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Stories of Hell and Healing: Internet Users' Construction of Benzodiazepine Distress and Withdrawal.

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Abstract

Benzodiazepines are a group of drugs used mainly as sedatives, hypnotics, anti-epileptics and muscle relaxants. Consumption is recommended for 2-4 weeks only (NICE CKS 2013) due to fast onset of dependency and potentially distressing withdrawal symptoms (Ashton, 2005; Lader, 2012). Few peer review studies have drawn on the user experiences and language to appreciate first hand experiences of benzodiazepine withdrawal or discontinuation syndrome (Fixsen, 2015). We looked extensively at patient stories of benzodiazepine withdrawal and recovery on Internet support sites and YouTube. Our analysis indicated that users employ rich metaphors to portray the psychologically disturbing and protracted nature of their suffering. We identified seven major themes: hell and isolation; anxiety and depression; alienation; physical distress; anger and remorse; waves and windows; and healing and renewal. By posting success stories, ex-users make known that "healing" can be a long, unpredictable process, but distress does lessen and recovery can happen.

Keywords: benzodiazepines, dependency, patient narratives, metaphor, electronic support groups, distress, recovery.

Introduction

Benzodiazepines (also called BZ drugs or "benzos") are a group of drugs used mainly as sedatives, hypnotics, anti-epileptics and muscle relaxants. Commonly used types include alprazolam (Xanax), clonazepam (Klonopin), diazepam (Valium), lorazepam (Ativan) and tamazepam (Restoril). The class of hypnotics known as "Z drugs" (e.g. zaleplon, zolpidem and zopiclone) are considered to have similar addictive qualities and side effects (Ford et al., 2014; NICE, 2004). Although not recommended for use beyond 2 to 4 weeks (NICE CKS, 2013) due to serious adverse effects (including dementia, cancer and increased accident risk (Uzun, Kozumplik, Jakovljevic, & Sedic, 2010) and the rapid development of tolerance and withdrawal symptoms (Reconnexion, 2010), benzodiazepines continue to be prescribed for months or even years (Ford et al., 2014). In the UK there are around 1-1.5 million long-term users (APPGITA 2014; Ford, Law, Barjolin, Betterton, & Carnwath, 2014), as well as an unknown number of illicit users, and figures are frequently higher in other countries (Islam, Conigrave, Day, Nguyen, & Haber, 2014; Neutel, 2005; Rosman, Le Vaillant, & Pelletier-Fleury, 2011). Estimates of long term use are highest in studies of the elderly (Kurko et al., 2015; Olfson, King, & Schoenbaum, 2014).

Clinical research into benzodiazepine withdrawal suggests that sufferers can experience a range of psychological symptoms (including rebound anxiety, depression, insomnia, depersonalization) and bodily symptoms (including pain, tension, spasm, tachycardia) which can extend far beyond drug cessation with no predictable ending (Ashton, 1991, 2005; Barker, Greenwood, Jackson, & Crowe, 2005). Very few peer review studies have considered benzodiazepines from the user

perspective (Cook, Biyanova, Masci, & Coyne, 2007; Gabe & Lipshitz-Phillips, 1982) and even fewer have drawn on the language employed by users themselves (Fixsen, 2015) to explore first-hand experiences of withdrawal or discontinuation syndrome. We conducted a comprehensive review of literature of relevant Internet support sites and YouTube videos, investigating benzodiazepine users' descriptions of their withdrawal distress and recovery, then compared these descriptions with published literature. After outlining what is known about benzodiazepines use and withdrawal, and highlighting socio-political issues surrounding benzodiazepine dependency, we investigate Internet user accounts of benzodiazepine withdrawal and recovery to better understand their experiences.

Published user accounts suggest that withdrawal, although differing from person-to-person, has the potential to place sufferers in an alien, disconnected, and sometimes, hellish world, which is hard describe using everyday parlance (Hobson-DuPont, 2006; Johns, 2012; Samet, 2013). Our searches indicate that users overcome the lack of available language by employing and sharing metaphors to portray the psychologically disturbing and protracted nature of their suffering. As they cycle between hope and hopelessness, people in withdrawal use blogs and discussion threads to examine and discuss the feasibility of issues like "100% healing," while authors of success stories use personal and collective idioms to describe and give meaning to their subjective experiences of recovery. By posting their success stories, ex-users make known to other users that recovery is possible, but that it its timescale is unpredictable and possibly measurable in years. Moving on from this experience is nevertheless described as a real possibility and some ex-users liken it to a type of "rebirth."

