Free] book, or I could've bought it myself...”* (David)

*“[The specialist organisation] sent me a really great book, that I could just read every day, but it was a big book like this, but more written in a magazine style so not a textbook, and I could read that every day, if I wanted, to sort of keep going...”* (Melissa)

Some expressed the view that prescribers need to adhere to NICE guidelines on not prescribing for longer than 2-4 weeks:

*“...a doctor should not be allowed to prescribe for longer than 28 days. I can say that given the experience that I've gone through...”* (David)

*“[Benzodiazepines] shouldn't even be prescribed long-term in this, you know, there's rules. I don't understand it, and I don't understand why you know, any doctor would repeat prescribe benzodiazepines, given the knowledge we've got now.”* (Melissa)

*“...for anybody that gets a new diazepam script, or a benzodiazepine script in the UK, in 2021, they should not be kept on them for more than 2 weeks max. It should never happen now. It should never happen.”* (Sarah)



## **Theme 2: Peer Support**

All participants described the value of receiving peer support, predominantly informally in online groups, but also formally through lived experience volunteers/staff in specialist charities or private therapists. While the previous theme in part highlighted that participants sought support outside of the mainstream healthcare system, peer support stood out as a theme in its own right, with participants describing the importance of receiving support from others who shared their lived experience. This was often used to seek reassurance, hope, advice, and learn from others' experiences, with almost all participants saying they particularly benefitted from the stories or support of those further ahead in their recovery. However, online peer support groups in particular were also described as a scary and negative place that participants used cautiously to protect their wellbeing. Almost all participants went on to help others by supporting them directly or raising awareness, which some described as therapeutic and part of their recovery. Some also expressed a willingness to work in local specialist services should these become available in the future.

### ***Subtheme: Receiving Peer Support: Invaluable, but Often the Only Resort, Risking Exposure to Vicarious Distress***

All participants received peer support whether informally online or formally via specialist helplines and private therapy. They described the value of being supported by someone with lived experience:

*“I think, honestly, the best people to talk to are the people that have been through it.”* (Rosalie)

*“Talking to the people on the helpline at the Bristol Tranquilliser Centre, was hugely helpful 'cause it's run by volunteers who'd been victims [of prescribed benzodiazepine dependence]...”* (Patricia)

*“...you need, like the team in Liverpool, you need people who've been through it to support you...”*  
(Melissa)

This was often used to seek advice, reassurance, and hope and learn from the experiences of others, with almost all saying they particularly benefitted from hearing the stories of or being supported by those further ahead in their recovery.

*“I had friends that had already come off online, a lot of them from America, and I would just message them and ask for their advice and if they'd been through it and if it was normal.”* (Rosalie)

*“I was quite despondent, I think when I was about 6 years, 6 or 7, maybe not, 4 years into the whole process. I am grateful to be able to ask somebody [on the online support forum] who was 9 years down the line who was recovering, to know that there was hope.”* (Simone)

*“She's like a therapist that's been through problems with benzodiazepine withdrawal [...] I have spoken to her and she really, really helped. She's full of hope [...] Yeah, definitely just hope, reassurance, speaking to somebody that's been through it and got better is priceless really...”* (Felicity)

*“[I] came across BenzoBuddies and, without a shadow of a doubt, that is the single biggest contributor to my recovery. Because I found somebody on there who was able to become my mentor and explained to me how - why I was feeling the way I was feeling and coached me through it.”* (David)

However, Sarah spoke about how patients should not have to rely on informal peer support, which many turn to due to lack of expertise in the healthcare system. In this vacuum, people who are still suffering themselves are often tasked with helping others who are suffering:

*“...there are no experts to help you come off, you know. Where is the expertise? I suspect that the expertise is with people like me [...] and others that have come off. [...] Where are the successors to Malcolm Lader and Heather Ashton? [...] Why is it the firefighters have not trained any other firefighters, and people whose houses are on fire are relying on other people, whose houses are on fire too, to help them? It's crazy.”*

Furthermore, as David identified: “*there are difficulties involved with asking untrained people to mentor others*”. Online peer support groups, while helpful, were also described by some participants as “*scary*” (Felicity), often containing upsetting or negative content. They thus used these groups cautiously to protect their wellbeing:

*“...I think witnessing other people suffering. Sadly, you know I’ve seen people like, you know, end their lives and it’s, there’s a lot of vicarious distress in the online groups with this sort of thing. So, I have to take a step away from that really and just look after myself...”* (Felicity)

*“[The online groups were] helpful in a lot of ways, but when you’re in that terror state, sometimes I had to come off there because people would write things that used to scare you. People mean well, but you know like, if I’d go on and somebody had killed themselves that day and I was in a bad phase, that would make me worse. So I had to dip in and out of it.”* (Rosalie)

*“BenzoBuddies was very useful. However, not 100 per cent because it’s full of negativity. I think the current terminology would be toxic. [...] So there were a couple of times I took a break from it, but when I felt stronger, when I felt ready, I went back to it.”* (David)

### ***Subtheme: Helping Others: Raising Awareness, Giving Back, and Part of Recovery***

Almost all participants spoke about going on to help others directly or by raising awareness, which some described as “*therapeutic*” (Rosalie), a way to “*turn a negative into a positive*” (Patricia), and part of their recovery:

*“I went back to Benzo[Buddies] and I became a mentor to help other people. So to give something back, which again reinforced my feelings of positivity about where I was in my recovery.”* (David)

*“I have been involved in setting up a support group. [...] that’s been good. It’s given me a bit of a purpose helping to do that sort of thing...”* (Felicity)

*“I’d found it a positive experience when I read about the [prescribed drug dependence organisation] looking for volunteers to go on the panel [...] then that got me thinking into, well, I’ve helped put together [prescribed drug dependence guidance], maybe I could be a talking therapist to help others on this journey. So then I started my training as a counsellor...”* (Patricia)

Some participants also spoke about wanting to be involved in local specialist services in the future, should these become available:

*“I’d quite like to get involved if there was a sort of a local service or something like that”* (Melissa)

*“I did look around the local area here for helping out. But I never found something - or anything that was really suitable, and I probably would, but I’ve stopped looking at this moment in time. I would still like to help out.”* (David)

### **Theme 3: Symptoms: Relationship to Symptoms, Coping, and Post-withdrawal**

Almost all participants described an initial relationship to their symptoms involving fear and uncertainty around their origin and potential duration. Over time, participants appeared to shift their focus toward trying to accept that only time would heal as withdrawal ran its course, based either on their personal experience of noticing patterns in or lessening of their symptoms or reassurance from others. They used idiosyncratic methods to cope with their symptoms and practiced self-care to promote healing. Participants described a prolonged, symptomatic post-withdrawal process spanning to present day, although they also experienced symptom improvement over time.

#### ***Subtheme: From Uncertainty and Fear to Acceptance That Time Heals***

Almost all participants described initially experiencing fear and uncertainty about their symptoms. For example, some described worries about whether their symptoms were indeed benzodiazepine withdrawal or something else due to the multitude of changing symptoms they experienced:

*“I’ve had to have all these scans, these tests and they’ve all come back, you know, mostly negative. Nobody can actually really explain what’s causing all of these symptoms, but I wasn’t so sure that was withdrawal ‘cause it was so physical and I started worrying I’d developed some disease, but it seems it’s all withdrawal still, so, yeah it’s just difficult when [the symptoms] change like that ‘cause you sort of think, oh is this something new?”* (Felicity)

*“...the symptoms just rotate. They just go from one thing to another constantly. But obviously, then when you get a new thing, you’re terrified that it’s something else.”* (Rosalie)

Many also described experiencing worries about whether their symptoms might be permanent or continue for a very long time:

*“I felt that I’m never gonna get back to reality, real life, you know?”* (Simone)

*“..I thought, it’s never going to go. And I sort of gave up hope by then. I just laid in bed and thought it’s never going to go.”* (Rosalie)

*“A racing chest: this was, one of the most gross symptoms that I had [...] it’s started; when is it going to finish? What if it never finishes? What if it’s still there when I go to bed tonight? What if it’s still there in the morning? Will it ever go?”* (David)

Participants described a shift over time where they either noticed patterns or lessening of symptoms, or were reassured by others that symptoms would lessen. They described trying to shift their focus away from their symptoms and associated worries toward acceptance that this was benzodiazepine withdrawal running its course, *“knowing it’ll fade away eventually”* (Rosalie), and *“healing would take time”* (Simone), but was indeed possible:

*“I’d get all these hideous withdrawals for about 2 weeks and then the windows of clarity would start to open up, and I started to see a pattern and I started to realise that this is just what I needed to go through...”* (Patricia)

*“...the main thing for me was just the reassurance, because I had a lot of really sort of quite severe sort of mental symptoms and suicidal thoughts and [the Bristol Tranquiliser Project] helped me to try to sort of detach myself from that and keep going really and they gave me hope, you know. They said that people do tend to eventually get over this...”* (Felicity)

*“...you can't fight it because it doesn't do what you want it to do. You have to just sort of wait for it to go and be patient. I mean, they say it's patience, but it's- It's a long time to be patient.”* (Rosalie)

Some also described passing this reassurance on to others based on their own experience:

*“I used to always say, 'Time is the only thing. Time.'”* (Simone)

*“I tell [people I am supporting online] that it will pass. It doesn't feel like it, but it will- It will go or, yes, I had this [symptom], but it's gone. It has lessened.”* (Rosalie)

### ***Subtheme: Coping and Self-care***

Participants described using a multitude of different coping and self-care strategies to manage withdrawal symptoms and their impact, including breathing (David), meditation (Felicity, Patricia, David), healthy eating including cutting out alcohol and caffeine (Patricia, Simone, Sarah, Felicity, Rosalie), exercise (Patricia), acupuncture (Patricia), and avoiding triggers such as stress (Simone, Rosalie) and tiredness (Sarah).

While there was thus some overlap, such as caring for and strengthening their bodies and minds to promote healing through strategies such as good nutrition and meditation, which specific strategies participants used appeared to be highly individual. Sometimes this was based on the specific symptoms people experienced, such as *“a hand-held massager [...] to deal with leg cramps”* (Simone), and *“audio books”* (Melissa) to help with sleep. However, for many participants one overarching aim seemed to be finding ways to *“calm their nervous system”* (Patricia), to *“relax”* (David), and *“soothing”* and *“comforting”* (Melissa). In relation to the strategies used, some

participants also spoke about *“be[ing] kind to themselves, self-care they can do to help them manage”* (Patricia) and *“whatever gets people through it”* (David). This appeared to connect to the previous subtheme about reaching a point where they understood and tried to accept that withdrawal symptoms would take their course and healing would take time. Thus, strategies seemed aimed more at managing, getting through, or coping, rather than resolving or stopping symptoms. In this regard, some participants also spoke about avoiding further prescribed drugs to treat symptoms. For example, Simone explained that based on her experience of supporting others online, typically doctors *“would start trying to treat the symptoms, which were really untreatable”* with further prescribed drugs. She describes her reasoning behind her choice of strategies:

*“If it was on the list [of symptoms in the Ashton Manual] then it was more than likely benzo damage and that use of further pharmaceuticals would be to no avail. Healing would take time, and one could only give the body the best possible chance to do so by eating healthily and avoiding stress which would, and still does, ramp up certain symptoms.”* (Simone)

David similarly spoke about his attitude toward managing his symptoms and prescribed drugs:

*“There's nothing else [the doctor] could've done, because he couldn't deal with my symptoms. [...] I'd have one of those pill things, wouldn't I, for every day. And I'd be taking four in the morning and three in the afternoon for my stomach, my headache, my funny legs. [...] I don't take paracetamol. I don't take anything. Nothing, Zero, zilch, nil, that's it, I'm done with it. [...] I will recover and I can feel my own pain. I can deal with my own pain.”*

In a similar vein, Felicity expressed that her aim was to focus on healing naturally:

*“The main things that, yeah, that helped me really now are just the natural things. You know, diet and trying to spend time in nature when I feel up to it and mindfulness, meditation, reading more around natural healing and, they're the main things and just, to be honest, living in the present moment as much as possible.”*

Sarah was the only participant who expressed that further (short-term) prescribing was beneficial for coping with her symptoms:

*“Sleep deprivation was horrendous [...] in the end they did give me zopiclone, which actually did help. I’ll be honest with you, that did help. I was so sleep-deprived, that just being zonked out for a couple of days helped enormously.”*

### ***Subtheme: Post-withdrawal: Persistence of Symptoms Long After Stopping***

All participants described experiencing symptoms for various lengths of time after stopping benzodiazepines, with some experiencing new or more severe symptoms. For some, their physical symptoms got worse:

*“People think you get off [of benzodiazepines] and all your symptoms go away. That’s not- In fact, some of the symptoms got a lot more intense once I got off. My balance was- Got a lot worse. The bladder pain got a lot worse. [...] Some things got better, and some things got worse. I would say more the physical symptoms get worse once you get off.”* (Rosalie)

*“...when I sort of finished the taper and came off, I developed a lot more physical symptoms, but some of the mental stuff has gone. [...] I started with one thing and I sort of, come off, come out with all these symptoms I never had before.”* (Felicity)

Some explained how their withdrawal symptoms worsened after stopping despite a long, careful taper:

*“I’d been weaning [tapering] for 16 months and that still wasn’t enough. So, what happened was, I finished in the May, and about, probably by September, I had a terrible crash of withdrawal symptoms. It didn’t happen straightaway...”* (Melissa)



*“...real hell started when I actually jumped off [of benzodiazepines], and that was after 2 years [of tapering]. Real hell started after I jumped off at 5 mls. I even think 2 years was too fast, and I went according to [the] Ashton [manual], but then I'd been on it a hell of a long time.” (Sarah)*

Many participants emphasised that symptoms can endure for years after stopping:

*“...I'm reiterating that it can take years to fully go and leg spasms carried on, I suppose for about 8 years, something like that, 8 years. Probably stopped about 4 years ago.” (Simone)*

*“...how can nobody know the suffering that goes on for years and years and years? I mean, it cost me and it's- I'm up to my fourth year now...” (Rosalie)*

While participants had been off of benzodiazepines for between 1-16 years, they all still experienced some symptoms to varying degrees or what they felt was fallout from the impact of the symptoms.

*“I am 16 years off and still have protracted [withdrawal symptoms], usually ramped up by stress.” (Simone)*

*“So now [22 months off] I experience a lot of like fatigue and I have lots of problems with, like heat intolerance and can't be in the sun too long and there's, well a host of sort of neurological things as well. I get like tremors, and I've got vision problems.” (Felicity)*

*“I've been diagnosed with chronic fatigue which I think is possibly a fallout from the strain on your, stress on your adrenal glands and the stress your body's been through.” (Patricia)*

However, almost all participants also spoke about experiencing improvement over time:

*“...in the last 3 years [since stopping], I have not been well for longer than 2 weeks apart from the last 4 weeks. So the longest window I have had has been 2 weeks. And then I've gone back into a wave, but the waves have diminished in strength.” (David)*

*“I still think I have some protracted symptoms [4 years after stopping]. They're a hell of a lot better now. [...] but I would say there are still some protracted symptoms.”* (Sarah)

#### **Theme 4: Severe Suffering That Can Impact Every Aspect of Your Life**

Participants described severe suffering while and after coming off benzodiazepines and many spoke of enduring trauma. This often came at great personal cost to their close relationships, employment, and life experiences. Participants described needing support across many different areas of their lives, often around the clock, highlighting that this cannot be done alone and the need for practical, emotional, and specialist support. As Rosalie summarised: *“This goes on for years and years and years and years and affects every aspect of your life completely.”*

##### ***Subtheme: Severity of Suffering and Enduring Trauma***

Almost all participants spoke of severe suffering while coming off benzodiazepines and after stopping, described as *“absolute hell”* (David), a *“nightmare”* (Sarah, David), *“terrifying”* (Patricia), *“traumatic”* (Melissa), and a *“life and death”* (Rosalie) experience, due to both the severity of their withdrawal symptoms and how they were treated in the healthcare system during the experience:

*“I can't even put it into words what [the withdrawal symptoms] felt like, but I actually thought I'd just lay down and die.”* (Melissa)

*“I haven't gone out and sought heroin, the GP has prescribed something for you that's caused you great harm and then they dismiss what's happening to you. That's very traumatic...”* (Melissa)

*“I've never suffered with anything like this in my life, honestly. I took an overdose. I ended up in a psychiatric hospital who had no idea. They kept giving me more diazepam. They gave me an antipsychotic which made the psychosis worse. They gave me other sorts of tablets. [...] I ended*

*up having like a seizure. I couldn't move. And they left me on the floor [...] I was terrified in there, absolutely terrified. They treated me like- Awful, awful experience.” (Rosalie)*

Some also experienced enduring trauma due to this experience:

*“...the severity of the suffering. You know I sometimes wonder how I'm still alive to be honest. It's just been so horrendous, and like I said if I hadn't have been through it myself [...] I wouldn't have been able to believe that a drug could induce so much torment. So yeah, and trauma, definitely trauma of the suffering and trauma of drugs, trauma around doctors, you know, thinking about if I just hadn't have taken that drug, you know, I would have still been healthy.” (Felicity)*

*“So, yeah, it's been very traumatic, very traumatic. You know, people say to me now, you know, 'Ooh you have to forget it now and get on with your life.' [...] And now is when I need to process it to help me move on. People don't understand that. They think that, you know, you're living in the past, but it's hard to move on from something like that.” (Rosalie)*

*“I had counselling for trauma. I had EMDR, [...] eye movement desensitisation, for the trauma and the anger I felt at the doctors that had let me down and the medical profession and I just had panic attacks during those sessions.” (Patricia)*

Both Patricia and Rosalie also reported that they still experience flashbacks:

*“I still get a lot of flashbacks, but they've got, again, it's less, it's 6 years now but it's got less over the years, but still I can get flashbacks if I'm triggered...” (Patricia)*

*“I find the hardest bit is flashbacks, when I get flashbacks. I find that quite hard. That's mainly from the hospital, I think.” (Rosalie)*

### ***Subtheme: Personal Cost***

Most participants described how benzodiazepine withdrawal had a significant impact on important areas of their lives, such as relationships, employment, and missing out on other life experiences. One of the participants who did not, was already housebound due to another chronic illness when they began to experience withdrawal.

*“I’m still very limited. I can’t work. I had to give up- I was working in the NHS, but I had to give that up.”* (Felicity)

*“I didn’t work for eight months in 2018.”* (Sarah)

*“My partner had to pack his job in to look after me, I was that bad.”* (Rosalie)

*“..damage gets done, you see. You lose contact, proper contact with your family. You know, I’ve nine grandchildren, all of them were born in the beginning of all this nonsense and I could not be a proper grandma to them and I regret that...”* (Simone)

*“I couldn’t work. [...] I had to give that up. I was actually due to get married in the September but I was just a mess and I’d lost so much weight, I couldn’t even - so the most humiliating thing was cancelling 70 guests saying I can’t get married 'cause basically I’m having a mental breakdown due to prescription medication was the hardest thing to actually say.”* (Patricia)

While participants were not asked to describe their experience while taking benzodiazepines in detail, Sarah also disclosed her experience of the personal cost while she was on benzodiazepines:

*“You know, it numbed me when I was taking them. I could function, but it came at a cost. I remember going through my wedding a little bit in a distance, you know, I couldn’t really feel happy. I couldn’t really feel joy. Everything was done in a bit of a haze. The same with birth of my kids. They were there, but they weren’t there if that makes sense. Any major occasions I had in my life was blunted and numbed, and I was very soporific, you know, all the time.”*

***Subtheme: It Can’t Be Done Alone: Emotional, Practical, and Specialist Support***

Almost all participants highlighted needing support across many different areas of their lives both emotionally and practically, such as with meeting their basic needs, financially, and tapering. For some this meant needing someone to be with them around the clock to provide support:

*“...you become almost incapable at times of looking after yourself and, yeah, it is 24 hour at times really. [...] my mum sat with me quite often during the nights where I couldn't sleep. I was just shaking and dry heaving and, you know very much acute type withdrawals, but they also, my dad makes food for me and, they do all my food shopping, cleaning- I can't do that. So, very practical stuff really and then my mum it's more I suppose emotional support really.”* (Felicity)

*“[My husband] sat with me day and night. I'd stay in bed for 3 days at a time. He'd watch videos with me from the minute I woke up to the minute I'd go to bed. And then he'd help me again in the morning when I was in complete terror, and I'd be crying and hysterical. He'd calm me down...”*  
(Rosalie)

Some described the need for practical support with tapering, including planning, adjusting, and the practicalities of measuring out dosages:

*“...[With the specialist helpline] we would just talk it through and, you know, any advice about taking a step back [in my taper], getting comfortable again, and then going down more...”*  
(Melissa)

*“They gave me bottles of liquid I had to get all the time and my partner did it all, drawn it all out for me for the next morning. I don't know how I'd have done if I'd had to have done it all myself.”*  
(Rosalie)

While many participants (see “Personal Cost”) spoke about being unable to work, Sarah specifically highlighted that financial support is thus necessary:

*“...for some people, withdrawal is so tough, they are gonna be off work long-term. And therefore, they need assistance with that. [...] I'm lucky, I had [my husband] that was able to, you know, earn money and pay the bills, but if I hadn't, I would have wanted state assistance...”* (Sarah)

Some expressed explicitly that they could not imagine having gotten through the experience alone, without the support of their families:

*I mean, I had a partner that gave up his job to look after me. I don't know what people would do if they didn't have support.* (Rosalie)

*...if I didn't have my support of my mum and dad, I don't know where I'd be really.* (Felicity)

Despite no participants living in areas with a local specialist service, many contacted these for support via telephone, often highlighting how vital this support was and the importance of having this type of support available to others:

*“I'm not sure where I would have gone without [the specialist helpline], so I'm very sad if people can't access that sort of support. They were brilliant...”* (Melissa)

*“I know the Bristol Tranquilliser Centre, which was a charity run so [the helpline] could only be available a few hours a week, was like a lifeline to me, so I think to have a government-funded helpline, would be hugely helpful.”* (Patricia)

In addition to some calls for a specialist “24-hour helpline” (Sarah) available to all, many called for more specialist, government funded support. As mentioned, while some accessed support via helplines, none were able to benefit from specialist support locally.

*“... [the Bristol Tranquilliser Project has,] for the people in Bristol, presumably, counsellors and nurses and group therapies and things, you know. I think Bristol Tranquilliser support group, as a minimum, should be replicated in every major city in the land.”* (Sarah)

*“I think to have a government-funded helpline, would be hugely helpful. And also, centres. I know there's a project in Wales, there's a centre, that's got counsellors and nurses in who understand people with withdrawal and they get referred from the GP to the centre and then they can be helped through their journey. I mean, it would be wonderful if there was a centre in each area, each county...”* (Patricia)

David felt that specialist support could be located in GP surgeries as *“they're your local support”*, your first port of call, by recruiting or training people with specialist knowledge in order to *“have a benzo specialist in each GP practice”*.

Some participants expressed that the same level of dedicated specialist services provided for addiction to drugs and alcohol needs to be provided to those dependent on prescribed drugs and a sense of injustice that it is not:

*“So, we desperately need a properly funded [system] because I think people who have been harmed by prescription drugs feel very cheated that if they suddenly started abusing recreational drugs, there's a system to help them. And yet, when you've been prescribed by a doctor, and it's harmed you in that way, there's no help at all.”* (Melissa)

*“...like other services, and I'm sure if you go into rehab, to recover from heroin addiction, you probably get nutrition and sleep advice, you know. It would be just nice for somewhere to go, where you can have a massage or, or physiotherapy or nutrition or just everything that other people in addiction services are offered.”* (Sarah)

Melissa felt that inpatient admission might be necessary when things were severe:

*“I think actually, in some cases, when it's severe withdrawal, people need actual inpatient care to keep them safe, but that's one end of the spectrum.”*

## **Generation of Themes**

Themes do not ‘emerge’ from a dataset but are “actively created by the researcher at the intersection of data, analytic process and subjectivity” (Braun & Clarke, 2019, p. 594). This is thus not the only way of interpreting and organising the data. For example, I discussed whether the subtheme “It Can’t Be Done Alone: Emotional, Practical, and Specialist Support” might instead be placed under the “Symptoms: Relationship to Symptoms, Coping, and Post-withdrawal” theme with my supervisor. We decided it belonged more under “Severe Suffering That Can Impact Every Aspect of Your Life” as it appears to tie in closely with the other subthemes. As no participants reported receiving adequate support within the mainstream healthcare system, but rather needed to rely heavily on their families and/or taking the initiative to find alternate support, we thought this was another reflection of how their suffering impacted many different aspects of their lives, with calls for specialist support stemming from these experiences. For example, participants needing around the clock support from their families appeared closely connected with the subtheme “Personal Cost”, as some participants’ partners needed to give up their jobs to provide this care.