Benzodiazepines- the background

Benzodiazepines have an extended history of use within and outside the medical sphere. With their range of sedative, anxiolytic, anticonvulsant and muscle relaxant actions and their early-on assumed non-addictive nature and low toxicity, benzodiazepines initially appeared an ideal medication for a range of common conditions (Ashton, 2005). The first benzodiazepine, chlordiazepoxide (Librium), was introduced into clinical practice in the 1960's when it was hailed as a safe and effective alternative to existing hypnotics and barbiturates, with less risks of abuse and overdose (Licata & Rowlett, 2008). By the late 1970's, benzodiazepines were amongst the most widely dispensed prescription medications in the world. Soon after their introduction however, evidence concerning their adverse effects and abuse potential began to accumulate (Hallstrom & Lader, 1982; Lader & Petursson, 1981).

Adverse effects of benzodiazepines are numerous and include impaired cognitive and motor faculties (Barker et al., 2005; Bierman et al., 2007), increased risk of accidents and increased morbidity including dementia, as well as cancer risks (Uzun, Kozumplik, Jakovljević, & Sedić, 2010). Even at regular "therapeutic" doses, not only are withdrawal symptoms extremely common, but are severe enough to leave some patients involuntarily addicted (Lader, 2012). In 2016 the BMA called for a concerted program to support people who wished to come off these addictive medications (BMA, 2016).

Effects and withdrawal

Benzodiazepines appear to exert their anxiolytic, anticonvulsant, muscle-relaxant and sedative-hypnotic properties by acting through specific GABA(A) receptor sites (GABA being the major inhibitory neurotransmitter in the central nervous system)

(Ashton, 2005). GABA(A) sites occur throughout the brain and body, and the nervous system rapidly habituates to this artificial GABA booster, thus discontinuation can cause considerable mental and physical distress (Tan, Rudolph, & Lüscher, 2011). An estimated 20-50% of benzodiazepines users will experience problems withdrawing, and in around a third these symptoms are very distressing (BBC Radio 4, 2011). Rarely used as the sole drug of abuse (Lader 2012, Ford et al. 2014), the "numbing" effects of "benzos" are often sought after by illicit drug users, who subsequently become progressively less capable of tolerating their emotions and life stressors (Longo & Johnson, 2000). While benzodiazepines can provide temporary relief, over time the pathological effects of the dependence can cause a secondary suffering which exceeds the original problem (Chen, 2010). Unlike most psychoactive medications however, benzodiazepines are equally used for recreational and medicinal purposes and the majority of long term benzodiazepine users have become unintentionally dependent after medical prescription (Ashton, 2005). Having mental health problems, being older, less educated and lonely have been associated with long-term prescriptions for benzodiazepines (Zandstra *et al.* 2004).

Current advice for discontinuing benzodiazepines is to taper the dose gradually over a timescale acceptable to the individual (Ashton, 2005; Ford et al., 2014). In some cases, withdrawing from benzodiazepines can prove relatively straightforward, however, particularly for long term users, symptoms of withdrawal can be protracted, highly distressing and sometimes incapacitating (Ashton, 2005; Lader, 2012). Patients can feel physically ill and suffer from disconcerting symptoms including severe panic or extreme hypersensitivity to noise and light. Other distressing withdrawal symptoms include depression, insomnia or nightmares, hallucinations, suicidal thoughts, tachycardia, muscle tension, tremor and tinnitus, and

many more mental and physical problems (Ashton, 2005; Busto et al., 1986; Ford et al., 2014; Lader, 2012). Serious effects such as fits, psychosis and death are rare, but do occur (Lader, 2012), especially if discontinuation is abrupt. Unsurprisingly, for long-term users the relapse rate is substantial (Morin, Bélanger, Bastien, & Vallières, 2005). Nevertheless, patients who do withdraw successfully report significant improvements in health and wellbeing over the longer term (Ashton, 2005; Vikander, Koechling, Borg, Tönne, & Hiltunen, 2010). No medications are specifically approved for treating benzodiazepine dependence, although some studies suggest that the drug flumazenil can lessen withdrawal symptoms and seizures (Ford et al., 2014). Other treatment approaches include switching patients to longer acting non-benzodiazepines, or where a formal diagnosis of anxiety has been made, prescribing adjunctive medications such as antidepressants or antipsychotics (Ashton, 2005).

Benzodiazepine Dependence

Despite considerable concerns about the overprescribing of BZ/Z drugs, many GPs still know little about their withdrawal effects, and they continue to be prescribed inappropriately (Sirdifield et al., 2013). The reasons for the continued high dispensing rates of benzodiazepines are complex (Ford et al., 2014; Sirdifield et al., 2013). In the short term, benzodiazepines have fewer side effects and more rapid anxiolytic effects than antidepressants (Price, Cole, & Goodwin, 2009). GPs can feel a sense of powerlessness in dealing with psychosocial problems, and with consultation times averaging 10 minutes in the UK, prescribing benzodiazepines is easier than addressing underlying causes. With inadequate alternatives in the medical armory, long-term benzodiazepine prescribing (over six months) is still widespread in many countries (Olfson, King and Schoenbaum, 2015).

A major factor leading to dependency is the relative rapidity with which dependency occurs, which can take both physician and patient by surprise. Benzodiazepines tolerance and inter-dose withdrawal symptoms can develop within months, which, when considered alongside existing symptoms, can make withdrawal effects harder to identify. Formerly used to describe uncontrolled drug-seeking behavior, the term dependence has been redefined to include the physiological adaptation that occurs when medications acting on the central nervous system are taken, resulting in rebound symptoms when the medication is abruptly discontinued (O'Brien, 2011). Benzodiazepines have been found to produce dependence even in low doses in both human and animal studies (Licata & Rowlett, 2008), and distinctions between physiological and psychological dependence are blurred (Ashton, 2005). Social perceptions of drug use and dependence have been slow to change however, and the prevailing public view of drug dependence is as primarily a social problem that requires interdiction and law enforcement rather than a health problem requiring harm-minimization and treatment (McLellan, Lewis, O'Brien, & Kleber, 2000). Users may be blamed for taking drugs in the first place and are perceived as having a choice as to whether or not to take them (Lloyd, 2010).

Support during withdrawal

While parallels can be drawn between benzodiazepine withdrawal and other psychotropic discontinuation syndromes, withdrawing from benzodiazepines appears to be particularly prolonged and distressing. At least one expert has described benzodiazepines as more difficult to withdrawal from than heroin (BBC Radio 4, 2011). A key feature of withdrawal is an exaggerated state of anxiety, in which many of the taken for granted aspects of everyday life (such as making a meal, going

shopping, talking on the telephone) become objects of dread or are experienced as overwhelmingly difficult (Hobson-Dupont, 2006; Johns, 2012; Samet, 2013). Along with the psychophysical symptoms of dependency and withdrawal, users face issues associated with a contested and debilitating illness that is not only stigmatized (Lloyd, 2010), but considered suspect by medical professionals (Hobson-Dupont, 2006; Pittman, Youngs, & Karle, 2013; Samet, 2013). Patients can feel a sense of anger and failure at being placed on the medication in the first place (Price et al., 2009), and/orat being unable to withdraw successfully. As benzodiazepine users are often put on antidepressants or painkillers (Ashton, 2005), they may face the prospect of side effects and discontinuation/withdrawal from other psychoactive drugs.

Social and psychological support from peers and support staff is an important part of drug dependence recovery (Redden, Tracy, & Shafer, 2013; Ridge & Ziebland, 2006). Clinical studies suggest that people receiving advice and help are more likely to succeed in stopping benzodiazepines for good (Ashton, 1994; Morin et al., 2004). In practice accessing specialized support is often difficult however, and the number of specialist benzodiazepine withdrawal and recovery programs is small (APPGITA, 2014). In the absence of coordinated help from governments, online benzodiazepine self-help groups and forums emerged from the late 1990's, providing information and support to users and their families. With the long-term diminution of users, the number of active forums has fallen. Some successful forums, on the other hand, continue to expand and attract comments and stories from users and their families across the world. Membership to the largest benzodiazepine support forum run by lay members, Benzo Buddies (www.benzobuddies.org) grew from 10,000 members in 2011 to over 18,000 in 2016. YouTube is also a highly popular and growing platform

through which users can upload and share home made videos recounting their own stories of benzodiazepine use and withdrawal.

There are good reasons why benzodiazepine users may prefer to utilize online communication channels rather than seek out face-to-face help (Tanis, 2008; Yeshua-katz, 2015). The anonymity of online sites means less risk of social embarrassment and people are able to exert more choice over what they say and with whom they interact. Health "communities" can develop online, established independent of time and geographical space (Douglas et al., 2008). People can connect with others in similar circumstances (April et al., 2007; Broom & Tovey, 2008; Hinton, Kurinczuk, & Ziebland, 2010) and can learn to better manage long term problems or conditions. Posting on YouTube is likely to have different rewards for the posters, such as gaining credibility, becoming a spokesperson for a stigmatized group and/or attaining hero status (Fixsen, 2015). In this study, we investigate user posts on these Internet support sites and YouTube videos, to better understand and interpret their experiences of benzodiazepine withdrawal and recovery.