Some themes were excluded, mainly due to being deemed more latent than semantic. For example, that withdrawal and recovery is a ‘lonely journey’ was stated explicitly by few participants but implied throughout participant narratives. Another was how much participants spoke about the experiences of others, indicating that engaging with others’ recovery narratives is how they made sense of their own experiences, including why some participants referred to themselves as ‘lucky’ despite enduring severe suffering (appearing to compare this with the experiences of others they had read/heard).



## REFLEXIVITY

In RTA, as in other qualitative approaches, researcher subjectivity is considered an essential resource which can contextualise and enhance the research process, not a ‘bias’ we seek to eliminate to ensure ‘accurate’ analysis (Braun & Clarke, 2022; Gough, 2003; Gough, 2016). Reflecting on how assumptions and emotional responses might constrain engagement with the data can open up new understandings and possibilities for interpretation (Braun & Clarke, 2022). I engaged in reflexivity during the research process through journaling, supervision, and personal therapy, reflecting on how my existing knowledge base, assumptions, and responses may have affected my topic choice, data collection, and engagement with the data (Braun & Clarke, 2022; Willig, 2012).

I chose this research area due to personal experiences. These experiences led to anger and some strong negative opinions about doctors and the use of prescribed psychiatric drugs. My experiences and the belief that we need better support services informed the sample of participants I chose to recruit, those who had found it difficult to come off/stop benzodiazepines or struggled with withdrawal/post-withdrawal symptoms, as I wanted to explore the experiences of people who needed support and how their needs could be better met. My experiences also informed my decision to recruit only benzodiazepine patients, whereas z-drugs and benzodiazepines are often researched together in the literature (e.g. Davies et al., 2017; Mokhar et al., 2018; Sirdifield, 2017).

I sometimes needed to moderate my tone when writing by editing initial drafts, as these sometimes came across as angry and inappropriate for academic writing. I similarly had to edit out overgeneralisations, by using words such as “some doctors” rather than just “doctors” in relation to findings in the literature and this study. I also reflected on the need to keep an open mind during interviews and analysis, as I anticipated that participants may speak about positive experiences with doctors or finding prescribed drugs helpful in aiding withdrawal. I took care to leave room for sharing such positive experiences by keeping questions brief, open, and neutral, so participants had significant leeway for choosing what to share. I did not ask directly about negative experiences. However, participants overwhelmingly shared negative experiences with doctors and prescribed drugs, so this was ultimately not a difficult stance to adopt.

During the recruitment phase, I was contacted by someone who had withdrawn from benzodiazepines but now takes them within prescribing guidelines (intermittently/short-term, thus avoiding dependence). This made me consider that the criterion that people need be completely off benzodiazepines was determined by my attitude toward benzodiazepines as generally harmful, despite there being legitimate reasons for short-term prescribing. This criterion could be changed in future research.

My intention, when I started this research, was to try to capture a fuller picture of people's experiences than is depicted in research available from the benzodiazepine patient's perspective. While I expected many of the findings in the Results chapter, my presumption was that participants would also describe post-traumatic growth, positive comparisons between how they feel now versus while on benzodiazepines/during withdrawal. This expectation was informed by my own experience and desire to give hope to others who might be thinking about or are withdrawing. However, silver linings were only mentioned by two participants. I did not ask about positive aspects of recovery and participants may have wanted to highlight their suffering when talking to a researcher to raise awareness and bring about changes in policy, as they were very passionate about helping others. In hindsight, given the wealth of valuable experience shared by participants and the already broad research questions, asking directly about positive experiences may have broadened to scope of the research too much and be best reserved for future research.

## DISCUSSION

The research aims were gaining a better understanding of patient experiences of ongoing recovery from prescribed benzodiazepine dependence, what they think helped, and what they think future services should look like. The themes broadly echo those documented in the existing literature, but also expand on these. What is expanded on here appears to be how prominent a role disbelief and failures in healthcare played far beyond being an obstacle to obtaining support. Disbelief and failures in healthcare appeared to have a global negative impact on participants' wellbeing and recovery process, exacerbating suffering by fuelling uncertainty, leading to harm through misdiagnoses and further prescribing, contributing to experiences of shame and stigma, negatively impacting family relationships, contributing to enduring trauma, and meaning participants had to undertake significant work to self-advocate to obtain alternate support amidst debilitating suffering. This discussion draws on some new research not examined in the literature review, due to the inductive nature of the analysis and new findings that extend and develop on the literature. For example, the extent to which disbelief and failures in healthcare permeated all participants' experiences prompted an examination of the literature on other chronic, invisible, and contested physical illnesses where this has been studied more extensively.

### **Understanding the Themes in the Context of the Existing Literature**

#### **Disbelief and Failures in Healthcare**

Much of the content of the theme "Disbelief and Failures in Healthcare" broadly echoes previous research on benzodiazepines and prescribed drugs more broadly. This includes participants' experiences of being disbelieved, having symptoms misinterpreted as caused by an existing/new mental health problem, being unable to obtain adequate NHS support, and thus seeking help outside of the mainstream healthcare system, particularly peer support (Guy et al., 2018; Guy et al., 2020; King et al., 2022).

#### ***Contested Illness***

Benzodiazepine dependence and withdrawal has been described as an ‘invisible’ illness that is socially/medically contested and stigmatised (Fixsen, 2015). This may be because doctors lack adequate knowledge and training, and an ‘objective’ diagnosis cannot presently be confirmed through medical investigations (Davis, 2005). Invisible illnesses involve symptoms not visually or easily discernible by others, or where the source of the limitations it imposes is not easily identifiable (Davis, 2005). Accurate diagnosis mainly relies on doctors’ assessment of patients’ self-reported symptoms, meaning that being disbelieved could delay recognition of difficulties and thus access to appropriate support (Moncrieff, 2020). Benzodiazepine patients’ experiences of interacting with the healthcare system have strong parallels with those of patients with other chronic physical illnesses often considered invisible and thus contested such as chronic fatigue syndrome, fibromyalgia, lupus, chronic pain, and long COVID (Armentor, 2016; Brennan & Creaven, 2015; Davis, 2005; Newton, 2013; Sloan et al., 2020; Witvliet, 2022). These patients have similarly reported being disbelieved, dismissed, or misdiagnosed with a mental health problem, and thus not receiving adequate acknowledgement of the problem or support, or receiving inappropriate treatment (Armentor, 2016; Au et al., 2022; McManimen et al., 2019; Merone et al., 2022; Newton, 2013). Misattribution of a physical problem, such as benzodiazepine withdrawal, to a mental illness can delay treatment and lead to severe complications (Nash, 2013). For example, for two participants in the current study, misdiagnosis not only delayed recognition of withdrawal but led to treatment with antipsychotics and inpatient admission to a psychiatric ward. NICE guidelines state that antipsychotics can exacerbate withdrawal and should not be prescribed (CKS, 2022). For one of these participants, inappropriate further prescribing led to a seizure. These experiences echo previous findings on withdrawal from benzodiazepines and other prescribed drugs where disbelief and/or misdiagnosis have been reported to lead to needing emergency care, hospitalisation, and medical testing, causing unnecessary suffering and costing the healthcare system (Guy et al., 2018; Guy et al., 2020; Haddad et al., 2001).

### ***Misdiagnosis, Diagnostic Overshadowing, Stigma, and Shame***

Misdiagnosis with a mental health problem may be partly due to doctors’ lack of knowledge of withdrawal symptoms and/or these seeming to mimic mental health problems. However, what has perhaps been explored less in the prescribed drug dependence literature, but was described by

participants, is that mental health (mis)diagnosis is associated with stigma (Nash, 2013). Public Health England's review states: "Patients who want to stop using a medicine must be able to access appropriate medical advice and treatment, and must never be stigmatised" (Taylor et al., 2019, p. 15), but did not explore experiences of stigma. Mental health stigma can contribute to patients not being believed as well as leading to diagnostic overshadowing, where physical illness symptoms are dismissed and misattributed to the mental health (mis)diagnosis (Nash, 2013). As Felicity explained: "*you're sort of disbelieved and, especially if you've got that history of like a bit of anxiety, you're sort of then seen as everything you experience is just your anxiety*". Thus, misdiagnosis with a new mental health problem or attributing symptoms to a previous one, means withdrawal can go unrecognised/undiagnosed. Patients with other chronic physical illnesses similarly report that once they received an initial psychological misdiagnosis, it was even harder to obtain a diagnosis for their actual physical illness (Merone et al., 2022; Dumit, 2006).

Another way that participants described being stigmatised is by being treated like '*an addict*' (Sarah), '*like you did it to yourself*' (Rosalie), by medical professionals. While this is a known problem raised by benzodiazepine patients (Fixsen & Ridge, 2017; Frederick, 2014; Lamberson, 2018) and professionals working with them (BMA, 2015), this stigma and its impact has received limited attention in the academic literature. Experiences of shame have also received limited attention, except in Hammersley's (2001) exploration of shame due to having been deceived into taking benzodiazepines because of a lack of informed consent. Participants in this study reported being "*made to feel shameful*" (Rosalie), like they were "*imagining*" (Sarah) or "*making it up*" (Rosalie), that it's "*all in your head*" (Melissa), like they were "*mad*" (Patricia) or "*crazy*" (Sarah). Thus, this study appears to expand on the literature by exploring patient experiences of shame, stigma, and being made to doubt their own reality or sanity due to dismissive or disbelieving responses from doctors, making them feel their symptoms were their own fault, imaginary, or fabricated.

Some of these experiences are reminiscent of the consequences of medical gaslighting in other contested illnesses, where doctors invalidate or dismiss patients by claiming their health problems are 'all in your head' (Sebring, 2021). For example, women with chronic conditions reported "a strong sense of trauma, including stigma, prejudice, shame, and blame received from health

services” (Merone, 2022, p. 1021). Sebring (2021, p.2) states that “gaslighting is one symptom of a larger problem in medicine, that is the continued privileging of biomedical expertise over lived experience”. Thus, it is important to disseminate research, like this study, which privileges lived experience and documents the impact on patients when lived experience is dismissed.

### ***Family Disbelief***

While family disbelief does not appear to have been explored in the benzodiazepine literature, some antidepressant patients have reported being disbelieved and seen as ‘overreacting’ by their families, thus straining relationships and making it difficult to receive their support (Davies et al., 2018). What is perhaps novel, is how some participants explicitly state that their family’s disbelief was a consequence of their doctor’s disbelief, due to their professional authority. Thus, for some benzodiazepine patients, who due to failures in healthcare may have to rely heavily on family support, disbelief and dismissal by doctors could have the knock-on effect of further depriving patients of one of the only avenues of support available to them.

### ***Validation***

Participants reported the importance of receiving validation, particularly following initial experiences of disbelief. For some, this appeared to mark a turning point in their recovery, allowing them to make sense of what was happening and move beyond the self-doubt instigated by doctors around whether they were ‘crazy’ (Sarah) or ‘*had gone completely mad*’ (Patricia). Benzodiazepine and antidepressant patients have described similar experiences (Fixsen, 2015; Guy et al., 2020). Other chronic illness patients also report valuing being believed/validation following initial invalidating experiences in healthcare (Merone et al., 2022; Au et al., 2022). These findings make sense as recognition is the first step to successfully managing dependence and withdrawal (Moncrieff, 2020).

### ***Self-advocacy***

Most participants engaged in self-advocacy, which for many meant challenging and educating their doctors. This was particularly necessary where prescribers tried to taper them faster than was tolerable and thus completely disengaging from them was not possible. Some participants also needed to educate their families to be believed and receive support. Others self-advocated through a formal complaint or legal action against their prescriber. Self-advocacy does not yet appear to have been explored in the benzodiazepine literature. The importance of self-advocacy, as well as how much work this requires from patients who are already suffering debilitating symptoms, to convince and educate medical professionals as well as friends and family, has been explored in research on other chronic illness patient groups (Au et al., 2022; Dumit, 2006; McManimen et al., 2019, Merone et al., 2022; Sloan et al., 2020). The current study highlights the exhausting lengths participants needed to go to simply be believed, secure their families' support, or be allowed to taper at a safe pace by their doctor. Furthermore, what perhaps goes unsaid explicitly, is the amount of work participants needed to do to become credible enough experts on dependence and withdrawal before engaging in self-advocacy, such as conducting online searches, reading the Ashton (2002) manual, reading current academic papers, and seeking guidance from others, which they reported sharing with their doctors and families.

### ***No Informed Consent***

None of the participants described being warned by prescribers about adverse effects, dependence, and withdrawal associated with benzodiazepines, contravening national guidelines (Department of Health, 2009; General Medical Council, 2020) and the core ethical and professional principle of informed consent. Some prescribers explicitly denied that benzodiazepines were dependence-forming at low doses, highlighting an alarming lack of knowledge given that the medical community have been alerted to their dependence potential at any dose since 1988 (CSM, 1988). Previous studies also found that the majority of patients reported not being informed of these risks (Finlayson, 2022; Guy et al., 2018).

### ***Education***

When asked what future services should look like, all participants recommended education for doctors, and many suggested information for patients and education for families. This makes sense, with recognition being the first step toward supporting patients in managing withdrawal (Moncrieff, 2020). “*Education is key, because the first step is to get recognition for what's actually happening to you*” (Rosalie). The need for training doctors and information was highlighted in the BMA (2015) report, Public Health England review (Taylor et al., 2019), and its implementation plan (NHS England, 2023). Working with families was identified as support provided in the few available specialist services (Cooper et al., 2023). Participants also said that prescribers need to follow NICE guidelines (BNF, 2022) on not prescribing beyond 4 weeks, a limit in place since 1988 (CSM, 1988). Adherence to guidance is also a goal of the NHS England (2023) implementation plan. Between 2015-2018, 67-72% of prescriptions went beyond 4 weeks (Davies et al., 2022), contravening national guidelines, with unnecessary prescribing estimated to cost £38.5-43 million a year.

## **Peer Support**

All participants highlighted the importance of peer support, predominantly sought informally online but also formally through lived experience practitioners. Participants described the benefits of seeking reassurance, advice, and hope, particularly from those further ahead in their recovery. While lived experience practitioners played a valuable role, these were rare and accessed through the limited specialist support available through telephone helplines or by paying privately. Echoing Lynch’s (2021) findings, informal online groups were reported to also sometimes be negative and upsetting, due to the “*vicarious distress*” (Felicity) experienced. Participants mainly sought peer support due to being unable to obtain adequate support in the mainstream healthcare system. The majority of withdrawal support in the UK appears to be sought online after unhelpful interactions with doctors (Guy et al., 2018), and using peer support in the absence of mainstream support is highlighted in the literature on benzodiazepines and other prescribed drugs (Fixsen, 2015; Fixsen & Ridge, 2017; Groot & van Os, 2020; King et al., 2022; Read et al., 2023; White et al., 2021). While peer support may always remain important, most patients have no other choice and their peers online provide difficult and sometimes triggering support that should be provided by the original prescriber (White et al., 2021) and the commissioning of specialist services (NHS



England, 2023). Rosalie explains: “*they are the people that act like doctors for you*”. However, as Sarah expresses: “*Where is the expertise? [...] people whose houses are on fire are relying on other people, whose houses are on fire too, to help them? It's crazy*”.

Almost all participants went on to help others. Thus, it is perhaps unsurprising that some also spoke about wanting to be involved in local services should these become available. Framer (2021) explains how members of an antidepressant online support forum are encouraged to help others, ‘pay it forward’. Patients’ willingness to be involved in raising awareness and bringing about improvements is demonstrated by benzodiazepine and other prescribed drug dependence experts-by-experience’s contributions to the academic literature (Finlayson et al., 2022; Framer, 2021; Lynch et al., 2022; Silvernail & Wright, 2022; Stockmann, 2019), *Guidance for Psychological Therapists* (Guy et al., 2019b), Public Health England review (Taylor et al, 2019), and its implementation plan (NHS England, 2023).

## **Symptoms: Relationship to Symptoms, Coping, and Post-withdrawal**

### ***From Uncertainty and Fear to Acceptance That Time Heals***

Participants described experiencing fear and uncertainty around the origin and potential duration of their symptoms followed by trying to accept that they will heal with time. This was helped by learning from their symptom patterns and reassurance from peers. This has previously explored by Fixsen and Ridge (2017). An attitude of acceptance/non-resistance toward symptoms and shifting focus away through distractions is also recommended by lived experience therapist Frederick (2014) and the *Guidance for Psychological Therapists* (Guy et al., 2019b). What stands out in the current study is that an attitude of acceptance/non-resistance may be difficult to adopt without acknowledgement that what patients are experiencing is indeed withdrawal and reassurance about what to expect. Doctors’ disbelief and lack of expertise, and thus inability to provide information or reassurance about what was happening, appears to have contributed to the initial fear and uncertainty experienced as participants went around in circles trying to find answers and learn how to best manage symptoms outside of the healthcare system. While peer support eventually provided acknowledgement and reassurance, perhaps a doctor that was educated, or open to

learning from patients, may have saved them the additional suffering caused by unnecessary medical investigations or constant symptom focus while seeking answers and looking for patterns. This could have enabled acceptance and a shift away from focusing on symptoms sooner. As Davis (2005, p. 212) explains, when patients with invisible illnesses are put in a position where they have to ‘prove’ that they really are ill: “many conditions are far more activity restricting, far more unpleasant, and potentially far more health compromising when a person is forced to dwell on his or her symptoms and pushed into exaggerating them, or merely having constantly to attend to them”.

### ***Coping and Self-care***

Coping and self-care strategies have been well documented by experts-by-experience (The Withdrawal Project, 2019; Frederick, 2014) and incorporated into the *Guidance for Psychological Therapists* (Guy et al., 2019a). The focus appears to be ‘self-management’ (Frederick, 2014), fitting with how participants appeared to try to adopt a relationship of acceptance toward their symptoms, with strategies seeming to centre around coping and calming their nervous systems rather than resisting or resolving symptoms. Trying to calm one’s nervous system makes sense, given that withdrawal symptoms are thought to be caused by GABA underactivity, causing nervous system hyperexcitability (Ashton, 2002). Participants focused mainly on non-pharmacological coping skills, as also recommended in the *Guidance for Psychological Therapists* (Guy et al., 2019a) and described in Fixsen & Ridge (2017). The NICE guidelines, however, recommend prescribing antidepressants if “depression or panic disorder coexist or emerge” (CKS, 2022) during withdrawal, despite these being known adverse effects and withdrawal symptoms (Ashton, 2002), antidepressants being another dependence-forming drug (Read & Williams, 2018), and other sections of the NICE guidelines contradicting this stating antidepressants “should be avoided where possible” (BNF, 2022) and to “not treat withdrawal symptoms with another medicine that is associated with dependence or withdrawal symptoms” (NICE, 2022b). While there is some mention of strategies described by participants in other academic literature, such as meditation and breathing, the language the researchers used focused on coping with the re-emergence of the condition benzodiazepines were originally prescribed for (Parr et al., 2006;

Lynch et al., 2021). Participants here are clear that these are strategies for coping with withdrawal symptoms, not an ‘original condition’ that has re-emerged.

### ***Post-withdrawal: Persistence of Symptoms Long After Stopping***

All participants experienced withdrawal symptoms long after stopping benzodiazepines, which for some were different or more severe than while tapering, for some despite a long careful taper. Many emphasised that while symptoms have improved over time, they can endure for years after stopping, with all participants still experiencing symptoms to varying degrees at present, despite being off benzodiazepines for between 1-16 years. Participants expressed the need for more awareness of the long-term nature of recovery, measured in years. The NICE guidelines were amended in 2022 to remove the arbitrary end date of 18 months for post-withdrawal symptoms, acknowledging some patients may take longer (BNF, 2022). These findings also demonstrate the importance of researching longer-term outcomes, whereas most RCTs follow up for less than 12 months (Darker et al., 2015; Parr et al., 2009).

The finding that some participants experienced a delay between stopping benzodiazepines and post-withdrawal symptoms starting is inconsistent with NICE guidance, which states “the benzodiazepine withdrawal syndrome may develop at any time up to 3 weeks after stopping” (BNF, 2022). Given the paucity of post-withdrawal research, it is unclear how this figure was arrived at, which seems to place an unnecessary boundary on what is possible for patients to experience. For example, Melissa described stopping in May but not experiencing a “*crash of post-withdrawal symptoms*” until September, at which point her doctor did not believe her.

The findings also highlight how the amount of time patients take to taper is not always a measure of how severe their withdrawal symptoms were, as it is sometimes used in research (Groot & van Os, 2020). For example, David was prescribed benzodiazepines for 7 months, tapered for 1 month, yet only begun experiencing 3 years of “*hell*”, withdrawal symptoms, after stopping. An initial absence of or only mild withdrawal symptoms during the taper does not necessarily mean patients will not suffer severe post-withdrawal symptoms. This also casts some doubt on considering

stopping benzodiazepines as a marker of success in some RCTs when there was no follow up on post-withdrawal symptoms or quality of life (e.g. Ten Wolde et al. (2008)).

## **Severe Suffering That Can Impact Every Aspect of Your Life**

### *Severity of Suffering and Enduring Trauma*

Participants' descriptions of suffering severe symptoms echo Fixsen and Ridge (2017) and Fixsen (2015), who similarly described withdrawal as 'hell', a 'nightmare', an 'ongoing trauma'. Due to the current study's broader focus and ability to elicit more detail about participants' journey from prescribing through to ongoing recovery using interviews, participant accounts could play an important role in raising awareness of how severe suffering can be even when patients are on what is considered a 'low dose' by their doctor. Fixsen (2015, p. 6) who described severe withdrawal, 'hell', also writes: "immediate withdrawal from benzodiazepines is never recommended, but in fairness to the doctor, I was on a very small dose". However, even at the lowest doses available, the drug manufacturer recommends the drug always be tapered (Sandoz, 2022), acknowledging dependence potential at any dose. NICE guidance states: "with slow tapering, many people experience few or no withdrawal symptoms" (CKS, 2022). Participants' accounts thus provide a picture of the breadth of possible withdrawal experiences, acknowledging that even with 'low' doses and slow tapers, people can still experience devastating consequences.

Fixsen (2015) also described withdrawal as causing enduring trauma that it will take time to move forward from. The *Guidance for Psychological Therapists* states that if patients experienced withdrawal as traumatic this may need considering in therapy (Rizq et al., 2019). What is perhaps new in the current study is that some participants described how experiences of disbelief and mistreatment in healthcare contributed to or were responsible for ongoing trauma. This highlights how iatrogenic harm is not just the harm done to the body through prescribing without informed consent and safe withdrawal methods, but also broader harm done through being disbelieved and for some consequently receiving incorrect and/or harmful treatment by professionals in positions of authority in whom participants placed their trust. While Patricia sought psychological therapy for trauma, Rosalie expressed that she was not ready, due to worries that a therapist would not

believe her about the severity of the experience. Thus, it may be important to bear in mind that trauma caused by disbelief and mistreatment in health services could mean that patients may also mistrust other healthcare professionals such as psychologists.

### ***Personal Cost***

Most participants described how dependence and withdrawal significantly impacted many important areas of their lives, including relationships, being unable to work, and missing out on valued life experiences. High personal cost has also been described in the literature, including breaking up families, losing jobs/home/friends, bankruptcy, and suicide (Finlayson et al., 2022; Guy et al., 2018).

### ***It Can't Be Done Alone: Emotional, Practical, and Specialist Support***

Almost all participants described needing emotional and practical support, including with meeting basic needs, finances, and tapering. Many called the only existing helplines, open only for a limited number of hours, but none were able to receive specialist support locally. Some needed around the clock family support. Almost all described receiving some form of essential support from their families, with some expressing that they do not know how one could get through this experience alone. While participants suffered significant personal consequences and losses, some acknowledged that they could not have managed without family support, including financially. Some participants called for government financial support, a 24-hour national helpline, and local specialist services at least on par with support provided for other public health problems such as addiction. There have been repeated calls for a 24-hour national helpline and commissioning specialist services (Kmietowicz, 2016; Taylor et al., 2019), but these have not materialised. The Liverpool helpline used by one participant no longer exists, and the Bristol Tranquilliser Project (2023) helpline used by the others is closing due to loss of funding. Disappointingly, the NHS England (2023) implementation plan of Public Health England's review makes no mention of the 24-hour national helpline. It does however recommend commissioning specialist withdrawal services and reviews existing services these may be modelled on. What is important now is making these services a reality.

## **Limitations and Opportunities for Further Research**

The aims of this study were to present findings that are transferable for clinicians, by providing as much rich detail and context as possible to allow readers to judge whether the findings are applicable to their clients (Smith, 2018). Limitations that may impact transferability and/or warrant further research are discussed below.

Some respondents to the participant advert offered to communicate via email or sent links to their written accounts because their symptoms were too debilitating to participate in interviews. Based on the level of disability that some benzodiazepine patients experience, interviews may not be sufficiently accessible and thus not inclusive of more severe experiences. Future research might benefit from a mix of audio and written data collection. While I argued for the benefits of conducting interviews versus using pre-existing accounts, it might be beneficial to include a mixture of pre-existing and new accounts in different formats to improve accessibility.