Methodology

While critics of narrative enquiry allege a naive approach to illness (Atkinson & Delamont, 2006), patient stories can provide fundamental insights into lived experiences, and can help "plunge" the researcher into the subjects' inner worlds of participants, thus capturing deeper essences of suffering while providing analytical clues about amelioration of distress and promotion of recovery (Franzosi, 1998). To construct our collective account we used a narrative approach, investigating the metaphors and language expressed by benzodiazepine users themselves. We, Alison Fixsen (first author) and Damien Ridge (second author) looked at data within a wide

range of publically available online accounts of benzodiazepine use and withdrawal. In addition, we employed autobiographical literature, including Alison's personal use and recovery from benzodiazepines, for comparative purposes (Fixsen, 2015). In selecting posts, we made no distinction between prescribed and illicit use, as our interest was on the lived experience of benzodiazepine withdrawal.

From May 2013- December 2014, Alison (while in personal withdrawal from benzodiazepines) had an online alias and an Internet presence on the Benzo Buddies site. User data viewed at this time is excluded from this study (see ethics section below), but nevertheless provided valuable "insider" cultural knowledge of the workings of such support sites. In the second phase (January-September 2014), we conducted over 500 general and focused searches of anonymous online BZ support forums and BZ user sites for personal accounts of withdrawal and recovery. From January to September 2014, Alison carried out over 800 searches of benzodiazepine related websites and webpages, using the search terms benzodiazepines, "benzos" and "tranquillizers." From September 2014- January 2017, we focused on the following search terms: "benzodiazepine/ benzo withdrawal,"' benzo "hell," "recovery" and "healing," and "benzodiazepine/ benzo success stories."

To ensure that as wide a sample of viewpoints on benzodiazepine withdrawal and distress was included, support sites with active and inactive forums (but with personal user stories), popular Internet blogs, and videos posted on YouTube, were all reviewed. On YouTube, we found over 14,000 videos (26/5/2017) under "benzo withdrawal," most of them describing personal stories, thus indicating the popularity of YouTube as a platform for benzodiazepine users. 10,100 videos were listed under "benzo hell," (the most frequently viewed having over 161,000 views), 2,260 under "benzo nightmare," 3,600 under "benzo anxiety" and 2,230 on "benzo recovery."

While it was not possible to view all these videos due to time constraints, Alison reviewed 300 of the most popular videos.

For ethical reasons, and to make the enormous amount of online data more manageable, we excluded: webpages only available for viewing with a user password; non-English sites; and information sites lacking facilities for people to post personal messages or narratives of benzodiazepine use and withdrawal. As the largest and most active benzodiazepine support site on the Internet, Benzo Buddies was the most frequently searched site. There are also a number of benzodiazepine sites (such as benzo.org.uk), which no longer have active forums, but can still be publically viewed. Details of the main searches conducted September 2014-16 are described in Table one.

(Insert Table one: online searches about here).

Analysis

We analyzed data using a stage-by-stage process. Careful attention was paid to the actual language and phrases describing user experiences, a notable feature being the use of strong and vivid metaphors. More than mere linguistic devices, metaphors are important vehicles for understanding our physical, social and inner world (Schmitt, 2005) and can transmit and evoke meanings beyond that of ordinary language, assisting the reader/listener to connect emotionally to the experiences described (Patton, 1990). Other studies have successfully employed metaphor analysis in the context of drug use and recovery (Redden et al., 2013) and to interpret distress (Kantrowitz-Gordon & Vandermause, 2016). Metaphor has been accused of projecting the researcher's views, distorting findings (Carpenter, 2008) or leading to loss of meaningful findings (Sandelowski, 1998). Mindful of these criticisms, we

searched extensively for user accounts and cross-referenced them with clinical models of benzodiazepine withdrawal described in the literature (e.g. Ford et al., 2014).

During the early stage of our research (January-September 2014), Alison collected and examined samples of patient writing from each of these sites, noting any characteristic words or phrases appearing repeatedly. Large extracts of written narrative accounts of benzodiazepine withdrawal and recovery on user sites were cut and pasted into Word to aid analysis. Words or expressions associated with benzodiazepine withdrawal and recovery were highlighted and cross-coded according to category headings. We then compared concepts and categories further, noting recurring themes, discussing and debating initial results. Alison then re-read these accounts, and conducted a second more focused Internet search (September 14-January 2017) based on broad themes identified in the first phase. Selecting and honing themes was an interpretative process, with the meaning of the theme and its indicators prioritized, inferred, interpreted, or signaled, rather than necessarily being directly present (Morse, 2015).