Six out of seven participants were female, six were above the age of 58, and all were White. While these are the groups likelier to be prescribed benzodiazepines (Taylor et al., 2019), the findings could be considered less transferable to clients outside these demographics. Group differences or other groups could be explored in further research, for example, whether female patients are less likely to be believed by doctors as all of the chronic illness literature cited above focuses on invisible illnesses that predominantly affect women. However, given that the findings broadly echo previous research, it may arguably be a better use of resources at present to instead explore how patient care can be improved.

Participants were recruited online through advocacy and support pages, meaning all participants had done enough online research to find these and access some information and/or support. The majority of those seeking help outside the mainstream healthcare system report that information and support sought online were the most helpful in a call for evidence, implying that the majority of patients may be seeking support online (Guy et al., 2018). However, these submissions may have similarly come from people already involved in online communities who thereby became

aware of the call for evidence. Thus, the participants interviewed here may be part a subgroup of benzodiazepine patients who engaged with their own research online and often became far better informed than their doctors. As Sarah explained: “*The thing is you will find very few people like me out there because I am a subject matter expert*”. Furthermore, even if patients are accessing information online, gaining enough of an understanding of this information to safely taper or self-advocate in the healthcare system in a potentially cognitively and physically impaired state due to adverse effects or withdrawal symptoms may conceivably be very difficult to impossible for some. Thus, while these participants became experts and fought back, there will be patients who were unable to do so and suffered more severe consequences whose experiences warrant highlighting in future research.

Perhaps due to the study’s broad aims and interview schedule, the wealth of experience shared by participants and thus time constraints, topics such as trauma or accessing therapy were not always explored in depth. One participant spoke about coping tools and psychological therapy specifically for trauma, but others mostly spoke more generally about strategies that helped with withdrawal and its impact rather than coping with trauma specifically. While interview quality was good in that questions were brief and participants provided spontaneous, lengthy, and rich responses, follow up questions often involved clarifying meaning rather than further exploring specific topics at times (Brinkmann & Kvale, 2014). For example, I did not always follow up by specifically asking what helped with recovery from the trauma of withdrawal or mistreatment in healthcare, sometimes asking only broadly what helped. Participants provided clues (see Implications for Counselling Psychology), but this could have been explored in more detail and warrants further exploration in future research.

Similarly, two participants received therapy during withdrawal with a lived experience therapist, with one describing some of the benefits. However, I did not explore in further detail what was beneficial about therapy or its duration. One participant said they spoke ‘a few times’ and no clarification was sought from the other. Two participants were referred for CBT, which one participant refused because they felt it was an inappropriate approach during withdrawal while the other was refused by the therapist on the same grounds. It may thus be beneficial to gain further insight into the nature of therapy that *was* helpful. While Hammersley (2001) provides insight into

this from the therapist's perspective, there is limited research from the patient's perspective. However, most participants did not receive therapy, and all participants provided a wealth of experience that psychologists can draw on to support recovery that is equally relevant to insight gained from experiences of formal support (Orford, 2008).

While participant experiences involved severe suffering and personal cost, they did not encompass some of the more severe outcomes documented in the literature. All participants had some degree of support from their families. Their experiences did not break up their marriages/relationships/families and while many lost their jobs, this did not lead to loss of homes/homelessness (Finlayson et al., 2022; Guy et al., 2018). To raise awareness of the severity of the impact of benzodiazepine withdrawal across all areas of people's lives, these experiences also need to be included in the academic literature.

An important related point, raised by one participant, is financial support. While one participant received some financial compensation, none spoke of trying to access benefits. In a submission to the House of Commons Select Committee Inquiry, Dr Peart, an atomic scientist who lost his career, marriage, home, and suffered severe cognitive impairment and long-term damage, wrote: "Many victims have been made unemployed and unemployable because of the long-term effects of benzodiazepines. Because of the relatively few studies in this area, lack of knowledge and denial by doctors, many are not receiving Disability Living Allowance and other benefits they should be getting" (Peart, 1999). 24 years on, it is unknown what proportion of those suffering withdrawal and consequent long-term impairment are able to access disability benefits, given that disbelief still appears to be common and medical professionals may be asked to submit supporting evidence (Royal College of Psychiatrists, 2023). As Sarah points out: "*I would have had to have said I was clinically depressed. I was suffering from panic and anxiety attacks. Maybe I'd have to say that in order to get a benefit, rather than the truth*". Whether benzodiazepine patients are able to access the necessary level of benefits and can obtain these without having to comply with misdiagnosis, warrants further research through large-scale survey data.

### **Implications for Counselling Psychology**



## ***Trauma and Recovery***

The *Guidance for Psychological Therapists* states that if withdrawal was traumatic, this may need consideration in therapeutic work (Rizq et al., 2019), and some participants here shed light on ways in which their experience was traumatic. Participants' experiences, and benzodiazepine patient accounts in the literature, appear to parallel Herman's (2015) work on trauma and recovery: traumatic experiences are often not socially validated, with attempts to discredit these and render them invisible (Fixsen, 2015; Guy et al., 2018). Herman (2015) argues that survivors need support from others to mourn their losses during recovery from traumatic events and being unable to do so can prolong the traumatic process. Benzodiazepine dependence and withdrawal's status as a socially and medically contested, invalidated, and stigmatised experience appears to prevent or isolate individuals from receiving this support (Fixsen, 2015) from doctors and at times their families. This study demonstrates the role of informal and formal support from others with lived experience in providing this validation to promote ongoing recovery, as also highlighted in Fixsen (2015) and Fixsen and Ridge (2017). In the absence of a willingness to hear these narratives in social and medical arenas, the online community and limited formal support available from lived experience practitioners may be the main avenue whereby individuals can share their experiences with others, which Herman (2015) describes as necessary for restoring a sense of a meaningful world. While some participants were able to convince their doctor or family through self-advocacy and thus obtain a degree of validation, this appears to have been an exhausting process during a time of already extreme suffering. Public acknowledgement of harm and community action that assigns responsibility may also be needed for recovery (Herman, 2015). This could involve filing a formal complaint as David did, or in Patricia's case, taking legal action for mis-/long-term prescribing and excessively rapid withdrawal and participating in public awareness raising through sharing her experience. This aspect of recovery has not been explored in the benzodiazepine literature so far, though Fixsen and Ridge (2017) highlight patients' sense of injustice at the lack of consequences for prescribers. Furthermore, recovery often involves discovering meaning in one's experience, such as through taking social action with others (Herman, 2015). In line with this, many participants described going on to help others, including through contributing to the development of new guidance for prescribed drug dependence as an expert-by-experience (Patricia), as an important part of their recovery. Helping others was described as "*therapeutic*"

(Rosalie), a way to “*turn a negative into a positive*” (Patricia), and providing a sense of “*purpose*” (Felicity).

While many participants went to great efforts to self-advocate and receive what little support and validation they could to safely promote recovery, it appears that their suffering and the traumatic process (Herman, 2015) was prolonged unnecessarily through disbelief and lack of support from the healthcare system, creating a cascade of other problems they needed to battle. The role that Counselling Psychologists, and others involved in their care including family members, can play is one where we try to provide and/or facilitate patients’ needs, which participants here have described, in order to promote recovery and avoid prolonging their suffering. Possible actions that may be taken are highlighted below.

### ***Establishing Trust and Providing Validation***

As also highlighted by Herman (2015), many participants spoke about the importance of being believed and validated, which is not included as a recommendation in the *Guidance for Psychological Therapists* (Guy et al., 2019b). While Counselling Psychologists likely think this goes without saying, the current study highlights that validation is particularly important when working with benzodiazepine patients who are likely to have had their experience disbelieved, dismissed, stigmatised, misdiagnosed, and suffered considerable harm at the hands of the healthcare system. It is not only about providing validation as an antidote to this experience, but also being aware that Counselling Psychologists may be perceived to be part of the same healthcare system that harmed them and thus understandably met with distrust or fear. Counselling Psychologists need to understand the power imbalance between themselves and clients (HCPC, 2015), including how previous experiences with medical professionals may be carried over into this context. For example, Rosalie spoke about how a barrier to her accessing therapy was worrying that she would not be believed, as she was not previously believed by doctors. While there does not appear to be research on re-establishing trust with benzodiazepine patients specifically, Clark (2021), who was eventually diagnosed with Ehlers-Danlos syndrome (another chronic, invisible illness) following initial disbelief and misdiagnosis, wrote an article for healthcare professionals titled “Help me trust you after my misdiagnosis”. Clark explains how compassion and empathy

are even more vital when clients might seem defensive due to previous negative experiences, and clinicians need to consider what it must feel like living with these symptoms, be honest where we do not have adequate training or experience to help, and acknowledge the perseverance and labour involved in trying to obtain the correct diagnosis and appropriate support in the healthcare system.

### ***Advocating for our Clients and the Prescribed Harm Community***

How can we relieve benzodiazepine patients of some of the additional labour they are currently having to undertake due to disbelief and failures in healthcare? As social justice-oriented Counselling Psychologists, we need to use our power to advocate and secure resources for our clients (Goodman et al., 2014). While this does not appear to have been explored in the benzodiazepine literature, women with other chronic illnesses reported that they associated positive experiences in healthcare with having healthcare professionals advocate for their treatment (Merone et al., 2022). Felicity similarly spoke about the benefits of having a specialist charity advocate for her by writing letters to her GP to confirm her experiences. While Counselling Psychologists can support clients through signposting to the limited specialist services available in the UK that can advocate for patients, we may also have a role to play in providing advocacy, by communicating with prescribers to validate clients' experiences and helping clients secure their support. It may also be important to avoid using diagnostic language and consult closely with clients on what they want communicated to their doctors in the standard letters psychologists send to GPs and other professionals when clients access therapy, as some participants reported (and the broader chronic illness literature corroborates) that a mental health diagnosis/misdiagnosis was an obstacle to obtaining appropriate support for dependence and withdrawal due to stigma and diagnostic overshadowing. These suggestions build on the *Guidance for Psychological Therapists*, which suggests therapists may be better positioned to communicate with other professionals (where appropriate and with consent) and consider doing so if they are concerned about prescribers' understanding and management of withdrawal (Guy et al., 2019a). Counselling Psychologists may also consider working with family members to educate them on what clients are experiencing, a role some participants described undertaking themselves. While we are not medical professionals, some participants reported being disbelieved by their families due to the doctor's professional authority, and we could play a role in counteracting this by using our own

professional authority to support the validity of the client's experience and thus help them obtain family support.

Counselling Psychologists can also show leadership by advocating for social justice through publishing research on patient experiences, bringing ideas to policy makers, and dissemination via community networks, the media, forums, op-eds, and social media to reach service providers and the general public (DeBlaere, 2019; Goodman, 2004; Marshall & Batten, 2004; Tribe & Bell, 2018). There is enough information available on the harms of dependence and withdrawal and safe and supportive ways to begin helping patients, but this does not appear to be reaching prescribers adequately given the lack of appropriate support provision reported by participants and in the literature. A good example of bringing findings to the right audience may involve publications read by a large number of prescribers, such as the recent publication of advice on withdrawing antidepressants in the *British Journal of General Practice* (Palmer et al., 2023), a publication aimed at GPs.

### ***Providing Support During and After Withdrawal***

Other types of support and coping tools participants found helpful broadly echo the *Guidance for Psychological Therapists* (Rizq et al., 2019), including acceptance/non-resistance, coping tools matching clients' needs and capability at a given time, reassurance that symptoms are due to withdrawal unless there is evidence to the contrary, and that these will pass (time will heal). While this guidance is freely available, services and Counselling Psychology training programmes should ensure this is widely circulated as well as providing training led by experts, particularly experts-by-experience. This training needs to be prioritised, given that 92.7% of psychologist therapists surveyed reported having had clients discuss withdrawing from or stopping their prescribed drugs with them (Blair et al., 2021).

### **Recommendations for Future Service Provision**

#### ***Improving Medical Education***

Participants' experiences indicate that prescribers were unable to recognise post-/withdrawal symptoms or did not know how to taper safely. Thus, in response to the third research question, all participants recommended better education when asked what future services should look like. Medical education would benefit from expert-by-experience involvement so doctors can gain an understanding of patient experiences (Clark, 2022), as also highlighted by some participants. As some participants reported that their doctor believed benzodiazepines were not dependence-forming at low doses, and NICE guidelines suggest that a slow taper usually leads to few or no symptoms (CKS, 2022), the potential for dependence and severe illness at low doses, even with a slow taper, that can last years, needs to be highlighted. As NHS England (2021, 2023) has announced Structured Medication Reviews to reduce overprescribing of dependence-forming drugs, including providing information about drug risks and decisions about stopping and tapering, clinicians need adequate education to have these conversations and support safe tapers.

### ***Improving Clinical Guidance and Adherence to Guidance***

'Enhancing clinical guidance' was recommended in Public Health England's review (Taylor et al., 2019), leading to updated NICE guidelines, but clinicians, withdrawal charities, and experts-by-experience stated that their testimonies and up-to-date research were excluded, and guidelines are incomplete and unsafe (Gornall, 2022; Montagu, 2021). NICE guidelines need changing to reflect up-to-date evidence on tapering and remove stigmatising language, considering some participants' experiences of stigma and shame in the healthcare system and Public Health England's recommendation on eliminating stigma when accessing support (Taylor et al., 2019). A good example that might act as a template of non-stigmatising guidance based on up-to-date research that takes patient experiences into account is *The Maudsley Prescribing Guidelines in Psychiatry* (Taylor, 2021). For example, these recommend hyperbolic tapering, state that symptoms arising during/after withdrawal are likely withdrawal symptoms (not 'relapse') and mental health often improves as symptoms wane, does not set time limits on when post-withdrawal symptoms may develop, gives information on how to support patients before and during their taper, such as bolstering 'non-pharmacological coping skills', and does not recommend further prescribing.

In contrast, NICE guidelines on managing benzodiazepine withdrawal explain that anxiety and depression should be managed before stopping (CKS, 2022), despite both being known adverse effects of long-term use (Ashton, 2022). They also recommend prescribing antidepressants if depression or panic emerge during withdrawal, despite these being known withdrawal symptoms (CKS, 2022), and antidepressants being another dependence-forming drug and thus not recommended for treating withdrawal symptoms (NICE, 2022b). Pathologising known adverse effects and withdrawal reactions by misattributing these to mental health diagnoses may lead to stigma, diagnostic overshadowing, inappropriate polypharmacy causing exacerbation of symptoms, and delayed recognition and support for dependence and withdrawal, as experienced by several participants in this study. Furthermore, there appears to be no evidence for the use of further prescribed drugs in supporting benzodiazepine withdrawal (Baandrup et al., 2018).

Inaccurate information is also used when referring to patients who struggle with the final steps of the taper and want to slow down: “reassure the person that this is usually an unfounded fear derived from long-term psychological dependence” (CKS, 2022). In fact, the final dose reductions are known to be the most difficult and need to be taken slower, an evidence-based approach known as hyperbolic tapering (Groot & van Os, 2020) commonly practiced in specialist withdrawal services (Cooper et al., 2023). Claiming that this is an ‘unfounded fear’, despite evidence to the contrary, and blaming ‘psychological dependence’, despite benzodiazepines being known to cause physical dependence, encourages gaslighting of patients experiencing known, common difficulties, and may encourage ‘addiction’ narratives that stigmatise patients.

Finally, the statement that “the benzodiazepine withdrawal syndrome may develop at any time up to 3 weeks after stopping” should be removed from NICE guidance (BNF, 2022), as it could undermine the credibility of patients suffering more delayed post-withdrawal symptoms.

### ***Informed Consent and Stopping New Long-term Prescribing***

The Department of Health and Social Care (2021) plan to reduce overprescribing includes more shared decision-making, including prescribers sharing benzodiazepine risks with patients and better guidance for doctors. None of the participants reported being warned of benzodiazepines’

dependence potential and adverse effects. Some also stated that prescribers need to adhere to NICE guidelines on not prescribing beyond 2-4 weeks. Increasing the likelihood that clinical guidance will be followed was also a recommendation of Public Health England's review (Taylor et al., 2019) and implementation plan (NHS England, 2023). The two issues are connected, because providing accurate information to patients encourages shared decision-making and predicts more patients stopping the drug (Burry et al., 2022).

New guidance on gaining informed consent and making decisions before starting a benzodiazepine prescription states that doctors should consider and discuss “the potential for developing problems associated with dependence and risk factors (such as mental health problems, history of drug misuse, taking an opioid with a benzodiazepine)” (NICE, 2022a). This warning conflates addiction with physical dependence, thus failing to give due attention to the potential risk of physical dependence for anyone on the drug for 2+ weeks. The main risk factors for physical dependence and withdrawal are dosage and duration of use (De las Cuevas, 2003), not mental health problems or a history of drug misuse. This type of language is reminiscent of advertisements and guidance from the 1960s/70s claiming that prescribing only posed a risk to those already ‘addiction-prone’ (Herzberg, 2009), when anyone who takes the drug for longer than 2 weeks is at risk of physical dependence, as also evidenced in this study. Some studies have found that ‘high rate’ benzodiazepine prescribers downplayed the risk of harm, whereas medium and lower rate prescribers were more aware of risks (Anderson et al., 2014). NICE (2022a) guidance appears to downplay the associated risks and is in need of amendment.

A positive step promoting accountability is in the NHS England (2022) *Quality and Outcomes Framework guidance* recommending that individual GP practices set SMART goals and monitor these, such as monitoring discussions of alternatives to dependence-forming drugs and ensuring no new benzodiazepine or z-drug prescriptions are issued beyond 14 days. While these are promising ideas, it is up to individual practices to choose whether to set these particular goals and monitor them. Some studies have found that prescribers’ awareness of and agreement with guidelines overall did not necessarily impact whether they felt long-term prescribing was appropriate for individual patients (Anderson et al., 2014), which suggests a need for more than education and thus perhaps an important role for monitoring.

### ***Stopping Prescribing Cascades***

“A prescribing cascade begins when a drug is prescribed, an adverse drug event occurs that is misinterpreted as a new medical condition, and a subsequent drug is prescribed to treat this drug-induced adverse event” (Rochon & Gurwitz, 2017, p. 1778). Four out of seven participants were prescribed benzodiazepines in an attempt to treat adverse effects or withdrawal from another prescribed drug (propranolol, antidepressants, contraceptives). Three then experienced psychosis or hallucinations and suicidal thoughts or took an overdose when trying to withdraw. Fixsen (2015), who experienced severe withdrawal, was also prescribed benzodiazepines for a bad reaction to antibiotics. Two participants were prescribed antipsychotics when benzodiazepine withdrawal was misdiagnosed as a mental health problem, one of whom was also prescribed antidepressants and pregabalin. Participants’ experiences indicate a need for more education on the harm caused by prescribing cascades, such as increased risk of adverse events, functional decline, and hospitalisation (Piggott et al., 2020). This is particularly relevant to benzodiazepine prescribing, because older adults are at greatest risk for prescribing cascades (Piggott et al., 2020), with women in this age group being at the highest risk for polypharmacy (Rochon et al., 2021). This is also the patient group likeliest to be prescribed benzodiazepines (Taylor et al., 2019).

### ***Improving Communication with Patients***

Participants experienced disbelief and dismissal from their doctors, with some reporting that this was despite referring their doctor to the NICE guidelines, Ashton (2002) manual, and up-to-date research. Other patients experiencing chronic, invisible illnesses have emphasised the importance of doctors demonstrating epistemic humility in fostering trust and positive experiences (Au et al., 2022; Clark, 2022). This means doctors acknowledging the limits of their own expertise and listening to patients’ lived experience (Au et al., 2022), given that medical literature tends to be 17 years behind current research (Clark, 2022). It also means doctors being open to acknowledging that their patients may know more than them. This is not just in terms of patients’ own lived experience but also through research conducted online, rather than dismissing or viewing it as a challenge to medical authority (Broom, 2005; Clark, 2022), particularly as this study and others



(e.g. Groot & van Os, 2020) point to the majority of withdrawal knowledge and support being located online.

### ***Specialist Services and a 24-hour National Helpline***

Participants indicated a need for long-term emotional and practical support, idiosyncratic coping strategies for symptoms, support provided by others with lived experience, specialist services, and a 24-hour national helpline. A survey of the few existing specialist services indicates that they incorporate many of these factors, such as practical support (e.g., with access to benefits), long-term emotional support through the post-withdrawal period (including reassurance that time will heal), teaching coping strategies, allowing patients to contact them flexibly outside of appointment times, and having lived experience embedded throughout services (Cooper et al., 2023). Importantly some services also described advocating for patients with their doctors, taking over as prescribers where there was patient-prescriber disagreement, or encouraging a change of prescriber. In light of the burden of self-advocacy participants disclosed here, this is likely an important type of support to provide in future services.

Thus, there are successful blueprints for establishing future services. What is important now is making these a reality. The need to act on prescribed benzodiazepine dependence and withdrawal has been known for decades, has the potential to affect 1.1 million people in England, and unnecessary prescribing was estimated to cost the NHS up to £43 million in England alone (Davies et al., 2022), yet there has been continual demand for more reports, research, and reviews, while services and a helpline are yet to materialise. Just one year after the start of the covid pandemic, NHS England (2020) announced a £10 million investment in 69 long-covid clinics. While this chronic illness of course merits this investment, it is an illness relatively little was known about when these clinics were established. “The overarching question is, at what point do [patient] experiences persuade clinicians, healthcare organisations and governments that there is an issue that needs to be fully addressed?” (White et al., 2021, p.15). While this was said in relation to antidepressants, the same can be said for support provision for benzodiazepines, where associated harms have been public knowledge for even longer.

## Conclusion

It is important to remind readers that the experiences of the participants in this study occurred in the last 16 years, with most taking place in the last 1-6 years. For a public health problem that has been publicly acknowledged since at least 1988, the extent of harm still being experienced in the healthcare system, as evident in this study and the wider literature, demonstrates an alarming lack of awareness, progress, and political will for change. In conclusion, thereby answering the three research questions, the current study demonstrates how some benzodiazepine patients experience extreme suffering that is unnecessarily exacerbated by disbelief and failures in the healthcare system which can result in ongoing trauma and distrust of healthcare professionals. What participants found helpful included peer support (including advice and reassurance), validation, coping and self-care strategies, and emotional, practical, and specialist support; most of these often needed to be accessed or learned outside of the mainstream healthcare system. Recommendations for future service provision by participants, and in reports (BMA, 2015; NHS England, 2023; Taylor et al., 2019), included better education for healthcare professionals. This should include education on dependence potential, adverse effects, prescribing cascades, and withdrawal/post-withdrawal symptoms, including through the involvement of experts-by-experience. Specialist services and a 24-hour national helpline must be established urgently, as highlighted by participants and in reports (BMA, 2015; Taylor et al., 2019). The NICE Guidelines need updating to be safe, evidence-based, inclusive of the true range of patient experiences in terms of post-withdrawal and ridden of stigmatising language. It may also be important to set specific goals and monitor the actions of prescribers in relation to these, as the relevant guidance has been in place for decades yet is not being followed by many, leading to the initiation of new long-term prescriptions, lack of informed consent, and unsafe tapering regimes.

All of these actions require time, government financial investment, and political will. However, one of the most important actions that healthcare professionals can take is accessible right now and completely free: believing and validating patients. Participant experiences here, in keeping with previous studies, demonstrate the catastrophic cascade of events that can be set off when doctors with inadequate knowledge disbelieve their patients, where epistemic humility could have helped them to identify withdrawal and provide appropriate support. Establishing trust and

providing validation may be particularly important when supporting this client group due to their previous negative experiences. Counselling Psychologists may be able to go even further by advocating for clients and the prescribed harm community as a whole to shoulder some of the burden of self-advocacy they currently bear by making use of our professional authority and power. In order to best support this client group, education and training on working with prescribed drug dependence should be prioritised, given that 96.7%% of psychological therapists surveyed reported working with clients taking prescribed drugs and 92.7% had clients discuss withdrawing or stopping (Blair et al., 2021).

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# APPENDICES

## Appendix A: Participant Advert Examples

Benzodiazepine Information Coalition website post:

**Researcher Seeking To Interview Prescribed Benzodiazepine Patients In The UK Off One Year Or More**  
By Asli Anik - June 29, 2021

Share

Hi, I'm a Trainee Counselling Psychologist at the University of East London researching people's experiences of ongoing healing from benzodiazepine physical dependence, withdrawal and/or protracted harm.

The aim is to explore the ongoing experience of healing and find out what people feel helped them to come off and stay off benzodiazepines and what, if anything, has helped/is helping them toward regaining a subjective sense of wellbeing. I would also like to hear people's views on what they think services to support people with physical dependence and harm in the UK should look like or include. The interviews will take place on Microsoft Teams (a video application similar to Zoom).

I am looking to involve people who:


- Are age 18 and over
- Live in the UK
- Took prescribed benzodiazepines continuously for at least one month
- Successfully stopped taking benzodiazepines at least one year ago (you do **NOT** need to be symptom-free or no longer experiencing harm from benzodiazepines)
- Who withdrew from benzodiazepines only at the time (not tapering/stopping multiple medications at the same time)
- Do not feel that they are currently struggling with other prescribed medicines
- Do not feel they are struggling with misuse of recreational drugs or alcohol
- Would not find it too upsetting to talk about their experience in an interview

Your privacy will be fully protected. Your name or any identifying information will not be included in the research findings.


If you are interested in participating or have any questions, please email me on [u1928290@uel.ac.uk](mailto:u1928290@uel.ac.uk). I'm happy to answer any questions you might have. If you know anyone else who might like to participate, please feel free to share this text and my contact information.

Thank you very much and I look forward to speaking to some of you.

Asli Anik

 Asli Anik

**Follow Us**



**Our Mission**

Educating about the potential adverse effects of benzodiazepines taken as prescribed.

[DONATE](#)

**CATEGORIES**

- Benzo Blunders (3)
- Blog (113)
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- FDA (8)
- Our Impact (31)
- Events (21)
- Updates (4)

Mad in the UK blog:

# MAD IN THE UK



BLOGS ▾ GET INVOLVED ▾ MIA GLOBAL ▾ ABOUT ▾



## CALL FOR PARTICIPANTS: Have you taken a benzodiazepine (such as Diazepam, Lorazepam, Clonazepam) and been off it for a year or more? Would you be willing to talk about your experiences?

By **MITUK admin** - 03/09/2021

596 0

Share on Facebook

Tweet on Twitter

G+

P

Have you taken a benzodiazepine (such as Diazepam, Lorazepam, Clonazepam) and been off it for a year or more? Would you be willing to talk about your experiences?



I'm a Trainee Counselling Psychologist at the University of East London researching people's experiences of recovery from benzodiazepine physical dependence, withdrawal and/or protracted harm, what they think helped them (if anything), and their views on what services to support people with physical dependence and harm in the UK should look like. I am looking to interview people who found it difficult to stop or come off of benzodiazepines.

The interviews would be one-to-one online over Microsoft Teams (a video application similar to Zoom) and last between 30-90 minutes depending on how much or little you would like to share.

This website gives you a bit more information about who I am looking to involve <https://benzodiazepineresearch.weebly.com/> and you can contact me at [u1928290@uel.ac.uk](mailto:u1928290@uel.ac.uk) if you think you might be interested in taking part or have any questions for me. This research is supervised by Professor John Read and has been approved by University of East London School of Psychology Research Ethics Committee.

I look forward to speaking to some of you.  
Aslı Anik

### TOPICS

addiction (6) a disorder for everyone (5)  
alternatives (5) antidepressant (7)  
antidepressants (27)  
antidepressant withdrawal (17)  
antipsychotics (9) anxiety (5)  
benzodiazepines (7)  
borderline personality disorder (5)  
child and adolescent mental health (4)  
clinical trials (6) conflicts of interest (4)  
coronavirus (7) COVID-19 (6)  
depression (12)  
**Diagnosis (58)**  
**Disorder (39)** DSM (25)  
ECT (9) Electroconvulsive Therapy (9)  
Electroshock (6) events (4)  
forced treatment (16)  
globalisation of mental health (10)  
humour (5) **Mental health (27)**  
mental health act (12)  
NHS mental health (4) podcast (9) poetry (5)  
power threat meaning framework (9)  
psychiatric drugs (24)  
psychiatry (31)  
psychology (22) psychosis (7)  
PTMF (7) RCPsych (6) research (6)  
Royal College of Psychiatrists (17)  
sectioned (7) social media (8)  
ssri withdrawal (14) trauma (8)  
withdrawal (6)

### MIA GLOBAL

Mad in America  
Mad in America Hispanohablante  
Mad in Asia Pacific  
Mad in Brazil

Example Facebook posts:



## Beating Benzos Protracted Withdrawal

Aslı Anık

10 September 2021 · 🌐

**\*\*\*RESEARCHER SEEKING TO INTERVIEW PRESCRIBED BENZODIAZEPINE PATIENTS IN THE UK OFF ONE YEAR OR MORE\*\*\***

-----

Hi everyone, I'm a Trainee Counselling Psychologist at the University of East London researching people's experiences of ongoing healing from benzodiazepine physical dependence, withdrawal and/or protracted harm. My research is supervised by Professor John Read and has ethical approval from UEL.

The aim is to explore the ongoing experience of recovery and find out what people feel helped them to come off and stay off benzodiazepines and what, if anything, has helped/is helping them toward regaining a subjective sense of wellbeing. I would also like to hear people's views on what they think services to support people with physical dependence and harm in the UK should look like or include. The interviews will take place on Microsoft Teams (a video application similar to Zoom).

I am looking to involve people who:

- Are age 18 and over
- Live in the UK
- Took prescribed benzodiazepines for at least one month
- Found it difficult to stop or come off of benzodiazepines
- Successfully stopped taking benzodiazepines at least one year ago (you do NOT need to be symptom-free or no longer experiencing harm from benzodiazepines)
- Who withdrew from benzodiazepines only at the time (not tapering/stopping multiple medications at the same time as the benzodiazepine)
- Do not feel that they are currently struggling with other prescribed medicines
- Do not feel they are struggling with misuse of recreational drugs or alcohol
- Would not find it too upsetting to talk about their experience in an interview

Your privacy will be fully protected. Your name or any identifying information will not be included in the research findings.

If you are interested in participating or have any questions, **please email me on [u1928290@uel.ac.uk](mailto:u1928290@uel.ac.uk)**

I'm happy to answer any questions you might have. If you know anyone else who might like to participate, please feel free to share this text and my email address.

Thank you very much and I look forward to speaking to some of you.



2 comments

## Aslı Anık ► Positives While Healing From Benzodiazepines

10 September 2021 · 🌍



Admins please delete if you feel this is not appropriate

\*\*\*RESEARCHER SEEKING TO INTERVIEW PRESCRIBED BENZODIAZEPINE PATIENTS IN THE UK OFF ONE YEAR OR MORE\*\*\*

-----

Hi everyone, I'm a Trainee Counselling Psychologist at the University of East London researching people's experiences of ongoing healing from benzodiazepine physical dependence, withdrawal and/or protracted harm. My research is supervised by Professor John Read and has ethical approval from UEL.

The aim is to explore the ongoing experience of recovery and find out what people feel helped them to come off and stay off benzodiazepines and what, if anything, has helped/is helping them toward regaining a subjective sense of wellbeing. I would also like to hear people's views on what they think services to support people with physical dependence and harm in the UK should look like or include. The interviews will take place on Microsoft Teams (a video application similar to Zoom).

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- Took prescribed benzodiazepines continuously for at least one month
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- Successfully stopped taking benzodiazepines at least one year ago (you do NOT need to be symptom-free or no longer experiencing harm from benzodiazepines)
- Who withdrew from benzodiazepines only at the time (not tapering/stopping multiple medications at the same time as the benzodiazepine)
- Do not feel that they are currently struggling with other prescribed medicines
- Do not feel they are struggling with misuse of recreational drugs or alcohol
- Would not find it too upsetting to talk about their experience in an interview

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If you are interested in participating or have any questions, please email me on [u1928290@uel.ac.uk](mailto:u1928290@uel.ac.uk)

I'm happy to answer any questions you might have. If you know anyone else who might like to participate, please feel free to share this text and my email address.

Thank you very much and I look forward to speaking to some of you.

1 comment

Participant advert website (<https://benzodiazepineresearch.weebly.com/>):

**Have you taken a benzodiazepine (such as Diazepam, Lorazepam, Clonazepam) and been off it for a year or more? Would you be willing to talk about your experiences?**

Hi, I'm a Trainee Counselling Psychologist at the University of East London researching **people's experiences of recovery from benzodiazepine physical dependence, withdrawal and/or protracted harm.**

The aim is to explore the ongoing experience of recovery and find out what people feel helped them to come off and stay off benzodiazepines and what, if anything, has helped/is helping them toward regaining a subjective sense of wellbeing. I would also like to hear people's views on what they think services to support people with physical dependence and harm in the UK should look like or include. The interviews will take place on Microsoft Teams (a video application similar to Zoom).

**I am looking to involve people who:**

- Are age 18 and over
- Live in the UK
- Took prescribed benzodiazepines continuously for at least one month
- Found it difficult to stop or come off of benzodiazepines or struggled with withdrawal/post-withdrawal symptoms
- Successfully stopped taking benzodiazepines at least one year ago (you do **NOT** need to be symptom-free or no longer experiencing harm from benzodiazepines)
- Who withdrew from benzodiazepines only at the time (not tapering/stopping multiple medications at the same time)
- Do not feel that they are currently struggling with other prescribed medicines
- Do not feel they are struggling with misuse of recreational drugs or alcohol
- Would not find it too upsetting to talk about their experience in an interview

Your privacy will be fully protected. Your name or any identifying information will not be included in the research findings.

If you are interested in participating or have any questions, **please email me at [u1928290@uel.ac.uk](mailto:u1928290@uel.ac.uk)**. I'm happy to answer any questions you might have. If you know anyone else who might like to participate, please feel free to direct them to this page and share my contact information.

Thank you very much and I look forward to speaking to some of you.

Asli Anik

***This research has received ethical approval from the University of East London School of Psychology Research Ethics Committee and is supervised by Professor John Read.***

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## Appendix B: Interview Schedule

1) Demographics

- Age
- Gender identity
- Ethnicity

2) The main focus of today will be what it was like to come off of and stay off of benzodiazepines, but could you give me a brief overview of how you came to be prescribed them?

*(Possible prompts: Which ones were you on? At what dose? What were they for? How long were you on them? How long have you been off them for?)*

3) Can you tell me your story of how you stopped taking them?

*(Possible prompts: How was a decision made to stop? What led to you stopping? What was the role of the doctor that prescribed you the benzodiazepines (or your current GP) in the process? How did you start that process? How long did it take? What was it like after you stopped? How long did you experience withdrawal symptoms for? What was that like? What happened next?)*

4) Was there anything that helped?

*(Possible prompts: Why do you think that was helpful for you (at that time)? Was there anything else that helped?)*

5) What is your experience like now? Are you still experiencing difficulties related to having been on benzodiazepines?



*(Possible prompts: What helps you cope now? What helps you maintain that? Are there ways in which you have changed since having this experience?)*

- 6) What would you want services for other people who need support with coming off of benzodiazepines to look like? What would you recommend?

*(Possible prompts: Why do you feel that would be helpful?)*

- 7) Is there anything else you would like to add?

**Appendix C: Notice of Ethics Review Decision**

**School of Psychology Research Ethics Committee**

**NOTICE OF ETHICS REVIEW DECISION**

**For research involving human participants  
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and  
Educational Psychology**

**REVIEWER: Maria Castro**

**SUPERVISOR: John Read**

**STUDENT: Asli Anik**

**Course: PROFESSIONAL DOCTORATE IN COUNSELLING PSYCHOLOGY**

**Title of proposed study:** How do individuals in the UK recover from benzodiazepine dependence and what helped?

**DECISION OPTIONS:**

- 1. APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
- 2. APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his

supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

- 3. NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

**DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY**

*(Please indicate the decision according to one of the 3 options above)*

2
---

**Minor amendments required** *(for reviewer):*

The length of time anonymised transcripts will kept is not in the body of the application, only in the appendices, this needs to be corrected. Relatedly, the time frame stated is five years, however, it's my understanding that we should only keep data for up to three years post-examination, please revise.
--

**Major amendments required** *(for reviewer):*

--

**Confirmation of making the above minor amendments (for students):**

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (*Typed name to act as signature*): ASLI ANIK

Student number: 1928290

Date: 11/05/21

*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**ASSESSMENT OF RISK TO RESEACHER (for reviewer)**

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

MEDIUM (Please approve but with appropriate recommendations)

LOW

**Reviewer comments in relation to researcher risk (if any).**

**Reviewer** (*Typed name to act as signature*):

Dr Maria Castro Romero

**Date:** 04.05.2021

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

**RESEARCHER PLEASE NOTE:**

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

## Appendix D: Ethics Approval of Title Change

### Change project title - Ms Asli Anik

Date	01 Jul 2021
Doctoral Researcher	Ms Asli Anik
Student ID	1928290
Doctoral Research Project	How do individuals in the UK experience recovery from prescribed benzodiazepine dependence and what helped?
Project type	DProf
Project mode	Full Time
Project start	17 Sep 2019
School	Psychology

---

### Change request form

#### Project title form

Please Note, if you have received Ethical Approval for your research you must also submit an Amendment to an approved Ethics Application. This can be done via the Ethics tab on your record and by starting a new application and choosing the 'Amendment to an application approved outside of ResearchUEL' option.

Failure to do this may result in a case of academic misconduct as your new research title will not have Ethical Approval.

#### Proposed new title:

How do individuals in the UK experience recovery from prescribed benzodiazepine dependence and what helped?

#### Reason(s) for proposed change:

More accurate and specific wording - no change in actual research process

### Researcher form

#### Did your research require Ethical Approval?

Yes

I confirm that I have completed an Amendment to an Approved Ethics Application form to change the title of my thesis

Having discussed the proposed change of title with my supervisory team, I am satisfied with the change proposed.

Yes

---

### Supervisor form

#### Supervisor form

**Did your student require Ethical Approval for their research?**

Yes

I confirm that my student has completed an Amendment to an Approved Ethics Application form to change the title of their thesis

**We recommend that the change in the registered title of the thesis progress as requested.**

Yes

**Notes**

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## **Research Degrees Leader form**

### **Second approver form**

**Recommend this application for consideration at the School's Research Degrees Sub-Committee**

Yes

**Notes**

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## **Counselling psychology review group report**

### **Committee report**

#### **Comments**

Both reviewers recommended approval.

#### **Recommendation**

Approve

## Appendix E: Risk Assessment

1.1 Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

Yes. Interviews about personal experiences can bring up difficult feelings that may not have been voiced or realised by participants before. Participants will be debriefed for 10 minutes at the end of the interview to discuss any feelings that may have come up and check they are OK. They will be provided with a custom debrief letter including local services as well as national ones that provide specialist support, crisis organisations, and psychological services. Participants will be informed that they can take breaks or finish the interview when they wish or should they feel distressed. I will handle distress sensitively by checking in with participants if I notice a change in their affect. I will let participants know they have no obligation to answer individual questions, in case they feel obliged to answer questions they wouldn't otherwise due to the power imbalance.

I will ask participants to agree a custom emergency plan that they would wish for me to follow should there be an emergency during the interview, and I was concerned for their safety. This is a group where participants may historically have had negative experiences with healthcare professionals and may have a preference for who is contacted.

1.2 Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

The risks to myself are similar to those to participants, in that I may feel emotionally impacted by the personal stories I am told, especially as this is a personal topic for me. I plan to minimise risk by discussing any feelings or stresses that come up in personal therapy, in my research journal, and with my supervisor.

1.3 Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?

Yes. I have provided mental health, prescription medication withdrawal, general and crisis support helplines and services. The prescription medication withdrawal resources include ongoing peer support resources that people in recovery can also benefit from. I will customise the information on the local primary care psychology service (IAPT) and local A&E based on the participant's location.

1.4 Does the research take place outside the UEL campus? If so, where?



Yes. Interviews will be conducted online or via video from my home.

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is required for this research, please tick to confirm that this has been completed:

## General Risk Assessment

<b>Name of Assessor:</b>	<b>Ash Anik</b>	<b>Date of Assessment</b>	<b>25/03/2021</b>
<b>Activity title:</b>	<b>Interviews with former benzodiazepine patients</b>	<b>Location of activity:</b>	<b>Interviews conducted remotely over Microsoft Teams – from the interviewer’s private home work space and a space of the interviewee’s choosing.</b>
<b>Signed off by Manager (Print Name)</b>	<b>Dr John Read (Director of Studies)</b>	<b>Date and time (if applicable)</b>	<b>Estimated dates May 2021-January 2022</b>

**Please describe the activity/event in as much detail as possible (include nature of activity, estimated number of interviewees, etc)  
If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:**

**Approximately 10 interviewees will be recruited who have experience of recovering from benzodiazepine use. Interviews will be conducted remotely between Ash Anik and each interviewee on the topic of recovery from benzodiazepine dependence, lasting between 30 to 90 minutes depending on how much or little each interviewee would like to share. Times and dates of the interviews will be agreed with the interviewee in advance and where they are conducted is the interviewee’s choice. Date and time of the interview will be agreed with the interviewee in advance. Interviews can be conducted from a place of the interviewee’s choosing.**

**Guide to risk ratings:**

<b>a) Likelihood of Risk</b>	<b>b) Hazard Severity</b>	<b>c) Risk Rating (a x b = c)</b>
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-4 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6/9 = High (Further control measures essential)

## Hazards attached to the activity

<b>Hazards identified</b>	<b>Who is at risk?</b>	<b>Existing Controls</b>	<b>Likelihood</b>	<b>Severity</b>	<b>Residual Risk Rating (Likelihood x Severity)</b>	<b>Additional control measures required (if any)</b>	<b>Final risk rating</b>
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Breach of confidentiality	Interviewee	<ul style="list-style-type: none"> <li>- The interviewer will conduct interviews in a private space</li> <li>- Microsoft Teams, which has been deemed secure for use in interviews by UEL, will be used to conduct and record the interview</li> <li>- Recordings will immediately be moved to the UEL One Drive for Business (and backed up on a password protected computer and hard drive) at the end of the interview. Copies on Microsoft Stream Library will be deleted following the completion of the upload.</li> <li>- Data will be stored on a password protected laptop and 2 password protected external hard drives.</li> <li>- The interviewee can choose a private space where they feel comfortable being interviewed and are informed that they are under no obligation to answer any specific questions they do not wish to</li> </ul>	1	2	2	<ul style="list-style-type: none"> <li>- During the interview, interviewees will be reminded that they can pause the interview if needed (e.g. if the space they are in is no longer private) and they can answer questions as fully or briefly as they wish, including being under no obligation to answer individual questions (to address the power imbalance between interviewer and interviewee where they may feel they have to answer)</li> <li>- If interviewees are interrupted during the interview, it will be stopped and postponed to a date and time convenient to the interviewee, or can be cancelled altogether if the interviewee wishes to do so.</li> </ul>	1
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		<ul style="list-style-type: none"><li>- Contact details of interviewees will be stored separately from the audio recordings and will be destroyed 3 weeks post-interview (the date at which they can no longer withdraw from the study)</li><li>- Interviews will be anonymised upon transcription, with identifying details removed and pseudonyms used – these will be stored separately from interview recordings.</li><li>- Data will be securely stored on the UEL OneDrive for Business, a password protected computer, and an encrypted hard drive</li><li>- Further details are included in the Data Management Plan</li></ul>					
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Emotional distress	Interviewee	<p>Interviewees will be provided interviewees with an information sheet that includes the risks that may be involved, such as that feelings may be brought up by telling their story, and those who self-identify that they would find participation too distressing on this basis will be excluded from participation. The information sheet will include the types of questions they will be asked and the aims of the research, to reassure interviewees that the research agenda is aligned with their experience and values as this is a group that I have been told would want to ensure that the research process and outcome would not involve addiction language or misrepresentation of their experience that stigmatises them as drug users.</p> <p>Interviewees will be informed that participation is voluntary. At the start of the interview, they will be told that that they can take breaks or finish the interview when they wish or</p>	2	1	2	<p>- Interviewees will be reminded during the interview that they are under no obligation to answer individual questions they find difficult or distressing and can answer as thoroughly or briefly as they wish</p> <p>- If the interviewee appears distressed during the interview, I will respond empathically, ask if they would like to take a break, move on to a different question, or finish the interview. If I feel concerned about the severity of their distress, I will ask if they would like me to contact their emergency contact.</p>	1
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		<p>should they become distressed. Interviewees will be told the interview is 90 minutes, to allow for breaks, an unrushed feeling when they are telling their story, and for a 10 minute debrief at the end of the interview to ensure they are not left with difficult feelings. I will ask interviewees to agree a custom emergency plan that they would wish for me to follow should there be an emergency during the interview, and I was concerned for their safety. This is a group where interviewees may historically have had negative experiences with healthcare professionals and may have a preference for who is contacted. If an interviewee were to disclose malpractice by their doctor, I would first discuss this with my supervisor to determine whether we have a legal obligation to report to the relevant regulatory authority or whether to offer information and support to the interviewee</p>				<div data-bbox="1518 1193 1836 1318" style="border: 1px solid black; padding: 5px; text-align: center;"> <p><b>Review Date</b> <b>01/07/2021</b></p> </div>	
--	--	---	--	--	--	---	--

		<p>on how they can report this themselves should they wish to.</p> <p>I will provide a debrief letter that is partially customised to the interviewee's location in the UK, including specialist support services such as those listed on the Council for Evidence Based Psychiatry's website (<a href="http://cepuk.org/support/">http://cepuk.org/support/</a>), crisis organisations such as the Samaritans or their local Accident and Emergency department, and local psychology services.</p>					
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## **Appendix F: Participant Information Sheet**

### **PARTICIPANT INFORMATION SHEET**

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

#### **Who am I?**

I am a Trainee Counselling Psychologist in the School of Psychology at the University of East London. I am studying for a Professional Doctorate in Counselling Psychology. As part of my studies, I am conducting the research you are being invited to participate in.

#### **What is the research?**

I am conducting research into people's ongoing experiences of healing from benzodiazepine physical dependence, withdrawal and/or protracted harm in the UK, what they think helped them, and their suggestions for what they feel support services for people who need support with coming off, staying off and healing from benzodiazepines should look like.

My research has been approved by the School of Psychology Research Ethics Committee.

This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

#### **Why have you been asked to participate?**

You have been invited to participate in my research as someone who has successfully withdrawn from benzodiazepines.

I am looking to involve people who:

- Are age 18 and over

- Live in the UK
- Took benzodiazepines continuously for at least one month
- Found it difficult to stop or come off of benzodiazepines or struggled with withdrawal/post-withdrawal symptoms
- Successfully stopped taking benzodiazepines and have been off them for at least one year (you do NOT need to be symptom-free or no longer experiencing harm from benzodiazepines)
- Who withdrew from benzodiazepines only at the time (not tapering/stopping multiple medications at the same time)
- Do not feel that they are currently struggling with other prescribed medicines
- Do not feel they are struggling with misuse of recreational drugs or alcohol
- Would not find it too upsetting to talk about their experience in an interview

The interview will be about your unique experience. You will not be judged or personally analysed in any way and you will be treated with respect.

You are free to decide whether or not to participate.

### **What will your participation involve?**

If you agree to participate you will be asked to attend a one-to-one interview, during which you will be asked about your experience of ongoing healing from benzodiazepine dependence, withdrawal and/or protracted harm. You will be asked to describe your experience starting from how you came to stop through to the process of withdrawal and ongoing recovery and what you feel helped. You will also be asked about your views on what services to support people with physical dependence and harm in the UK should look like or include.

The interview will take place online via video call using Microsoft Teams, lasting from 30-90 minutes (depending on how much or little you would like to say). The interview can be arranged at a time that is convenient for you, so you feel comfortable speaking and can ensure you have privacy. The interview will be like an informal conversation but will be recorded.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of the experience of healing from physical dependence and harm.

### **Your taking part will be safe and confidential**

Your privacy and safety will be respected at all times.

- You will not be identified on any written material resulting from the data collected, or in any write-up of the research.
- You do not have to answer all questions asked and can stop your participation at any time.

### **What will happen to the information that you provide?**

- Recordings of interviews and personal contact details will be stored securely and not available to anyone but myself and my University research supervisor, Professor John Read
- The interviews will be transcribed and any identifying data will be removed/replaced with pseudonyms – at this point the recordings of interviews will be destroyed
- Only the researcher and research supervisor will have access to the anonymised transcripts. Sometimes transcripts need to be verified. If this was to happen, anonymised transcripts (decontextualised of any identifiable information) may also be viewed by examiners from the School of Psychology.
- Quotes from the anonymised interviews will be included in a doctoral thesis that will be published in a public university repository and may be used in future publications such as journal articles or books
- Consent forms will be destroyed by April 2024 upon completion of doctoral examinations
- Anonymised transcripts of the interview will be stored on a password protected computer only accessible to the researcher for 5 years after which it will be destroyed

### **What if you want to withdraw?**

You may withdraw your data even after you have participated, provided that this request is made within 3 weeks of your interview (after which point the data analysis will begin, and withdrawal will not be possible).

### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Aslı Anık [u1928290@uel.ac.uk](mailto:u1928290@uel.ac.uk)

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor Professor John Read. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: [j.read2@uel.ac.uk](mailto:j.read2@uel.ac.uk)

**or**

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

Email: [t.patel@uel.ac.uk](mailto:t.patel@uel.ac.uk)

**Appendix G: Consent Form**

**UNIVERSITY OF EAST LONDON**

**Consent to participate in a research study:  
How do individuals in the UK experience recovery from prescribed benzodiazepine dependence and what helped?**

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw more than 3 weeks after the time of my interview, the researcher reserves the right to use my anonymous data as analysis of the data will have begun.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Date: .....

## **Appendix H: Debrief Letter**

### **PARTICIPANT DEBRIEF LETTER**

Thank you for participating in my research study on the experience of recovery from benzodiazepine dependence. This letter offers information that may be relevant in light of you having now taken part.

#### **What will happen to the information that you have provided?**

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

All data collected during this research project will be stored on a password protected computer, which only I have access to. Recordings of the interviews will be kept until they have been transcribed and any identifying data removed. Consent forms will be kept until doctoral examinations are complete, April 2024 at the latest. Participant contact details will also be destroyed at this date. No one but the researcher and research supervisor will have access to this data.

The anonymised interview transcripts may be shared with my research supervisor Professor John Read to assist with data analysis. Sometimes transcripts need to be verified. If this was to happen, anonymised transcripts (decontextualised of any identifiable information) may also be viewed by examiners from the School of Psychology. Excerpts from the anonymised interviews may be quoted in the writeup of my doctoral thesis that will be published in a public university repository. These may also be used for future publication, such as in academic journals or books. None of these would include identifying personal details. The anonymised interview transcripts will be stored for 5 years, after which all files will be deleted. You can request to withdraw your data within 3 weeks of the interview, after which point the data analysis will begin and it will not be possible to remove your data.

#### **What if you have been adversely affected by taking part?**

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging,

distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

### **Mental health support**

- **Samaritans:** call 116 123 (available 24/7)
- Local psychological therapy service: [Click here and search by your postcode](#)
- A list of mental health helplines provided by Mind:  
<https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/helplines-listening-services/>

•

### **Support services for prescription medication withdrawal**

The Council for Evidence-Based Psychiatry provides a list of resources:

<http://cepuk.org/support/>

### **Other support**

- An emergency GP appointment
- Local A&E (type in your postcode): [Click here and search by your postcode](#)
- Emergency: 999

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Aslı Anık [u1928290@uel.ac.uk](mailto:u1928290@uel.ac.uk)

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Professor John Read. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: [j.read2@uel.ac.uk](mailto:j.read2@uel.ac.uk)

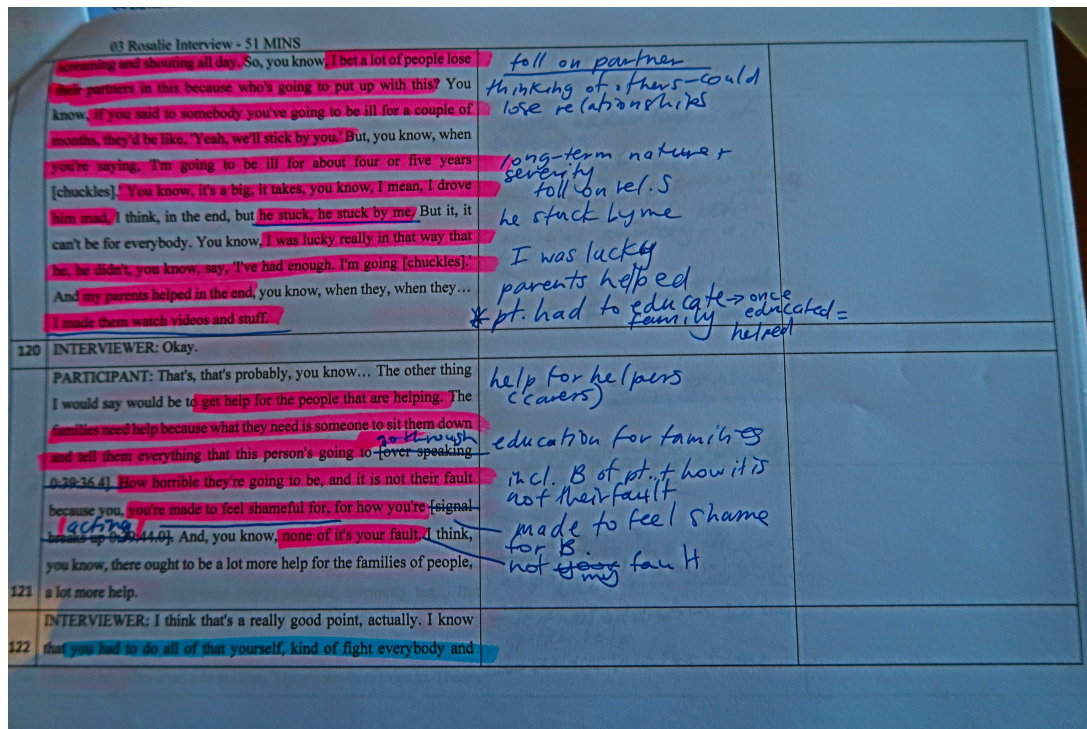
**or**

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ

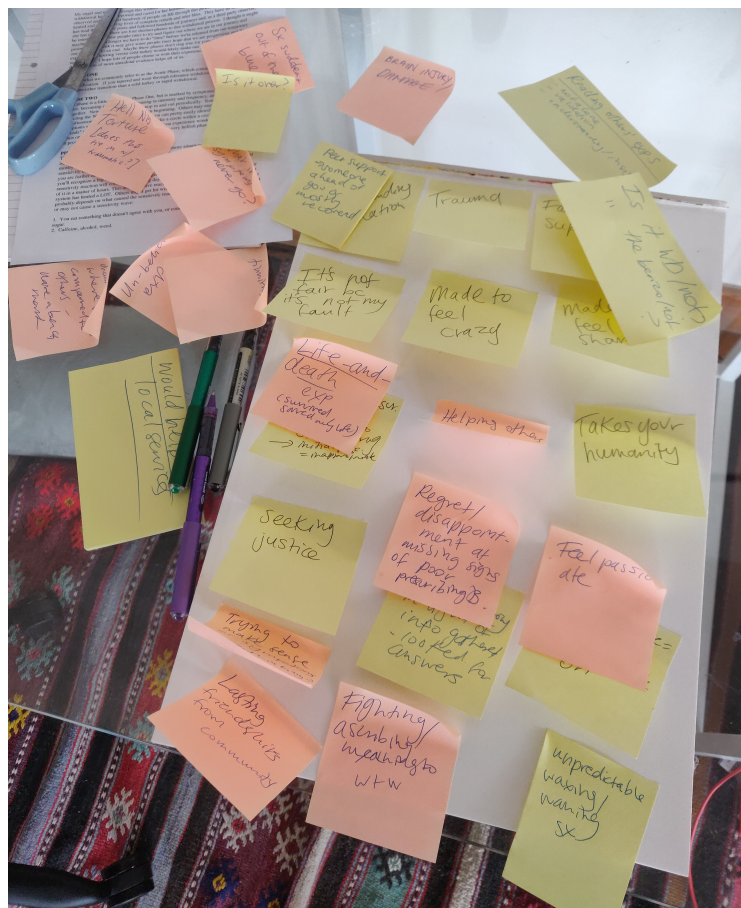
Email: [t.patel@uel.ac.uk](mailto:t.patel@uel.ac.uk)

## Appendix I: Examples of Generating Codes and Themes

First round of coding by hand and checking transcripts



Writing initial codes on post-it notes







Organising codes into refined potential themes based on shared meaning and ideas (themes in darker orange post-it notes on top):

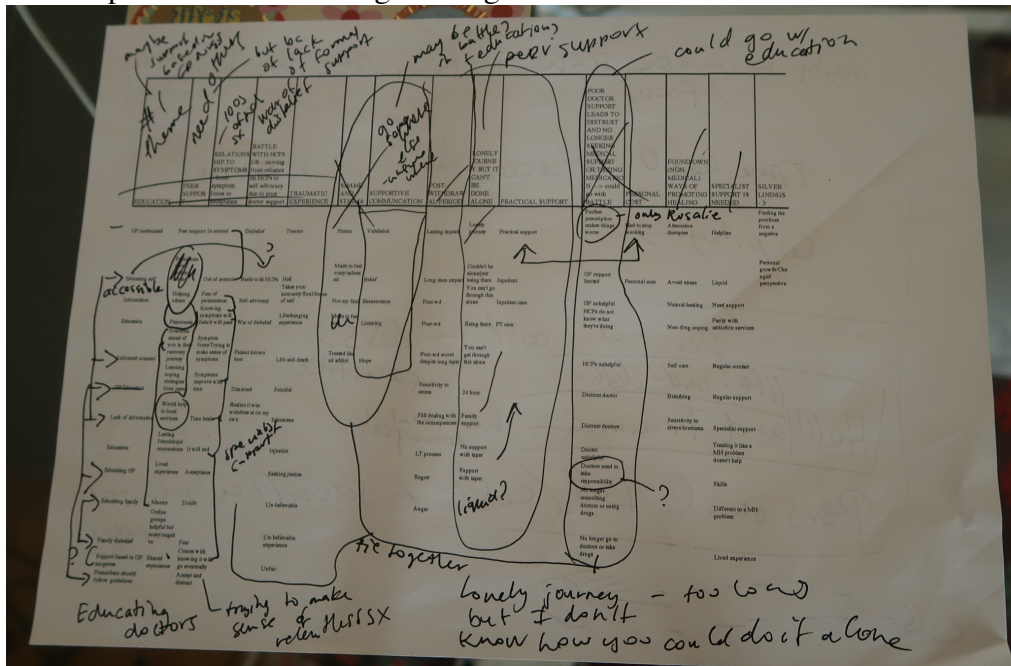


Further rounds of coding on the computer, with all 520 extracts transferred to Microsoft Excel:

A		B	C		D		E	
Participant	#	Quote	Code 1	Code 2				
1								
515	Simone	216-218	Validation	Information				
516	Simone	219-222	Validation	Shared experience				
517	Simone	229-232	Validation	Peer support				
518	Melissa	181-187	Validation					
519	Rosalie	116-118	Withdrawal amplifies existing symptoms					
520	Rosalie	367-368	You can't go through this alone					



On computer and handwriting refining themes:



TRAGIC EXPERIENCE	EDUCATION	VALIDATION	PEER SUPPORT	PRACTICAL SUPPORT	NATURAL HEALING	TRYING TO MAKE SENSE OF \$x	ACCEPTANCE	SELF-ADVOCACY	POST WITHDRAWAL PERIOD
Severity of suffering Life-and-death experience Traumatic, hell, 7 nightmare, torture, takes your humanity/soul/sense of self Treatment by HCPs 7 Seeking justice / unfair 7	Dr accessible info Family Educating doctors Educating families	Reading others' experiences - not alone, understanding Made to feel crazy and/or ashamed 7 Being believed Lived experience workers in specialist services/GP surgeries 7 Would help in local services Lasting friendships Helping others as therapeutic, measure of own progress, prevent it from happening to someone else	Helping others Someone ahead in journey maybe leave out peer support or at all, stont? treated like an addict Support planning Someone ahead of you in their recovery journey Feel passionate Support based in GP surgeries Lived experience workers in specialist services/GP surgeries 7 Would help in local services Lasting friendships Helping others as therapeutic, measure of own progress, prevent it from happening to someone else	Support planning Diet 7 Prescribing liquid 7 Financial assistance Family support Inpatient admission - event and recommendation	Diet 7 Mindfulness in benzo, the solution, false +/- accupunct avoid meds 7 FT care for basic needs Financial assistance	Fear it will never end Doubt: is it over, WD, in benzo, the solution, false +/- Symptom focus - overthinking in absence of explanations, ascribing meaning/causal explanations Fighting unpredictable symptoms Symptoms are unpredictable out of 7 control	Accepting unpredictability and untreatability of symptoms Had to educate the doctor myself Using distraction Battle No longer consulting doctors or using insight but no support medication Lonely 7 Pi knows best: knows it's WD (even when dr doesn't), knows pace 7 7 7 realized it's WD on own planned paper alone 7	Education Self-advocacy Educatng myself 7 Healing post 5x 7 on my own w/ it psychosis 7 trapped 7 professionals do it 6	

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
EDUCATION	LONELY JOURNEY BUT IT CANT BE DONE ALONE	BATTLE WITH HCPS	POOR DOCTOR SUPPORT LEADS TO DISTRUST AND NO LONGER SEEKING MEDICAL SUPPORT OR TAKING MEDICATION	SHAME AND STIGMA	PEER SUPPORT	RELATIONSHIP TO SYMPTOMS: from symptom focus to acceptance	SUPPORTIVE COMMUNICATION	TRAUMATIC EXPERIENCE	SILVER LININGS	PERSONAL COST	PRACTICAL SUPPORT	FOUND OWN (NON-MEDICAL) WAYS OF PROMOTING HEALING	POST-WITHDRAWAL PERIOD	SPECIALIST SUPPORT IS NEEDED
GP uneducated	Lonely journey	Disbelief	Further prescription makes things worse	Shame	Peer support	In control	Validation	Trauma	Finding the positives from a negative & strong negatives from a negative / Silver lining	Had to stop working	Practical support	Alternative therapies	Lasting impact	Helpline
Educating self	Couldn't be alone/just being there	Battle with HCPS	GP support limited	Made to feel crazy/ashamed	Passionate about helping others	Out of control	Belief	Hell	Personal cost	Inpatient	Avoid stress	Long-term impact	Helpline	
Information	You can't go through this alone	Self-advocacy	GP unhelpful	Not my fault	Helping others	Fear of permanence	Reassurance	Takes your humanity/Soul/Sense of self	Personal growth/Changed perspective	Inpatient care	Natural healing	Post wd	Liquid	
Education	Being there	War of disbelief	HCPS do not know what they're doing	Made to feel mad	Passionate	Knowing symptoms will fade/it will pass	Listening	Lifecchanging experience		FT care	Non-drug coping	Post-wd	Need support	
Informed consent	You can't get through this alone	Patient knows best	HCPS unhelpful	Treated like an addict	Someone ahead of you in their recovery journey	Symptom focus/Trying to make sense of symptoms	Hope	Life-and-death			Self-care	Post-wd worst despite long taper	Parity with addiction services	
GP Education	24 hour	Dismissed	Distrust doctor		Learning coping strategies from peers	Symptoms improve with time		Suicidal				Sensitivity to stress	Regular contact	

A	B	C	D	E	F	G
EDUCATION	PEER SUPPORT	RELATIONSHIP TO SYMPTOMS: from symptom focus to acceptance	BATTLE WITH HCPS - OR - moving from reliance on HCPS to self-advocacy due to poor doctor support	TRAUMATIC or HELLSH EXPERIENCE	POST-WITHDRAWAL PERIOD	LEVELS OF SUPPORT
Educating doctors	Helping others	In control	Disbelief	Trauma	Lasting impact	Lonely journey
Educating family	Hope	Out of control	Battle with HCPS	Hell	Long-term impact	Couldn't be alone/just being there
Educating self/information	Lasting friendships/connections	Fear of permanence	Self-advocacy	Takes your humanity/Soul/Sense of self	Post wd	You can't go through this alone
Prescribers should follow guidelines	Lived experience	Knowing symptoms will fade/it will pass	War of disbelief	Lifecchanging experience	Post-wd	Being there
	Lonely journey	Symptom focus/Trying to make sense of symptoms	Patient knows best	Life-and-death	Post-wd worst despite long taper	You can't get through this alone
	Online groups helpful but scary/negative	Symptoms improve with time	Dismissed	Suicidal	Sensitivity to stress	24 hour
	Reassurance ahead of you in journey	Time heals	Realize it was withdrawal on my own	Inhumane	Still dealing with the consequences	Family support
		It will end		Injustice	LT process	No support with taper
		Acceptance		Seeking justice	Regret	Support with taper
		Doubt		Un-believable	Anger	
		Fear		Un-believable experience		
		Comes with knowing it will go eventually		Unfair		
		Accept and distract				
		Relentless symptoms				



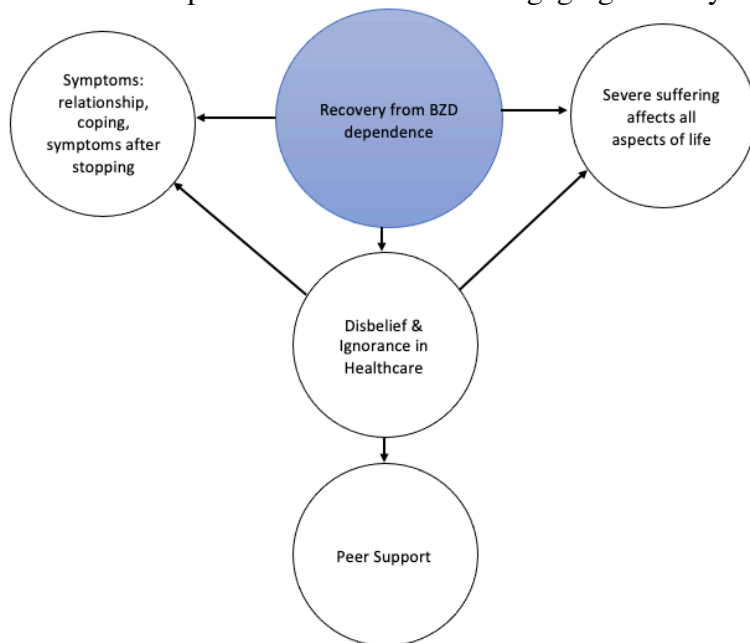
Codes refined and separated out into themes and subthemes by tabs in Excel:

30	Rosalie	Because if people haven't got somebody, I don't know how they'd ever get through it.	367-368																	
31	Rosalie	They gave me bottles of liquid I had to get all the time and I'd- Well, my partner did it all, down it all out for me for the next morning. I don't know how I'd have done if I'd had to have done it all myself.	301-303																	
32	Rosalie	[For my taper,] I did tablet shaving bits with help of people online. Well, my partner helped me... I think there should be services just for this drug. [...] This is a long-term illness. There needs to be some sort of: You know like Heather Ashton had a class. <i>Did's she, when some could see??</i> That's common like that. I used to have people doing me up twice. <i>Did you go on into a date</i>	57																	

Theme and subtheme table before further collapsing some subthemes into single subthemes:

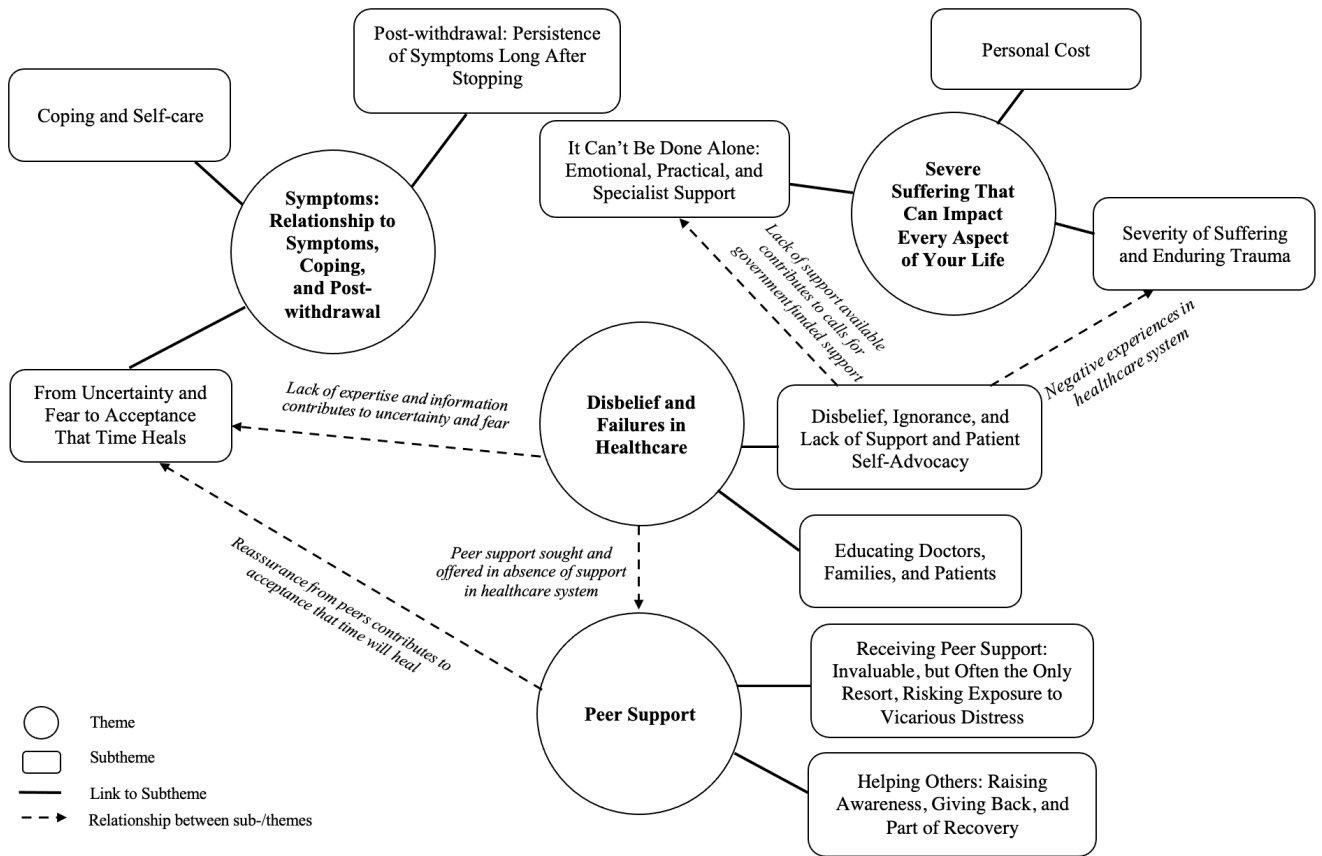
Theme	Subtheme
<b>Battling the healthcare system and its impact</b>	<b>Disbelief, Stigma, and Ignorance and the Fightback through Patient Self-Advocacy</b>
	<b>The Importance of Validation</b>
	<b>Educating doctors, families and patients</b>
<b>Peer support: Receiving help and helping others</b>	<b>Receiving peer support</b>
	<b>Helping others</b>
<b>Relationship to symptoms and the post-withdrawal period</b>	<b>Uncertainty, fear and loss of control in the face of relentless symptoms</b>
	<b>Acceptance: Only time heals</b>
	<b>Self-care, coping, and natural healing</b>
	<b>Post-withdrawal symptoms</b>
<b>Severe suffering that impacts every aspect of your life</b>	<b>Severity of suffering: "Hell", "Nightmare", and "Trauma"</b>
	<b>Personal cost</b>
	<b>It can't be done alone: Emotional, practical, and specialist support</b>

Initial mind map of connections before engaging in analysis write-up helped refine this:



Final themes and connections (as included in Results chapter):

<b>Theme</b>	<b>Subtheme</b>
Disbelief and Failures in Healthcare	Disbelief, Ignorance, and Lack of Support and Patient Self-Advocacy
	Educating Doctors, Families and Patients
Peer Support	Receiving Peer Support: Invaluable, but Often the Only Resort, Risking Exposure to Vicarious Distress
	Helping Others: Raising Awareness, Giving Back, and Part of Recovery
Symptoms: Relationship to Symptoms, Coping, and Post-withdrawal	From Uncertainty and Fear to Acceptance That Time Heals
	Coping and Self-care
	Post-withdrawal: Persistence of Symptoms Long After Stopping
Severe Suffering That Can Impact Every Aspect of Your Life	Severity of Suffering and Enduring Trauma
	Personal Cost
	It Can't Be Done Alone: Emotional, Practical, and Specialist Support



## Appendix J: Illustrative Extracts for Themes

### *Theme 1: Disbelief and Failures in Healthcare*

Subtheme: Disbelief, Ignorance, and Lack of Support and Patient Self-Advocacy

Quote	Participant
I never, until I started having the symptoms after I'd come off of clonazepam, I never realised that you could only take benzos for 4 weeks. [...] The first prescription - a private prescription - [the neurologist] gave me 50 tablets [...] Now, you know, 4 weeks, 28 tablets.	David
[I] said, 'Doctor [neurologist], my GP is telling me I shouldn't be on [benzodiazepines].' And he said, 'No, you're on a low dose' - another classic - 'You're on a low dose; it's fine.' [...] He gave me another prescription - for 100 tablets this time.	David
...I found BenzoBuddies Christmas Eve, because I was feeling so ill. I was just searching, you know, googling and, came across BenzoBuddies	David
I made a complaint to the General Medical Council about [my neurologist]. [...] and they decided that he would get a written warning for the way that he prescribed me the clonazepam and the way I came off of it and his response to it.	David
...when I started to have symptoms - withdrawal symptoms - [the doctor's] response was, 'Go back on it.' And again, what I know now that I didn't know then was that, restarting can be the absolute worst thing that you could ever do. But luckily, I didn't.	David
...reassurance was a massive thing. You know, [the Bristol Tranquilliser Project] telling me it's not, it really is - the drug can do this and [...] you've not got this new mental health condition.	Felicity
I didn't get any help from the NHS or there was no sort of all they could offer really was CBT, but it's not really like that. It's quite different to sort of like a normal anxiety disorder so [...] I did get in touch with a lady called [name] who, I have spoken to her a few times. She's like a [private] therapist that's been through problems with benzodiazepine withdrawal...	Felicity
And I was told by my doctor that, you know, very low dose and it's sort of impossible to get addicted at that dose...	Felicity



<p>I had to get my family to watch different things, you know, videos, films like <i>Medicating Normal</i> and Joanna Moncrieff talks, Mark Horowitz talks. Just David He[aly], you know people, doctors that knew about this sort of thing and how difficult it can be to get off psychiatric drugs and the withdrawal syndromes and how long they can last. And, it was educating them about, you know, that really, that this is the drug and that's what's happening and it can cause these symptoms, and that I needed help.</p>	<p>Felicity</p>
<p>My GP [...] hadn't heard of, you know, diazepam being particularly addictive at low doses...</p>	<p>Felicity</p>
<p>I noticed I was taking the diazepam and then about 3 days later was having the most horrendous panic attacks that I've ever experienced. So they were so much worse than anything I'd had before, and I had started to notice this was happening like a few days after I'd taken some diazepam. [...] but then I went to, you know, my doctor. I spoke to a psychiatrist. I spoke to my family and they were all saying it can't be the diazepam.</p>	<p>Felicity</p>
<p>...over the years now I've obviously gained, you know, not to sound arrogant but I know far more than my doctor. So, it's been a very difficult, difficult journey educating my GP...</p>	<p>Felicity</p>
<p>[My GP] really struggled to grasp this notion that it wasn't an underlying sort of mental illness coming through and she also struggled to understand that when you came off it that you could have symptoms that carry on. That was something she really struggled with. So, it took a lot of education and, you know, I had to write her letters and get other people to write her letters and yeah. She's you know, she's probably about- She's not- I wouldn't say she's fully on board still, but she's a lot more on board than she was.</p>	<p>Felicity</p>
<p>I got the Bristol Tranquiliser Project, a lady there [...] she wrote a letter to, to my GP, explaining what had happened and I wrote a letter which was really difficult actually 'cause I have a lot of cognitive stuff going on with the withdrawal. [...] I just sent [my GP] lots of links and journals and the Ashton Manual and, yeah. I basically bombarded her...</p>	<p>Felicity</p>
<p>You have to become your own sort of advocate really. It's wrong really. It's 'cause you're sort of disbelieved and, especially if you've got that history of like a bit of anxiety, you're sort of then seen as everything you experience is just your anxiety and it's just not- I, you know, I keep saying to my doctor I live in my body. I know my body and I'm the expert..</p>	<p>Felicity</p>

<p>...luckily I did actually get referred to a mental health team that knew about withdrawal, which I nearly fainted when that happened 'cause I was so shocked, you know, so my GP didn't know what to do with me basically. [...] she did refer me and, yeah, the mental health nurse just discharged me straightaway and said, basically wrote to my GP saying, 'Felicity doesn't have mental health problems. Please read Joanna Moncrieff's book on psychiatric drug...' and I couldn't believe it. I just, I said to her, 'You're the first NHS professional I've spoken to that actually has some sort of like understanding.' And she wrote, 'It will be counterproductive to prescribe more drugs', which is what I really needed my GP to understand. [...] So, yeah so that was, that was a positive thing, but I didn't think it would be. I thought I'd just get totally gaslighted and told that I was mentally ill...</p>	Felicity
<p>...it would have been great if somebody had said to me how dependence-forming these drugs are, you know, the informed consent type thing, because I feel like they're not really knowledgeable on that at all and also like adverse effects of these drugs...</p>	Felicity
<p>I've become a lot more sceptical about sort of, er, western medicine and healthcare in general [...] I suppose I've got a bit of trauma really.</p>	Felicity
<p>So it's a very difficult road and from my experience, if you talk to any GP about it, they'll just dismiss that there's a problem, and that's very difficult when we've, when you've been prescribed something, you haven't actively gone out and sought it. [...] but I think I was one of the lucky ones that I got, I did get that support from the Liverpool organisation [...] and I also was very lucky that I made contact with [an expert in the field] [...] she actually responded and said, 'You are actually in withdrawal, don't let people tell you it's your other illness because you've described perfectly somebody in withdrawal from a benzodiazepine.'</p>	Melissa
<p>...the medical professional will just dismiss you as, you know, it's all in your head.</p>	Melissa
<p>...they often are met with a war of disbelief from their GP or whoever's prescribing that.</p>	Melissa
<p>Because you do actually start blaming yourself and is there, you know, is there something wrong with me that, you know, maybe I'm not tough enough? Maybe I'm not, you know- But, I mean, I never thought along those lines because as soon as I made contact with the team in Liverpool you know, they validated everything that I was saying.</p>	Melissa
<p>I actually did mention to the GP, 'Do you wanna oppose somebody who's like the European, probably world-best, authority on benzodiazepine withdrawal? Do you think your opinion's more valid than hers?' Because sometimes you have to. You have to challenge. You don't have to do it in a hostile or aggressive way but, yeah, I put that question to my GP and said, 'You know, maybe you wanna read her [research].'</p>	Melissa
<p>...[My benzodiazepine prescription] should have been questioned after the first 4 weeks, because that's all it's licensed for in the UK, where do we go with this now, but nobody ever did and my previous GP just repeat prescribed it for 6 or 7 years...</p>	Melissa

...in all the time [it was prescribed, 6-7 years], nobody ever rang me from the GP surgery for a medication review ever so... And I'm well aware that long-term clonazepam isn't licensed in this country. Well, I am now anyway.	Melissa
...at one point, I went to my GP and said, 'There must be some help. There must be' and they referred me to the local drugs and alcohol team. And somebody did ring me from there and said, 'Well, we don't deal with prescription drugs' and I said, 'Well, I know that' I said, 'but I thought what I'd do is wait 'till you rang me so that I can then go back to the GP to say, 'Why did you do that?'	Melissa
I was in a desperate state, and he said somebody should have, you know, repeat prescribing that for 7 years is not right. So he was really great and he said to me, we talked about it, and he said I'd like to see if you could wean off a bit, and I'll help you, and he said I'm gonna give you a few months to think about it because [...] when you start you're gonna feel very unwell...	Melissa
I had a terrible crash of withdrawal symptoms [4 months after stopping]. It didn't happen straightaway, I spoke to the GP about it and he was like, no, that can't happen and I said, I'm afraid it is happening. [...] Anyway, I managed to find a helpline in Liverpool.	Melissa
..that was the first breakthrough for me to speak to someone who could tell me that I hadn't gone completely mad and it's because of this drug. I mean, as hideous as it was to learn that it could be 'cause of a prescription drug, it was comforting to know that I hadn't actually completely lost it...	Patricia
I felt so ashamed. I still felt ashamed even though I'd got it in writing [as the outcome of a negligence claim] that it wasn't my fault. I still felt a lot of shame.	Patricia
I'm still absolutely shocked that GPs are still prescribing this without warning. I mean, I meet people in my community from time-to-time and it's still happening, and it's just shocking. I can't understand...	Patricia
...[Support should] be offered so you don't feel like some - you know, so you don't feel shame around it. You realise that it's something that's acknowledged and as is any other treatment that, you know, if you've got cancer, you'll need this amount of support. Well, if you've got benzo withdrawal, you'll need this amount of support and you don't need to feel ashamed or it's your fault...	Patricia
[I was] Just cheated and misdiagnosed, as depression and put on another medication which has also in its own way ruined, every time I try to wean off it.	Patricia
He then gave me 14-days prescription of zopiclone, the sleeping tablet. [...] without warning me how addictive benzos were if used for more than a few nights at a time. After 2 weeks, I hadn't improved and I was given another 14-days prescription of zopiclone.	Patricia

<p>[...] I received no help or sympathy from my GP and I had to plan my own escape from the hell I found myself in. The only help I could find was the Bristol Drug Project helpline and the one in Camden..</p>	<p>Patricia</p>
<p>...when I felt my GPs didn't understand, I paid privately to go to see a consultant psychiatrist at the [name] clinic in [city], and unbelievable, he told me that the low dose I was on, I wouldn't become dependent and he actually gave me 2 more months of it [...] This is a couple of days before I collapsed. And so he actually prescribed 2 months more, which is really scary that a psychiatrist would not even warn you.</p>	<p>Patricia</p>
<p>I said I'm sure it's the zopiclone, I feel very strange, I, you know, can't sleep without it, I'm, I feel I'm dependent. [...] I was very clear in my head that I knew that there was something not right about these drugs, and in email, [the psychiatrist] actually put, wrote back and said, at the low-dose you're on, there's no risk of er, getting addicted, and so carry on taking them. And then, but then I realised that I was in danger. And then it was the Bristol helpline who confirmed that and helped me make a plan to come off..</p>	<p>Patricia</p>
<p>...that consultant, I've got it in an email that he told me you wouldn't get dependent and clearly, you know, I have been dependent...</p>	<p>Patricia</p>
<p>A negligence claim, and it wasn't really for the money. It was just to raise the profile that I felt I'd been given poor advice... I got £4,000. Which as I say, it wasn't the money, but it was the validation that I was given basically another 2 months' worth of the stuff without being given a warning...</p>	<p>Patricia</p>
<p>[Patients need someone] to speak to them regularly to help them manage through that period. I mean, I had no one. What happened was the GP did eventually get me the [IAPT service] CBT counsellor to come and she came to do one visit and she could see clearly, she understood actually that she could see it clearly that I was in withdrawal and she said nothing's going to help at the moment. There's no point me doing a course of CBT. How can I see it differently? You know, I was in the midst of crisis, and she said I can see that, you know, until you're off this drug, there's nothing I can do to help you, so bye-bye, and that's all I got, you know.</p>	<p>Patricia</p>
<p>I had to argue with them. They were- Even the drug and alcohol team wanted to take me off 2 milligrams a week, like, 'No.' I had to argue with them. I said, 'I know my rights. I am tapering how I'm tapering,'</p>	<p>Rosalie</p>
<p>[The doctors] kept saying to me, 'Put your mirtazapine up. Do this. Do that.' [I said,] 'Like, no, because I know it's not that.' So, it was quite a battle..</p>	<p>Rosalie</p>
<p>...the only people that helped me were the people online. I used to ring a woman [a private therapist]. Yes, I paid to speak to her because there was no one else.</p>	<p>Rosalie</p>
<p>...they said [tolerance] didn't exist. And that's worse. You know where you're in such a bad way to not be believed.</p>	<p>Rosalie</p>

I'd go to the doctors and they would be like, 'Ooh, that's not withdrawal.' I'm like, 'Yes, it is.' You know, I had to go doctors sometimes because obviously I was concerned. And they used to say, 'It's nothing to do with withdrawal. It wouldn't make your bladder bad or...' I used to get pain in my bowels and all sorts of weird things, and they'd be like, 'No, no.'	Rosalie
You know if you was in that bad state, but then there was people that understood and helped you, it would give you some relief, but to be in that state with no help, no one believed me. No one would help me. They just wanted to give me more pills.	Rosalie
They used to have meetings [on the hospital ward] and say, 'Right, we've offered her to put her mirtazapine up and we've offered to do this.' And I'd be like, 'I'm not...' 'We've offered to give her an antipsychotic.' I'd be like, 'I don't want them. It's withdrawal.' You know and they'd look at me gone out like, 'Oh she's completely lost the plot. Just leave her there.' So, they just left me.	Rosalie
Then I just carried on taking it for 5 years until I reached tolerance, but no- every doctor told me I was making it up, that there's no such thing. That unless you're withdrawing off it, it can't do anything to you.	Rosalie
They made me feel like I was insane. Every doctor I went to made me feel like I was crazy...	Rosalie
I didn't feel validated. I didn't feel like anyone believed me at all. You know, they'd be sort of, 'Oh well, you're off it now. You'll be fine,' you know, or, 'You're near the end. It's not...' I think they said at 5 milligrams it wasn't- Or 4 milligrams it wouldn't do anything now. I wouldn't get any withdrawal. I did, a lot.	Rosalie
It didn't make me very popular because no doctor or psychiatrist or the drug and alcohol team, they didn't want to be told how to do their job which I wasn't telling them how to do their job. I was telling them, 'I am not going to do what I don't want to do.' I had to be really forceful with them. The drug and alcohol lady used to say to me, 'Well, you know your own mind,' because I'd argue with her. She'd be like, 'We get people off at 2 milligrams a week.' And I'm like, 'That is not happening. That is not happening to me. You are not doing that to me.' I went and I had to- I had to argue with her continuously, but in the end, she gave up and she just let me do my taper my way, you know, and they supported it...	Rosalie
I think [patients] need just someone to believe them, just someone to believe them. I think that's key, just someone that can actually say, 'Okay, this- I believe you and this is what you're going through, and I know you're going through this, and we will help you.' But you don't get that.	Rosalie
...I mean one doctor I seen in particular, she was like, 'That's ridiculous. There's not such thing as tolerance.'	Rosalie
I had heard of tolerance, and I was saying to the doctor that I thought I was in tolerance because my anxiety was a million times worse than I've ever had it. I was having intrusive thoughts, thought the Devil was talking to me. It was horrific. And I was going from pillar to post seeing doctors and they're all like, 'Are you withdrawing off it?' I'm like, 'No, I'm still on 10	Rosalie

milligrams. It was like, 'No, no, no, there's no issue with diazepam unless you're coming off it.' I'm like, 'Well, I've heard of tolerance.' 'No such thing.' They all said to me, 'There's no such thing. It's your hormones.'	
But that's the thing is because [the doctors are] saying it, they spoke to my mum and dad, they spoke to my partner, and told them that I was making it up, basically. So then they were starting to think, well, you know, is it her hormones? Is it something else? You know and they sort of didn't believe me because they were being told by professionals...	Rosalie
And they was also told by professionals, 'She'll be off it in- We can get her off [benzodiazepines] in 6 weeks, 8 weeks, something like that. I know, I was like, 'Not a chance. Not a chance.' You know, by then I'd already met some people [online] and I knew that that wasn't how you do it.	Rosalie
...you're treated like, like you did it to yourself, you know, like you was addicted to something, you know, like I'd took heroin or something, something I did to myself. I took a tablet that the doctor assured me would help my vertigo...	Rosalie
...my parents helped in the end, you know, when they- I made them watch [educational] videos and stuff.	Rosalie
...you're made to feel shameful for how you're acting and, you know, none of it's your fault.	Rosalie
...it's added layers on top of what you're already suffering. You suffer enough, you don't- You want people to believe you and you want people to just go, 'I understand.' But they didn't because, you know, my doctors were telling [my family], 'It's not true.' You know, 'She's just anxious.'	Rosalie
...[the doctors had] convinced me that it wasn't tolerance. So, I thought it was my hormones [...] I went to see the drug and alcohol team. I insisted on seeing somebody and they said straight away, 'You're in tolerance withdrawal.' So, that's how I ended up- And then I cried for about 2 weeks solid because I was terrified of coming off it, but I've just got to do it. So, I started a very slow microtaper [...]	Rosalie
I think if [the doctors] at least have sort of gave you the benefit of the doubt, you know, if they'd have just said, 'Well, okay, it could be true and, you know, we'll listen to you...	Rosalie
They started a taper again and then no one knew how to do it. No one knew how to do my diazepam. They'd go- One nurse would go, 'I gave you a bit extra because I couldn't measure it out properly,' because they'd changed me over to liquid [diazepam]. Another one said there was all bubbles in it. I was arguing with him going, 'I can't have it because you've got bubbles in it. It needs to be accurate.' She kept coming back in, the drug and alcohol woman, 'Yes, we'll do it right tomorrow.' They never did it right. They carried on doing it wrong every day. So, I was having all sorts of different measures.	Rosalie
...even in hospital in a psychiatric ward, they didn't even know how to take me off [diazepam]. They didn't know how to measure it. They've got no understanding of diazepam at all.	Rosalie

<p>... the doctors made it worse. The psychiatrist gave me something to calm me down [...] That was when the akathisia started. The tablet [antipsychotic] he gave me set the psychosis off. [...] because the drug and alcohol team when they seen me and knew that I'd had that, she said, 'That would have made it a million times worse.' And this is a psychiatrist that should know what things interact with other things, I would have thought.</p>	Rosalie
<p>Yeah, I do think that perhaps I will have to have counselling at some point. They keep offering it me, but I'm not ready yet. I don't feel like sharing it with anybody else yet [...] They'd be just like, 'Oh, you know, it couldn't have been that bad.'</p>	Rosalie
<p>I can't talk to the medical profession because I don't trust them anymore. I've lost all trust in them. I literally won't go to the doctors for anything...</p>	Rosalie
<p>I didn't really want to go to the doctors and ask for any help because I just didn't trust them.</p>	Rosalie
<p>...the early stages wasn't too bad, but then my doctor got impatient and he tried to cut me quicker than I was happy about. [...] He's maintaining a big cut and I went, 'That's an 18 per cent cut.' He said, 'You'll be fine', and I said, 'I'm not happy about this. Why can't I just do 5 or 6 per cent?' 'No, no, you'll be fine.' Now I give him attitude, you know, my doctor is so arrogant, and I said, 'No, no, that's too fast', and he wouldn't budge. [He said,] 'Do you think you know more than me?' I stupidly said, 'Yes, I do actually', and I gave him stuff from the Bristol Tranquiliser Project, I gave him the Ashton Manual. I gave him a 13-page printout from Wikipedia about benzo withdrawal and protracted withdrawal, which I think he probably threw on the floor. I put it on the desk, you know, I said, 'Well, have a look at this.' [He said,] 'Do you think you know more than me?' [I said,] 'Yes.' [He said,] 'Well, you don't.' That's right, that's what he said, 'You don't', which, you know, when you're trying to withdraw is not a very helpful way of behaving. And I'm thinking, shit, how am I going to get enough pills to make the slower cut? I don't want to be effing cutting by 18 per cent. I know that's not a good idea. So in the end, I then looked up the NICE guidelines, which was based on Heather Ashton's Manual anyway. So I printed them off and I thought, I'm not gonna go back to [the same GP].</p>	Sarah
<p>I went, 'Look, Dr [name] is flipping well cutting me too fast. Here's your NICE guidelines. What does it say? It says blah, blah, blah.' I said, 'I am not [tapering] this fast. You need to give me some more tablets.' [The doctor said,] 'Oh, you sound like an addict.' I said, 'I don't care, it's my body, it's my brain. You know, I want some more tablets.' Well then she did give them to me, reluctantly...</p>	Sarah
<p>And [previous doctor] goes to me - this is the next month - 'You can't be trusted. I'm gonna, I'm going to put you on a daily [supervised consumption]' 'Cause I took more pills than I should [in order to taper slower], you see. I overrode him. Instead of cutting by 18 per cent, I went to another doctor, shoved the NICE guidelines under her nose. Told her that it was too fast. Demanded extra tablets.</p>	Sarah

<p>So, [the doctor] wanted me to think that he saw me as an addict that couldn't cope without those extra [benzodiazepine tablets]. So, there was a threat, a threat that if I didn't play ball [taper at the rate they wanted me to], he would make me go to the chemist every single day to pick up a limited prescription, so that I couldn't take more than I should.</p>	<p>Sarah</p>
<p>I think it was [a volunteer at the Bristol Tranquilliser Project] that said to me, 'Show [the doctor] the NICE guidelines [...] And if he doesn't believe you, you can refer him to us.' Nobody outside the medical profession has credibility. You know, I don't even know whether a doctor probably, even would listen to someone like [a volunteer] at the Bristol Tranquilliser support group.</p>	<p>Sarah</p>
<p>You know, for most of us, if the doctors don't believe us, sure as hell our families don't. If the doctors say, 'You're imagining it. You know, this is GAD, treatment-resistant depression. This is not withdrawal. Blah, blah, blah.' Why on earth would our families believe us? You know, we're all sitting here and, you know, our nearest and dearest think we're a bit mad because, you know, we're talking about things that our doctors don't validate us for. So why would our families validate us if the doctors don't?</p>	<p>Sarah</p>
<p>...we're not even believed, so we're seen as making it up, delusional conspiracy theories, scientologists, crazy.</p>	<p>Sarah</p>
<p>I told them, I just stopped coming, taking benzodiazepines, after 32 years. I've been off them about 6 weeks. Could it be related? 'No. No. No, no, not related.' And then I was strapped up to some heart thing to monitor my heartbeat, and then I was, bloods were taken. I'm not quite sure what they were looking for. It seemed pretty obvious to me what it was. And, so no, this is the catalogue of people, I remember I kept it in my head, people who don't believe it's withdrawal.</p>	<p>Sarah</p>
<p>I remember saying to [the doctor], 'You might see this again.' I said, 'It's none of [the things you're doing tests for in the hospital].' I said, 'It's benzo withdrawal.' I said, 'You're in training.' I said, 'Remember this. You might see this again.' I said, 'This is because I've come off benzodiazepines.'</p>	<p>Sarah</p>
<p>I said, 'Well, it's probably the benzos.' [The doctor said,] 'No, no, it isn't. You're just anxious at the moment. You've got GAD.' My husband's happy at this point, he's been told what's wrong with me. I have got GAD. So my husband's well pleased, and I'm like rocking at this point. So, so [doctor's name] doesn't believe it's anything to do with the benzos, it's GAD.</p>	<p>Sarah</p>



<p>I said [to my new psychiatrist], 'You don't think any of this could be to do with me coming off the benzos, do you?' And he said, 'Yes, I think it could well be.' And that was what I needed to hear. I wasn't crazy. I wasn't treatment-resistant depression. I wasn't this, that, and the other. [...] And as soon as he said that, it all made sense. And I thought, bingo, I can understand now why I'm feeling like this. It makes sense. Nothing made sense up to that. I don't care if [my husband] or the boys don't get it. I don't care anymore. I don't care if they think I'm this, that, and the other. I'm gonna tell them that it's benzo withdrawal. And therefore, it gave me a reason to think I wasn't crazy, it wasn't this, that, and the other. And I began a long fight back, long, slow fight back from that day onwards.</p>	Sarah
<p>...you're in a vicious circle and you absolutely think you're going crazy, have no hope, and you don't know what's causing it because everybody's saying it can't be this. If you don't understand why you're feeling the way you do...</p>	Sarah
<p>I've been trying to get off Effexor now - I'm doing well, I'm down from 2 to 24, but I've done it myself, quietly. Don't tell the doctors. I just don't tell them. [...] I've got boxes and boxes of repeat prescriptions that I've just stored in the cupboard. Why would I give [the doctor] control of anything?</p>	Sarah
<p>Interviewer: Yeah, and it sounds like even the doctor that reduced you to one milligram, they didn't necessarily warn you about long-term prescribing. Simone: No, definitely didn't. I don't think she was aware of the possibility.</p>	Simone
<p>[I] decided that then was the time to give up my sleeping tablet. I had no instruction from my doctor except not to do it "too quickly".</p>	Simone
<p>[What helped about being on the online peer support forum was] also knowing that you weren't alone, there's no point in talking to a doctor because the doctor, ones that I eventually spoke to when I moved to a different area from where I was caring for my mother, 'Oh, we don't prescribe them now, anyway. Oh, we don't prescribe them.' That was it, you know.</p>	Simone
<p>I was told about Ativan [lorazepam] by a pharmaceutical rep. who extolled the virtues as it has a very short half life. At that time I began to take 2mg each night not realising that it was the equivalent to 20 mg Valium. Not understanding the dependency...</p>	Simone

Subtheme: Educating Doctors, Families, and Patients

Quote	Participant
[For future services you need] a GP that's been educated so they can do their own reading. A GP that's had a conference or had a session, or a series of sessions, with people that have been through benzo [withdrawal] that can give them real-life, 'This was my experience' sort of stuff.	David
[In recommended future services] if I had a mentor, so a GP mentor [...] That mentor would provide the knowledge gap. Or fill in my knowledge gap. And I didn't have anybody to fill in my knowledge gap.	David
If they'd have given me [the] <i>Ashton [manual]</i> , if they'd have given me Benzofree.org's book if they had have given me the Four Phases I wouldn't have needed any of the rest, because there's no one here that was giving it. Not only the GP not giving it, the neurologist wasn't giving it.	David
...have somebody in the GP practice that is benzo trained	David
Some reading suggested reading [provided by your GP] would be useful, but not for everyone because not everyone is gonna wanna read or be able to do it.	David
...[my GP] could've prescribed, if you like, BenzoBuddies and Benzofree.org. And the NHS could've provided me with the book, or I could've bought it myself...	David
I do not know how benzos are still allowed to be prescribed without a sign-off by a second doctor. Or a maximum of 28 days.	David
...a doctor should not be allowed to prescribe for longer than 28 days. I can say that given the experience that I've gone through...	David
I would like people not to be allowed to be prescribed benzos for longer than 4 weeks.	David
I mean, what more can one do? Not allow [prescriptions] to go longer than 4 weeks.	David
...but in fact none of us would be out there if they didn't prescribe them for longer than 4 weeks, would we? None of us. So I'll come back to that; that's my solution.	David
If you did nothing more than stopped it being prescribed for longer than 2-4 weeks that would be a start.	David
...let's bring in benzo law, you know? No more than 4 weeks under any circumstances, end.	David

Where's the sensible person in this country in NICE or, you know, Chris Whitty or whatever, er- Yeah, I'd rather not think of Chris Whitty. I wish I hadn't mentioned it! That's saying, 'Yeah, it's bloody ridiculous, isn't it, that we know it's 4 weeks, yet they get prescribed longer than 4 weeks.' Let's stop that and press a button; that's that fixed.	David
Don't let people take [benzodiazepines] too long...	David
...it would have been helpful if [my GP] could have spoken to someone like a service or that could really educate her.	Felicity
...educating GPs, family, 'cause I had to do all of that and it's very difficult when it's coming from you. When you're unwell, you know it's better coming from an outsider that can explain all of this. Definitely education...	Felicity
...we need far more education of doctors.	Melissa
[The specialist organisation] sent me a really great book, that I could just read every day, but it was a big book like this, but more written in a magazine style so not a textbook, and I could read that every day, if I wanted, to sort of keep going...	Melissa
...I do a lot of work with the charity I work for raising awareness and we need to do it with [benzodiazepine dependence and withdrawal] too because the medical profession needs to hear it...	Melissa
...the pharmacist leading her wean [off antidepressants] is trying to take her down 50 per cent at a time so we really need the knowledge to be disseminated, otherwise there's no point. There's no point if nobody knows about it. So, I would hope that, you know, we get similar guidelines with benzodiazepines.	Melissa
[The specialist organisation's] literature was brilliant.	Melissa
[Benzodiazepines] shouldn't even be prescribed long-term in this, you know, there's rules. I don't understand it, and I don't understand why you know, any doctor would repeat prescribe benzodiazepines, given the knowledge we've got now.	Melissa
...even though benzodiazepines should be very limited, if you're in any sort of chronic-illness group, you'll find those sort of drugs being prescribed for things that you think, what? You know, and I always say, 'Do, you know, do question that, you know, they're not licensed for long-term use...'	Melissa
...more education - and the biggest thing, more education to GPs and psychiatrists, which again, seems unbelievable to even say it, but it's not there. It really is not.	Patricia
...there was a separate team that were gonna put together education for GPs. So I think that's vital that, you know, that - start at the very starting point when these drugs are prescribed, they should come with the warning of how addictive they are...	Patricia

I imagine, that [in recommended future services] there would be a counsellor there [...] who's got knowledge of the guidance that can help educate the patient that what they're going through is not their fault, that this cascade of withdrawal symptoms, is a fallout from their withdrawal...	Patricia
There's just no education for it at all and unfortunately, the doctors, most doctors I spoke to didn't even know what tolerance was. Or they said it didn't exist.	Rosalie
I think doctors need to be educated because if they don't know- It's hard.	Rosalie
So that's another thing, they need to educate the doctors that what a horrible long-term illness it is and get people support.	Rosalie
Education is key, because the first step is to get recognition for what's actually happening to you. Without that, you know, you're going round in circles spending money, seeing specialists that are telling you it's one thing or another. There needs to be more awareness that this can happen to you, that you can get tolerant to this drug, or it can make- Start making you really, really ill.	Rosalie
...get help for the people that are helping. The families need help because what they need is someone to sit them down and tell them everything that this person's going to go through. How horrible they're going to be, and it is not their fault...	Rosalie
The only way I could think that anything would help was to take all the doctors new information, email, tell them what's going on, how horrific it is. How desperate- When somebody comes to see, how desperate they will be, how close to, you know, wanting to end it all because what's coming. You know, I mean, you're not talking support for a week or 2, are you? It's years.	Rosalie
[...] the 2018 benzodiazepine NICE guidelines, I think they make allowances for it to be under the control of the patient. But, you know, I can know what I'm doing, but how many patients would, would know what they're doing? [...] what is catastrophic is if the doctors say, 'Yeah, you need to come off this. Okay, we'll cut it in half. Then we'll cut it in half, then we'll cut it in half.' And, you know, 4 weeks down the line, they think its job done. Like I said, [doctors] need to be educated about how difficult it really is.	Sarah
You know, we should be in schools now, educating kids about the dangers of prescribed medication.	Sarah
For me, what helps is [the Bristol Tranquilliser Project's] website. The minute you click on to them, there's a website with different things that you can refer to. Information, education, resources, yeah. [...] for me, just having the information in an accessible form was so important.	Sarah
...Heather Ashton, in her clinic, [...] wouldn't have just involved the patient. She would have involved their nearest and dearest, and said to them, 'Yes, you know, they are suffering withdrawal. This is what's going to happen to them, and this is what you can do to help. You know, be patient with them. Believe them. You know, this is gonna be tough.'	Sarah

<p>[...] so for me, just having information, you know, you've been on benzos for 32 years and a doctor wants you off but doesn't even attempt to tell you how to do it, and you're so scared that they're gonna cold-turkey, you need that information. How am I going to somehow withdraw?</p>	Sarah
<p>...a lot of people coming off, they would not have had my tenacity to go and do all this research. That's why it's got to be there for them, and it's got to be in a very user-friendly way. [...] you need proper information.</p>	Sarah
<p>Up to date websites. People are on the internet increasingly, especially younger people, so, you know, information on the internet, that's easily accessible</p>	Sarah
<p>...for anybody that gets a new diazepam script, or a benzodiazepine script in the UK, in 2021, they should not be kept on them for more than 2 weeks max. It should never happen now. It should never happen.</p>	Sarah
<p>[...] doctors really should not, after 1988, have been prescribing for more than 2 to 4 weeks max anyway.</p>	Sarah
<p>INTERVIEWER: [...] what would you recommend for UK services, what do you think we should provide in the UK to help other people like yourself, who are going through something similar? SIMONE: It's information and education and knowledge on the part of the professionals to, how to and to recognise the possibility that the symptoms that people have got are down to the cessation of benzos or the tolerance withdrawal that they're in.</p>	Simone

***Theme 2: Peer Support***

Subtheme: Receiving Peer Support: Invaluable, but Often the Only Resort, Risking Exposure to Vicarious Distress

Quote	Participant
It helped me during my own recovery. [...] I found [Benzofree.org] useful that- helpful because his experiences were my experiences. So I wasn't alone.	David
BenzoBuddies was very useful. However, not 100 per cent because it's full of negativity. I think the current terminology would be toxic. [...] So there were a couple of times I took a break from it, but when I felt stronger, when I felt ready, I went back to it.	David
I think there are difficulties involved with asking untrained people to mentor others...	David
...gave up with BenzoBuddies in the end because it was still, hideously, negative. And from a lot of long-termers. It wasn't the new people. The new people needed help but the long-terms, the protracted if you like, would always get their claws into those people that are new and be saying, 'Oh, well, I've been on here for 4 years and I'm still not okay.' All of that sort of stuff.	David
...[I] came across BenzoBuddies and, without a shadow of a doubt, that is the single biggest contributor to my recovery. Because I found somebody on there who was able to become my mentor and explained to me how - why I was feeling the way I was feeling and coached me through it.	David
...[My BenzoBuddies mentor] was 3.5-4 years into her recovery and I'm pleased to say now, after nearly 6 years, that she has fully recovered [...] she saved my life. Maybe she didn't but I, if anyone got me through this it was her.	David
So I did use the [online peer support] groups. That's another source of support I suppose. Yeah that did, it helped but it also was quite a scary place...	Felicity
...witnessing other people suffering. Sadly, you know I've seen people like, you know, end their lives and it's, there's a lot of vicarious distress in the online groups with this sort of thing. So, I have to take a step away from that really and just look after myself...	Felicity
I did [use online groups], yeah, for a little while, just to get some advice with tapering and symptoms and checking it was all other people had experienced it and sadly they have. So, finding that, you know, like commonalities and that sort of thing.	Felicity
...peer support as well, you know, speaking to others that have, that are going through it...	Felicity

It's for all prescribed psychiatric drug withdrawal, and it's just peer support and we meet online on Zoom, and yeah just support each other really. Everyone's at different stages. People are tapering. Some people have been off for years. Some people have been off for months, so, and we get- So like the last, on [day of the week] night we, we invite people to come and talk. So, we've had like Mark Horowitz. We've had Joanna Moncrieff. We've had David Healy, and on [day] we had a lady called Stevie Lewis who's done a lot of campaigning in Wales.	Felicity
She's like a therapist that's been through problems with benzodiazepine withdrawal [...] I have spoken to her and she really, really helped. She's full of hope [...] Yeah, definitely just hope, reassurance, speaking to somebody that's been through it and got better is priceless really...	Felicity
...you need, like the team in Liverpool, you need people who've been through it to support you and say, 'It's okay.' You know, 'This will end.'	Melissa
And it was actually one of those people who had all been through it themselves. They'd all been prescribed benzos, benzodiazepines, and got through the other side. It was one of those guys who helped me the most of all.	Melissa
...stories from other survivors were very inspiring.	Patricia
Talking to the people on the helpline at the Bristol Tranquiliser Centre, was hugely helpful 'cause it's run by volunteers who'd been victims [of prescribed benzodiazepine dependence]	Patricia
It was helpful in a lot of ways, but when you're in that terror state, sometimes I had to come off there because people would write things that used to scare you. People mean well, but you know like, if I'd go on and somebody had killed themselves that day and I was in a bad phase, that would make me worse. So I had to dip in and out of it.	Rosalie
I'd go on [the online peer support site] to ask a question, get reassurance about that everything I was going through was normal and then I would have to come off if, once I was bad if I, you know, I couldn't handle things that I'd read that was terrible.	Rosalie
...the only people that helped me were the people online.	Rosalie
I only found people online that helped me.	Rosalie
I've got one girl that I speak to [online] in Sweden, and she always reassures me. If I have a symptom, I message her now...	Rosalie
...I had friends that had already come off online, a lot of them from America, and I would just message them and ask for their advice and if they'd been through it and if it was normal.	Rosalie

I think, honestly, the best people to talk to are the people that have been through it. I think everybody that's going through it should- Somehow the doctor should help them get with somebody that's been through it, that- Cause just because they don't know, help them find somebody that does know and that, they are the people that act like doctors for you. They reassure you, they help you.	Rosalie
I armed myself with online contacts.	Sarah
...there are no experts to help you come off, you know. Where is the expertise? I suspect that the expertise is with people like me and [name], and others that have come off. I don't think there is any expertise out there. Where are the successors to Malcolm Lader and Heather Ashton? [...] why is it the firefighters have not trained any other firefighters, and people whose houses are on fire are relying on other people, whose houses are on fire too, to help them? It's crazy.	Sarah
We're [tapering] quietly. I don't even tell anyone. My husband doesn't know. Nobody knows. [...] [I] talk about things online maybe or in blogs [...] You know, a lot of us in the movement, [name], yeah, we've exchanged emails...	Sarah
...it was around this time that I found this benzo.org and then I found the forum [name] and I started to read other people's experiences and I thought, that's me, that's what's happening.	Simone
I am, as you say telling you about other people's experiences but this, in a way, was how the forum worked, was hearing how other people coped and what they did.	Simone
I also became very informed on the subject by other sufferers on [online support forum]	Simone
We were the blind leading the blind [on the online support forum] but our mutual experiences confirmed papers written by Professor Heather Ashton.	Simone
...I thought at night I'm going to have camomile tea and, blow me down, if camomile tea didn't set us off. At night I could not sleep, and of course, we put it out there amongst the [online peer support] group and, you know, 'Yes, camomile tea sets me off,' you know?	Simone
...it was obvious that we were the blind leading the blind [on the online support forum], but were able to draw on the experience of those further along the path.	Simone
I still have tinnitus but, again, because I could talk to people who were 5, 6 years further down the line, they all say it's the last thing to go.	Simone
...I was quite despondent, I think when I was about 6 years, 6 or 7, maybe not, 4 years into the whole process. I am grateful to be able to ask somebody who was 9 years down the line who was recovering, to know that there was hope.	Simone



Subtheme: Helping Others: Raising Awareness, Giving Back, and Part of Recovery

Quote	Participant
...that was why I [helped others on] BenzoBuddies; 'cause I wanted to give back.	David
I went back to Benzo[Buddies] and I became a mentor to help other people. So to give something back, which again reinforced my feelings of positivity about where I was in my recovery.	David
I used to get lots of PMs or DMs, whatever you call them, from BenzoBuddies that people would just write to me directly and you just help them through the next 24 hours.	David
...firstly I was a patient if you like on BenzoBuddies and I was receiving from people on there and then after a while I became one of the people that helped others...	David
I did look around the local area here for helping out. But I never found something - or anything that was really suitable, and I probably would, but I've stopped looking at this moment in time. I would still like to help out.	David
I have been involved in setting up a support group. [...] that's been good. It's given me a bit of a purpose helping to do that sort of thing...	Felicity
I've seen over the last year, two or three people have been prescribed Clonazepam long-term by a GP and I've done my best to help them.	Melissa
I ended up passing that book [from specialist organisation] on to somebody else in the same position...	Melissa
I've learned a lot and, you know, if I ever have the opportunity to help other people, I will.	Melissa
So, if anybody comes to me [for help] now, you know, I'll try and point them in the right direction...	Melissa
I'd quite like to get involved if there was a sort of a local service or something like that, because you need, like the team in Liverpool, you need people who've been through it to support you...	Melissa
Because you don't want people to go through what you've gone through. And, you know, I've got, obviously I've got a nursing background as well, so that helps, and, yeah, I would definitely [get involved] if there was any sort of local service...	Melissa
...then that got me thinking into, well, I've helped put together [prescribed drug dependence guidance], maybe I could be a talking therapist to help others on this journey. So then I started my training as a counsellor...	Patricia

...the client base I help in my placement, which is actually at [organisation], but a lot of them are on prescription medications, and so I have already been able to help two people in the crisis point. So that's all helped.	Patricia
I'd found it a positive experience when I read about the [prescribed drug dependence organisation] looking for volunteers to go on the panel, I was very passionate about wanting to make a difference, and it was mixed, you know. I was excited to get on the panel. It was, half of it was like wishing the experience had never happened, but then half of it feeling excited to be among such amazing people [...] it was good to turn a negative into a positive.	Patricia
I do it now to people that are going through it. I've stayed on the [online peer support] groups now because I can cope with it, and I help people.	Rosalie
I do find it quite therapeutic helping people because if you can just help one person get through the day.	Rosalie
I do feel very passionate about it. I share everything, you know, on World Benzodiazepine Day and stuff because I believe strongly that- I just don't know how doctors don't know about this stuff.	Rosalie
...[I] eventually became a moderator on this [online peer support] forum.	Simone
I became a moderator on this [online peer support] forum	Simone
...[When helping a woman online:] it was difficult talking to her because, well all I could say, you know, I understood exactly how she felt, constant pain and the paranoia and sleeplessness and I thought, I took- not advice, I consulted another friend of mine who tried to cope with the withdrawal for many years.	Simone
I had a, almost a plea from somebody [online] in [country] and I did do a link [to support her]...	Simone

***Theme 3: Symptoms: Relationship to Symptoms, Coping, and Post-withdrawal***

Subtheme: From Uncertainty and Fear to Acceptance That Time Heals

Quote	Participant
A racing chest: this was, one of the most gross symptoms that I had [...] it's started; when is it going to finish? What if it never finishes? What if it's still there when I go to bed tonight? What if it's still there in the morning? Will it ever go?	David
...I keep focussing on symptoms and focussing on trivial symptoms when probably it's best just not to think about it or to move on and just accept it and move on. It keeps me - it can lead to me overthinking, and that's been massive issue over 3 years, overthinking.	David
...you get so many symptoms and you can overthink it; oh, it must be that, oh it must be this, oh, it must be that. It's benzo; it's not benzo, it's something else, and so on and so forth...	David
...[my BenzoBuddies mentor] gave me lots of good advice. Accept was one of the pieces of advice; accept, accept, accept she wrote to me once in bold...	David
...it goes. A combination of its weakening, plus the fact I think I don't give it the attention that it wants, but- So yeah, so it's still going on. But it's not bothering any more.	David
I could still be massively twisted about it but luckily I've gone past that point in withdrawal. But there seems to be [a symptom] most days that's brief. And is it benzo or isn't it? I just don't know but it goes. I and myself and my wife now laugh about anything that, whatever we get, we just say, 'It'll go' and you know what? It does!	David
Accept and distract are the best remedies.	David
...tinnitus has been an ongoing all the way through from beginning to end and I can still catch it now sometimes but now I know that it's going to get better again, so I don't give it that much attention. It gets better. I believe that's the reason for it. Obviously the more you stress about it, the worse it's gonna get...	David
...he was able to offer insight. [...] enabling me to understand exactly where I was in the whole scheme of things, and that things would improve even though it may be a long time before they improved to the level that I am now.	David
You know, I do know that if I get a peak tomorrow, the peak will be lower than the peaks I've had in the past, and I will recover from it.	David

It's been a huge teacher in that, 'cause if I start thinking about how long I've been unwell I get, you know, get down about that and then if I start thinking about how long it could go on I get worried so it's just living in the day...	Felicity
... the physical stuff started after I came off and it's been very neurological and almost like resembling diseases like MS sometimes and I've had to have all these scans, these tests and they've all come back, you know, mostly negative. Nobody can actually really explain what's causing all of these symptoms, but I wasn't so sure that was withdrawal 'cause it was so physical and I started worrying I'd developed some disease, but it seems it's all withdrawal still, so, yeah it's just difficult when [the symptoms] change like that 'cause you sort of think, oh is this something new?	Felicity
...the main thing for me was just the reassurance, because I had a lot of really sort of quite severe sort of mental symptoms and suicidal thoughts and they helped me to try to sort of detach myself from that and keep going really and they gave me hope, you know. They said that people do tend to eventually get over this...	Felicity
I'd get all these hideous withdrawals for about 2 weeks and then the windows of clarity would start to open up, and I started to see a pattern and I started to realise that this is just what I needed to go through...	Patricia
[During an acute phase] It didn't go off for about 16 days and I thought, it's never going to go. And I sort of gave up hope by then. I just laid in bed and thought it's never going to go.	Rosalie
I had a lot of intrusive thoughts when I first got off that carried on and I'm thinking, oh please don't let these carry on all the time, but- The more you worry about them the worse they got. I had to sort of just let them be and just sort of tell myself that they weren't real.	Rosalie
You have to promise them that it'll go at some point. It won't last forever. It's- You know, if you can stop one person from ending something that's not going to last forever because, you know, when it's relentless and you- That's what I said to the other person. I said, 'At any point it can turn, any point.'	Rosalie
...the symptoms just rotate. They just go from one thing to another constantly. But obviously, then when you get a new thing, you're terrified that it's something else.	Rosalie
...towards the end I sort of got used to all the symptoms I had and just they'll either go or they won't.	Rosalie
When I had the 16 days in bed, I'd sort of just thought, well, this is it now, there's- You know, I didn't fight it. I think for- Halfway down I was starting to fight it and you can't fight it because it doesn't do what you want it to do. You have to just sort of wait for it to go and be patient. I mean, they say it's patience, but it's- It's a long time to be patient.	Rosalie
INTERVIEWER: Is there anything you find that helps you now in terms of coping? ROSALIE: Knowing that it'll fade away eventually...	Rosalie

I tell [people I am supporting online] that it will pass. It doesn't feel like it, but it will- It will go or, yes, I had this [symptom], but it's gone. It has lessened.	Rosalie
That's what I said to the other person [I was supporting online]. I said, 'At any point it can turn, any point.' I went from being: psychosis, in hospital, taken an overdose, to coming out and going away with my partner. Complete window. In fact, I was completely back to my normal self. No voices, no- You know, absolutely fine, but then obviously, it come back again. But because I'd been through that then and I knew that I'd come out the other side, I could cope when it come back again. I couldn't- I mean- You can never cope, but you know it's going to go eventually.	Rosalie
I felt that I'm never gonna get back to reality, real life, you know?	Simone
...[I] slowly began to realise as I became familiar with the [online peer support] forum and realising that there wasn't anything that could do it, just time and it took me about 6 months or so to realise that...	Simone
Acceptance. It was a very key word, actually...	Simone
The thing about the healing process is, I do regard it as a healing process, is that all of a sudden you realise that, oh, I haven't had that. I haven't experienced that for a while, you know? [...] all these things are slowly receding, well, have slowly receded...	Simone
I used to always say, 'Time is the only thing. Time.'	Simone
Healing would take time...	Simone

Subtheme: Coping and Self-care

Quote	Participant
...whatever gets people through it, so for me, it was the meditation, it was the breathing.	David
...there's an app called Balance, which is similar to Calm [...] it helped me to meditate, to relax. [...] Meditation I did a lot of in the first couple of years...	David
I would manage it via breathing. Telling myself, 'I'm gonna be okay, everything's fine, you're just in the supermarket.'	David
There's nothing else [the doctor] could've done, because he couldn't deal with my symptoms. [...] There's nothing he can do. I'd be, you know, I'd have one of those pill things, wouldn't I, for every day. And I'd be taking four in the morning and three in the afternoon for my stomach, my headache, my funny legs. [...] I don't take paracetamol. I don't take anything. Nothing, Zero, zilch, nil, that's it, I'm done with it. [...] I will recover and I can feel my own pain. I can deal with my own pain.	David
The main things that, yeah, that helped me really now are just the natural things. You know, diet and trying to spend time in nature when I feel up to it and mindfulness, meditation, reading more around natural healing and, they're the main things and just, to be honest, living in the present moment as much as possible.	Felicity
...I started downloading audio books and to this day I still go to bed with one earphone in. [...] I often wake up and the whole book's still talking to itself. It's been talking all- So, er, but it's much better than drugs, isn't it?	Melissa
I had acupuncture the last 3 months, I found one thing, the things that were helpful, I found - I went to a local man who gave me acupuncture and, some sort of electrical stimulation. [...] that all seemed to calm my nervous system, a bit and I tried to eat very healthily. So those things helped.	Patricia
I had to just start building my strength up. I got a personal trainer and tried to just go jogging and then running and I made a challenge to do the Race for Life to raise money for cancer the following year or following June, so I tried to just exercise every day to build my strength up...	Patricia
...how they can be kind to themselves, self-care they can do to help them manage...	Patricia

Yes, I do sound therapy. So I've got a gong and a drum [...] it helps calm, I do, I listen to, it's like a meditation track but it's got EMDR bilateral stimulation on it and I find that very soothing, and more recently, I've found buzzers that you hold in your hands. [...] I've got pebbles. My grounding stones. But they're about that size and you just hold them in your hands or you put them in a wristband and it just, bilateral stimulation. I just find that calming so I do that. What else do I do? Oh, when I get in a real bad way and I have to dig myself out, I try and do positive affirmations, oh, the, I read the book, the Lightning Process.	Patricia
I do a creative art well-being session. It's online with the mental health team. [...] I find that really helpful...	Patricia
...visual things like that help me. I also did a sand tray therapy...	Patricia
...all the things that helped me, eco-therapy, music therapy...	Patricia
...even caffeine and alcohol. I avoid both really as a rule, but if I do eat, have a coffee or something, I feel it affects something in my brain.	Patricia
...no stress, no noise. Because the noise, you can't stand the slightest noise. Good nutrition, somebody making nice food for you. I mean, I know it sounds a lot, but it's, it's sort of what you need...	Rosalie
I think I'm mindful when I'm tired that the symptoms might get worse, so rest.	Sarah
I started to slowly go out the house and walk the dog. I slowly started to eat properly.	Sarah
Sleep deprivation was horrendous, but they wouldn't give me anything to help me with the sleep, and in the end they did give me zopiclone, which actually did help. I'll be honest with you, that did help. I was so sleep-deprived, that just being zonked out for a couple of days helped enormously.	Sarah
...what I had was a hand-held massager that I used to deal with leg cramps, another symptom in the middle of the night.	Simone
I thought, I'm going to get healthy here. So I cut out caffeine, I wasn't drinking...	Simone
I'm hoping to avoid any stressful situations to bring on the vibrations [a withdrawal symptom]...	Simone
...chances are doctors never really come up against it, or, and this was typical, would start trying to treat the symptoms, which were really untreatable. [...] The side effects of any medication that you happen to sort of - for instance, people did have a lot of problems with gastro-intestinal stuff. and they were often prescribed a PPI, you know what it is? A proton pump inhibitor. It's to do with acid reflux of the stomach but there's dreadful side effects and the people were finding the side effects even worse than the acid reflux, you know? Of course, many times, I've got, I say many times we've recommended and it was successful, to just have ginger tea, rather than any kind of pharmaceutical, if you like.	Simone

If it was on the list [of symptoms in the Ashton Manual] then it was more than likely benzo damage and that use of further pharmaceuticals would be to no avail. Healing would take time, and one could only give the body the best possible chance to do so by eating healthily and avoiding stress which would, and still does, ramp up certain symptoms.

Simone



Subtheme: Post-withdrawal: Persistence of Symptoms Long After Stopping

Quote	Participant
...measuring improvements week-on-week is pointless. Measuring it month-on-month is probably pointless, but looking at it twice a year, then I've been able to see improvements and changes.	David
At the start the waves were significant; they have diminished. But they have never gone away.	David
...when I was off [benzodiazepines] completely- I've been going through the waves and windows scenario that [Heather] Ashton talks about constantly for 3 years.	David
...in the last 3 years, I have not been well for longer than 2 weeks apart from the last 4 weeks. So the longest window I have had has been 2 weeks. And then I've gone back into a wave, but the waves have diminished in strength.	David
You've gotta measure recovery in months, not in days. Of course that's not true; it depends on the person, doesn't it? I had to measure it in months.	David
...when I sort of finished the taper and came off, I developed a lot more physical symptoms, but some of the mental stuff has gone. So now I experience a lot of like fatigue and I have lots of problems with, like heat intolerance and can't be in the sun too long and there's, well a host of sort of neurological things as well. I get like tremors, and I've got vision problems, yeah it's a lot of stuff that I, you know, I started with one thing and I sort of, come off, come out with all these symptoms I never had before.	Felicity
I'd been weaning for 16-months and that still wasn't enough. So, what happened was, I finished in the May, and about, probably by September, I had a terrible crash of withdrawal symptoms. It didn't happen straightaway	Melissa
I was given liquid, and I [tapered] very carefully for 16 months in total and the crash still came [after stopping].	Melissa
It started when I was weaning, so I would be doing something- I mean, I'm not as active as a, you know, somebody 100 per cent fit and healthy, but, you know I keep myself going, and when I was weaning [tapering], I would get sort of episodes where I would go really hot. But it wasn't like a hot flush. There was no redness there. It was just like, oh, I'm really, really hot, and then it would slowly pass off, and that still happens. Well, it didn't happen before before going through the process.	Melissa

...but I do have sort of I think I do have mild memory problems. Nothing that you would worry about, and probably a GP would say, 'Oh, it's just your age'. I'm not sure I believe - I'm really not sure I go with that because I'm quite active brain-wise whether that's left over from it, I don't know.	Melissa
I still suffered withdrawal for a long time afterwards. I'm not even sure that I still don't, sometimes. It's difficult to pick it apart because my chronic illness is neurological too, but I know that, you know, I have little waves of it, and did have big waves of it for a long, long time.	Melissa
I've been diagnosed with chronic fatigue which I think is possibly a fallout from the strain on your, stress on your adrenal glands and the stress your body's been through.	Patricia
I think a lot of my migraines are because of emotional stress and anxiety and I think that's been increased because of the experience, so I feel that I don't know when it's gonna completely, I'm gonna completely heal and that I won't have, be in that cycle, 'cause I do get ten, average of 10 headache days a month still.	Patricia
I did go back to work, did plan another wedding but I was very shaky and stressed. I don't react to stress very - how it's changed me since that time, I have to be very careful 'cause I will react quite quickly to stress or anxiety.	Patricia
People think you get off [of benzodiazepines] and all your symptoms go away. That's not- In fact, some of the symptoms got a lot more intense once I got off. Me balance was- Got a lot worse. The bladder pain got a lot worse. I had acute a couple of times after I come off, but it- Not as bad. Some things got better, and some things got worse. I would say more the physical symptoms get worse once you get off.	Rosalie
I still get a lot of pain in my shoulders and my neck and across my back, like muscle pain. My balance is still quite poor, and I get a lot of the bladder stuff, but not as severe as it was.	Rosalie
...you're not talking support for a week or 2, are you? It's years.	Rosalie
...how can nobody know the suffering that goes on for years and years and years? I mean, it cost me and it's- I'm up to my fourth year now...	Rosalie
This goes on for years and years and years and years and affects every aspect of your life completely.	Rosalie
I still get a lot of symptoms now and I've had a lot since I've been off it. You know, especially the balance. I struggle with my balance all the time and vertigo. I don't get the intense fear anymore. I get a slight bit of panic and a bit of anxiety, but not- Nothing like withdrawal.	Rosalie
...real hell started when I actually jumped off, and that was after 2 years [of tapering]. Real hell started after I jumped off at 5 mils. I even think 2 years was too fast, and I went according to Ashton, but then I'd been on it a hell of a long time.	Sarah

I still think I have some protracted symptoms [4 years after stopping]. They're a hell of a lot better now. What is it? 2021 now, they're a hell of a lot better, but I would say there are still some protracted symptoms.	Sarah
I did experience what I thought were normal withdrawal symptoms at that time, but severe symptoms did not kick in for several months [after stopping].	Simone
[Tinnitus] was what kicked in 3 months after, 2 months after I did withdraw.	Simone
That level of tinnitus has definitely faded now [16 years after stopping] so I, talk to me in 5 years, maybe I won't have tinnitus.	Simone
...it's receding so slowly that I do think it will be another several years before the tinnitus can stop. It may never stop, you know, but just the way it's gone, how bad it was 10 years ago and how it's receded over the last 10 years, and changed, I think.	Simone
...I'm reiterating that it can take years to fully go and leg spasms carried on, I suppose for about 8 years, something like that, 8 years. Probably stopped about 4 years ago.	Simone
...I think once [the tinnitus is] gone then I would say I'm healed, but that would probably be about 20 years.	Simone
I am 16 years off and still have protracted [withdrawal symptoms], usually ramped up by stress.	Simone
I'm still capable of having a symptom, even, what? Fifteen years down the line.	Simone

***Theme 4: Severe Suffering That Can Impact Every Aspect of Your Life***

Subtheme: Severity of Suffering and Enduring Trauma

Quote	Participant
...it's 7 months [of prescribing] that led to 3 years of pain and yeah, absolute hell in my life	David
I was in a dark place; I was far more ill than I was with the migraine [they were prescribed for] while I was on the tablets. Life was hell, absolute and utter hell.	David
I had three awful Christmases on the trot. First one when I'd just come off the propranolol and then the two when I'd come off the benzo. Oh my God! Those days are days that I don't ever really want to remember...	David
That was a nightmare! For 6 or 9 months.	David
I've become a lot more sceptical about sort of, er, western medicine and healthcare in general [...] I suppose I've got a bit of trauma really.	Felicity
...the level of suffering, the severity of the suffering. You know I sometimes wonder how I'm still alive to be honest. It's just been so horrendous, and like I said if I hadn't have been through it myself I wouldn't have been able to believe it. I wouldn't have been able to believe that a drug could induce so much torment. So yeah, and trauma, definitely trauma of the suffering and trauma of drugs, trauma around doctors, you know, thinking about if I just hadn't have taken that drug, you know, I would have still been healthy.	Felicity
...I think witnessing other people suffering. Sadly, you know I've seen people like, you know, end their lives and it's, there's a lot of vicarious distress in the online groups with this sort of thing. So, have, I have to take a step away from that really and just look after myself, but, yeah there is definitely a lot of trauma.	Felicity
I can't even put it into words what [the withdrawal symptoms] felt like, but I actually thought I'd just lay down and die.	Melissa
I haven't gone out and sought heroin, the GP has prescribed something for you that's caused you great harm and then they dismiss what's happening to you. That's very traumatic...	Melissa
...you can't think really of a disease or an illness that actually puts you in such a bad place as these put you. It's unbelievable. I don't think anyone who's not had this experience could possibly imagine what it's like...	Patricia
So, it was a very terrifying journey.	Patricia

When I got off [of benzodiazepines] in the December, I was a broken person.	Patricia
It was the worst time of my life and has taken me a couple of years to get my life back on track.	Patricia
I had counselling for trauma. I had EMDR, I don't know if you've heard of that, eye movement desensitisation, for the trauma and the anger I felt at the doctors that had let me down and the medical profession and I just had panic attacks during those sessions.	Patricia
I still get a lot of flashbacks, but they've got, again, it's less, it's 6 years now but it's got less over the years, but still I can get flashbacks if I'm triggered...	Patricia
So, I definitely feel damaged, injured from the experience. Although, I mean, hugely better as each year goes by, but I mean, if you met me and saw me, you probably wouldn't think there's any residual effect, but I know in myself that, I have to talk myself through a lot of stuff. I don't take things particularly in my stride. It's, some days more than others, it's a bit of a struggle to kind of sometimes just put the whole thing behind me and just the horror of it and just try and separate myself from it.	Patricia
I was sort of euphoric when I first got off it, you know, the thought that you'd done it and you'd made it and you'd lived and- Because it basically was a life and death thing really. That's what it felt like.	Rosalie
That was the most horrific part, the psychosis. I mean, I would never take an overdose. I would never do anything like that if I was in my right mind. I literally took all the pills in the house, anything I could find while I was under the psychosis.	Rosalie
I was terrified to be left alone with my own mind in case it happened again, you know. Psychosis isn't something that, I don't know how I ever go to a place that I took an overdose because I don't understand how it happened.	Rosalie
And if I had to go doctors, I'd sit outside the doctors shaking with terror because I can't bear to see a doctor. I've got, just got no trust left at all. I just was treated appalling...	Rosalie
All of a sudden, your brain will go into like an acute phase where you're literally terrified of the tap. I couldn't stand the sound of a voice. I couldn't have anybody in the house. I couldn't let the phone ring. I just- I'd sit there and cry for probably 3 days until it went off like hysterical from the minute I woke up to the minute I went bed.	Rosalie
I mean, I went from being an absolutely normal human being, functioning, to hearing the Devil talking to me, in tolerance. And this was in tolerance before I'd even come off the drug. You know, I was petrified. I didn't know what it was	Rosalie

I've never suffered with anything like this in my life, honestly. I took an overdose. I ended up in a psychiatric hospital who had no idea. They kept giving me more diazepam. They gave me an antipsychotic which made the psychosis worse. They gave me other sorts of tablets. I don't know what they gave me, but I ended up having like a seizure. I couldn't move. And they left me on the floor [...] I was terrified in there, absolutely terrified. They treated me like- Awful, awful experience.	Rosalie
It literally destroyed me almost as a human being. It's, the suffering is- I can't describe to you the suffering. It's out of this world. Just from, you know, a pill that your doctor gives you and- Yeah, it's bad. It's really bad. And I still do get flashbacks..	Rosalie
The trauma I put my parents through taking an overdose and my children and, you know, I am getting a bit- That's the only bit I get a bit upset about because psychosis is horrendous.	Rosalie
...I don't think anything can be as bad as diazepam or benzodiazepines. It's horrific. And the group I was on, there were people that didn't make it that just killed themselves all the time and it was awful. All these beautiful young lives lost, you know, from...(tearful) That's upsetting because they weren't believed or put on loads more psych meds which just- Ridiculous to me, I'm surprised I lived, honestly. But when I took the overdose, my partner found me.	Rosalie
And then section, they said they were going to section me, but I agreed to go back anyway, but- I was treated like an animal.	Rosalie
Yeah, very traumatic. They was awful to me, awful in [the hospital], awful. I was in there for 5 weeks. I mean, for the first 2 weeks I laid in a corner, and I didn't speak to anyone. I didn't eat. I didn't do anything. [...] Beyond cruel it is, honestly.	Rosalie
I wasn't myself at all. I was gone. I was gone completely. I was having conversations with the Devil and all sorts. I didn't, you know, it's- You can't believe it could do that to you. So, yeah, it's been very traumatic, very traumatic. You know, people say to me now, you know, 'Ooh you have to forget it now and get on with your life.' [...] And now is when I need to process it to help me move on. People don't understand that. They think that, you know, you're living in the past, but it's hard to move on from something like that.	Rosalie
I have the odd day where I just cry just because, just because I'm traumatised from it, I think. But mainly I am starting to get on with my life again. I am starting to pick the pieces up.	Rosalie
I find the hardest bit is flashbacks, when I get flashbacks. I find that quite hard. That's mainly from the hospital, I think.	Rosalie
But on the whole [the flashbacks are] getting less, but I don't really know what the end goal is. I don't know whether- I don't think I'll ever, ever, ever in my lifetime get over it. I don't think- It's something that I've got to learn to live with not- You know, there's nothing I can do about it now, but sort of time, I think time's a healer, isn't it?	Rosalie

It's the most challenging thing, honestly, it's- It takes away your soul. You feel like you've got no soul at all. You've got nothing left of you...	Rosalie
I'm in severe benzo withdrawal, so she whips away the sertraline, and gives me mirtazapine. [...] So cold-turkey off sertraline. Put on mirtazapine. That's great if you're suicidal, isn't it, in hindsight. So I'm taking this mirtazapine. Course, 6 weeks later, still severe insomnia, still akathisia, still can't get off the sofa, still mute. Nightmare. Go back 6 weeks later, 'Oh, oh, I see, are you still suicidal?' 'Yes.'	Sarah
[...] as the derealisation, depersonalisation, severe insomnia, the akathisia started, I really descended into a nightmare really. I didn't, I could barely talk. I would sit on the sofa all day, just looking at the telly.[...] I think my husband was beside himself at this point, really worried, and my sons. Suicidal ideation. I'd never had suicidal ideation in the past. Severe suicidal ideation.	Sarah

Subtheme: Personal Cost

Quote	Participant
I'm still very limited. I can't work. I had to give up- I was working in the NHS, but I had to give that up.	Felicity
I became housebound, couldn't work or drive for 5 months due to shaking most of the time.	Patricia
I couldn't work. [...] I had to give that up. I was actually due to get married in the September but I was just a mess and I'd lost so much weight, I couldn't even - so the most humiliating thing was cancelling 70 guests saying I can't get married 'cause basically I'm having a mental breakdown due to prescription medication was the hardest thing to actually say.	Patricia
But it became my whole world. I'd withdrawn obviously from lots of friends. I couldn't bear to see people.	Patricia
My partner had to pack his job in to look after me, I was that bad.	Rosalie
It's literally cost us everything, everything. You know, my partner had to give up work.	Rosalie
I couldn't have my grandchildren. I couldn't go on holiday. I couldn't walk down the road. I couldn't see my parents because they didn't understand. You know, it impacts on everybody around you. My partner literally had to look after me for 3 years, basically.	Rosalie
...I bet a lot of people lose their partners in this because who's going to put up with this? You know, if you said to somebody you're going to be ill for a couple of months, they'd be like, 'Yeah, we'll stick by you.' But, you know, when you're saying, 'I'm going to be ill for about 4 or 5 years.' You know, it's a big, it takes, you know, I mean, I drove him mad, I think, in the end, but he stuck by me.	Rosalie
I mean there's not everybody that's got a partner that can give up their job and, and take care of a person, is there?	Rosalie
This goes on for years and years and years and years and affects every aspect of your life completely.	Rosalie
You know, people have lost their lives, their families, their jobs, their homes, everything because- Just because of a pill that a doctor gives you.	Rosalie
I didn't work for 8 months in 2018.	Sarah



<p>You know, it numbed me when I was taking them. I could function, but it came at a cost. I remember going through my wedding a little bit in a distance, you know, I couldn't really feel happy. I couldn't really feel joy. Everything was done in a bit of a haze. The same with birth of my kids. They were there, but they weren't there if that makes sense. Any major occasions I had in my life was blunted and numbed, and I was very soporific, you know, all the time.</p>	<p>Sarah</p>
<p>...my stay in Spain did not work out how I wanted or I hoped it would. I was going to buy a place down there but I felt so ill and could not walk well, hardly any distance without getting aches and pains...</p>	<p>Simone</p>
<p>I'd run out of money trying to find solutions...</p>	<p>Simone</p>
<p>I'd love to have the years back but because damage gets done, you see. You lose contact, proper contact with your family. You know, I've nine grandchildren, all of them were born in the beginning of all this nonsense and I could not be a proper grandma to them and I regret that...</p>	<p>Simone</p>

Subtheme: It Can't Be Done Alone: Emotional, Practical, and Specialist Support

Quote	Participant
It has to be the GPs [that provide support], doesn't it? They're your local doctor. They're your local support.	David
...have a benzo specialist in each GP practice...	David
My mentor - if you had a series of mentors, okay, why can't we have a mentor per practice? A benzo mentor per [GP] practice.	David
[An example of what would happen in the recommended service:] David has got a problem with benzo withdrawal so he goes to his general practitioner - the specialist in that - who gives him an action plan.	David
[The Bristol Tranquiliser Project helpline] helped me, you know, think about my cuts and when to cut and get off, you know, gave me advice on my taper...	Felicity
I did all the tapering stuff myself and in that state to try and cognitively work out cuts and 10 per cent, 5 per cent, how much do I do? I did all that myself and that's, I mean it would be really great if, there was a service that could devise tapering advice and support you with that and listen, you know, listening to your body...	Felicity
...I found just various sources, the Bristol Tranquiliser Project, but nothing, there was nothing local to me 'cause Bristol is about [distance away]. So it was all over the phone.	Felicity
...it's difficult 'cause there was no, apart from that there was no support on weekends or evenings or, but you know, I was lucky to have, to have found [the Bristol Tranquiliser Project].	Felicity
...you become almost incapable at times of looking after yourself and, yeah, it is 24 hour at times really. So, you know, my mum's had to, had to be with me, through the night at times [...] you do need practical support as well and if I didn't have my support of my mum and dad, I don't know where I'd be really. [...] my mum sat with me quite often during the nights where I couldn't sleep. I was just shaking and dry heaving and, you know very much acute type withdrawals, but they also, my dad makes food for me and, they do all my food shopping, cleaning- I can't do that. So, very practical stuff really and then my mum it's more I suppose emotional support really.	Felicity
I mean 'cause I had many nights where I was up 4 o'clock in the morning ringing the Samaritans, you know. I mean, I feel for the level of suffering and really there needs to be sort of 24-hour support, reassurance.	Felicity

...[With the specialist helpline] we would just talk it through and, you know, any advice about taking a step back [in my taper], getting comfortable again, and then going down more...	Melissa
I managed to find a helpline in Liverpool and I can't remember their name now, and they were such a brilliant helpline, and I managed to get hold of them. [...] I spoke to one of their support workers regularly.	Melissa
...I think I was one of the lucky ones that I got, I did get that support from the Liverpool [specialist] organisation, I wish I could remember their name because they were brilliant, and I also was very lucky that I made contact with [an expert in the field]...	Melissa
I'm not sure where I would have gone without [the specialist helpline], so I'm very sad if people can't access that sort of support. They were brilliant...	Melissa
I mean, there definitely needs to be a funded service in this country for people who have been prescribed drugs that have caused them harm...	Melissa
So, we desperately need a properly funded [system] because I think people who have been harmed by prescription drugs feel very cheated that if they suddenly started abusing recreational drugs, there's a system to help them. And yet, when you've been prescribed by a doctor, and it's harmed you in that way, there's no help at all.	Melissa
I think actually, in some cases, when it's severe withdrawal, people need actual inpatient care to keep them safe, but that's one end of the spectrum.	Melissa
...[We need] a helpline that you can ring any time of day and even if somebody's not available sort of on that spot, you know they'll come back to you fairly quickly.	Melissa
...it's a tough old road for people especially if you don't have any support. I had a lot of support from my family...	Melissa
I think just being there. So I would ring up [the specialist helpline] and say I needed to speak to somebody, and very rarely did I wait very long for them to ring me back.	Melissa
I think [it would help to have] a nurse or pharmacist to sit down with you and do you a tapering plan, someone who's qualified to do a tapering plan....	Patricia
...so someone in the centre who could help you with your tapering plan, and then liaise back to the GP so that the GP knows where you are so that they can adjust your prescription.	Patricia

I think to have a government-funded helpline, would be hugely helpful. And also, centres. I know there's a project in Wales, there's a centre, that's got counsellors and nurses in who understand people with withdrawal and they get referred from the GP to the centre and then they can be helped through their journey. I mean, it would be wonderful if there was a centre in each area, each county	Patricia
The only help I could find was the Bristol Drug Project helpline and the one in Camden and they advised me to use the Ashton Manual.	Patricia
...once or twice I spoke to the lady at the Camden Centre, but that was more difficult to get 'cause I wasn't in the area, wasn't really able to get an actual appointment, but she gave me a bit of advice...	Patricia
...[support] needs to be there, because there's thousands of people that are too, have been on it for years and, and just can't come off it 'cause they've probably tried and just felt so terrible so they just stick with it. I mean, God knows how they can do that, but they seem to have no alternative or they think there's no alternative. Whereas, if it was a service that was provided, it would encourage people to take that big step and start the journey to freedom.	Patricia
I know that the All-Party Parliamentary Group have been campaigning for a helpline and I think that would be hugely helpful. As I said, I know the Bristol Tranquilliser Centre, which was a charity run so it could only be available a few hours a week, was like a lifeline to me...	Patricia
I imagine, that [in recommended future services] there would be a counsellor there [...] who's got knowledge of the guidance that can help educate the patient [...] [on] how they can be kind to themselves, self-care they can do to help them ma-, to speak to them regularly to help them manage through that period.	Patricia
Because if people haven't got somebody, I don't know how they'd ever get through it.	Rosalie
They gave me bottles of liquid I had to get all the time and my partner did it all, drawn it all out for me for the next morning. I don't know how I'd have done if I'd had to have done it all myself.	Rosalie
[For my taper,] I did tablet shaving bits with help off people online. Well, my partner helped me...	Rosalie
I think there should be services just for this drug. [...] This is a long-term illness. There needs to be some sort of- You know like Heather Ashton had a place, didn't she, where people could go? [...] But somewhere like that [...] I used to have people ringing me up saying, did I want to go into a detox place? That's not going to work. That's not going to work for people, is it? It gets you off it, but the suffering's a million times worse.	Rosalie

<p>...[my husband] cooked all my meals. I couldn't cook for myself. I could barely stand up to cook anyway. [...] Get me to have a drink because I didn't eat much when I was in that state. He sorted anything that needed sorting out. I couldn't cognitively sort anything out, not a bill, you know, anything that needed doing like if it was the kids' birthdays, I couldn't sort anything out. I could barely leave the house when I was bad.</p>	Rosalie
<p>...there's so much help for alcohol addiction and cocaine addiction and heroin addiction [...] They get help. That was, that's what they're saying, if it was any other drug there's help, but because it was diazepam, there was no help for me.</p>	Rosalie
<p>I mean, I had a partner that gave up his job to look after me. I don't know what people would do if they didn't have support.</p>	Rosalie
<p>I think if you haven't got support, I don't think you'd ever get through it. [...] I don't think I would have got through it if I hadn't have had some sort of help. I don't think I'd have ate. The, just the, the thought of going downstairs is terrifying, so I think people need support.</p>	Rosalie
<p>The whole taper I couldn't be left alone for one minute. I could not be left in the house on my own for one minute. The terror it would inflict on me if someone left me on me own.</p>	Rosalie
<p>[My husband] sat with me day and night. I'd stay in bed for 3 days at a time. He'd watch videos with me from the minute I woke up to the minute I'd go to bed. And then he'd help me again in the morning when I was in complete terror, and I'd be crying and hysterical. He'd calm me down</p>	Rosalie
<p>I managed to find out about the Bristol Tranquilliser Project. [...] I thought, well, there's a start, thank God. So I phoned them, and they were an absolute godsend. They sent me all the printed stuff to do with the Ashton Manual. They had a website, which I could read, and they had some links. I wasn't eligible to go and see any of their counsellors 'cause in, I live in [town] which is [distance away] of [city] but that to me was a godsend, absolute godsend.</p>	Sarah
<p>...if people are asking what is needed, Bristol Tranquilliser support group, they were only open, 10:00 till 3:00, Monday to Thursday. Getting through was a hell of a job. You know, when people are withdrawing, they might feel really lousy, you know, in the evenings or at night or in the mornings or at the weekends. How diabolical that there was only a helpline if you could get through, of course in those limited hours.</p>	Sarah
<p>And I actually could find nothing else to help me. I mean, thank God for them, but, you know, how outrageous that there are not more Bristol Tranquilliser support groups, in every city in the land. And I mean, at least Bristol Tranquilliser support group also has the website and they have, for the people in Bristol, presumably, counsellors and nurses and group therapies and things, you know. I think Bristol Tranquilliser support group, as a minimum, should be replicated in every major city in the land.</p>	Sarah

There were three [specialist organisations] that I would say were exemplary. You had, um, Bristol Tranquilliser support, one at Oldham, and there was one in Camden, in London. [...] Now, there was three models, and, you know, it's all there. That's the minimum people need, you know.	Sarah
The other thing I'd like to see is doctors especially realising that for some people, withdrawal is so tough, they are gonna be off work long-term. And therefore, they need assistance with that. You know, there are people out there losing everything, and they're not given any help. [...] I'm lucky, I had [my husband] that was able to, you know, earn money and pay the bills, but if I hadn't, I would have wanted state assistance [...]	Sarah
...like other services, and I'm sure if you go into rehab, to recover from heroin addiction, you probably get nutrition and sleep advice, you know. It would be just nice for somewhere to go, where you can have a massage or, or physiotherapy or nutrition or just everything that other people in addiction services are offered.	Sarah
24-hour support line would be helpful, that people, so that people can know that there's someone to talk to at the end of a phone.	Sarah
What services should look like [...] 24-hour helpline, manned by people who know what they're doing.	Sarah