We then developed a final coding system (e.g. hellish, alien, healing) to apply across the data, and manually coded them under themed headings. To check validity of online accounts of withdrawal we compared them with descriptions used in unpublished autobiographies of benzodiazepine users (Hobson-Dupont, 2006; Johns, 2012; Samet, 2013) and in the clinical literature. In addition, scenarios lying outside our experience and our "model withdrawal scenario," such as users with no symptoms, users who do not wish to discontinue, or users who went back on benzodiazepines, were also examined. Through interpreting the idioms and metaphors employed by all users, we were able to construct what we regard as a relatively accurate picture of distress and recovery during benzodiazepine withdrawal.

Ethical issues

We received ethical approval from our institutional committee, on the agreement that no real names were used. To address the new ethical and legal issues and other problems associated with conducting online research (Convery & Cox, 2012), the Associate of Internet Researchers (AoIR) advocates guidelines to Internet research so that ethical research can remain flexible, be responsive to diverse contexts, and be adaptable to continually changing technologies (AoIR, 2012). To protect privacy we have used only brief, anonymous accounts of benzodiazepine withdrawal and limited these to our topic area of benzodiazepine withdrawal and recovery. Informed consent was not asked or obtained, as all data examined in this project constituted open messages, which anyone could access via their own computer. In addition we considered issues around the legitimacy and reliability of data collected from online sites, weighing these against the advantages of the naturalistic and spontaneous nature of Internet posts. Our motivation in conducting the current research is to develop better conceptual frameworks for the personal experiences of users and ex-users, based on publically available data, so we do not consider there to be a conflict of interest. Our searches and comparisons have been rigorous and we have constantly sought to test out concepts emerging from our readings from one source with other sources.

Findings

As evidenced by the millions of hits on YouTube and benzo support sites, users going through benzodiazepine withdrawal frequently search online for stories about others who have had, or are having, similar experiences. Users want to find accounts that

resonate, and many accounts are geared towards reassuring users that they are not alone, e.g. “I was there too. I plan on completely recovering from this, and so will you.”

Hell and isolation

While some users and ex-users admit to being recreational or multi-drug users, others describe how they found themselves inadvertently dependent on prescribed benzodiazepines and suffering from their effects in relatively short spaces of time; e.g., “If someone told me about the hell I would have to endure a little more than a year ago, after being handed a couple of little innocently enough looking white pills from one careless medical doctor, I would just think he’s having a seriously bad joke.” For people who find themselves in a state of benzodiazepine dependency, withdrawal can be a protracted and distressing experience. After prolonged use or a too rapid withdrawal (such as in a detox clinic) symptoms can be particularly harrowing. Users and ex-users employ a variety of idioms to describe the hellish quality of acute withdrawal; the “deep dark unmentionable”; ”pure hell”; “my invisible hell;” as if “someone ripped your soul out of your body and left you with just a shell of a person.” YouTube videos, mostly personal stories of benzodiazepine users, reference hell, choosing video titles such as “I’m walking out of hell,” and sounding a warning to others to “Never abuse this drug. Never take it as prescribed. My life is hell.”

Anxiety and depression

Heightened or rebound anxiety is a common symptom of withdrawal (Hulse et al., 2012; Lader, 1994) frequently described by users on Internet sites. One user describes

it as a “primal feeling that you’re about to be attacked by a lion; you’re about to be killed”; another as a constant sense of dread and foreboding that leaves them “hidden from the world, stricken with panic and fear.” For long-term users, reducing their dosage slowly over time, the greatest fear can be attached to taking the final dose when the time comes to “jump off” (discontinue benzodiazepines completely). Depression is also a commonly discussed side effect of withdrawal, which for some people can be profound and protracted; “I can see why people kill themselves feeling like this. I've only been taking (benzodiazepines) for a few months, and when I've taken psych drugs for months, I've not found the withdrawal too bad, but this is just awful.” With the depression can come such a sense of hopelessness and despair that it many be “impossible to ever be the same again.” Users express a sense of numbness and separation of self; “my emotions are completely flat . . . No joy, happiness, or even normal, healthy sadness.”

Alienation

De-realization, dissociation and cognitive impairment are well documented symptoms of benzodiazepine withdrawal (Ashton, 2011). User accounts generally describe a spaced out, disconnected dreamlike state in which cognitive functioning is impaired, senses distorted in disturbing ways, and normality replaced by a sense of otherworldliness. Users also describe a host of perceptual and sensory distortions, leading to an altered reality, which is “dreamlike” yet “nightmarish”; “like being a zombie”; and ”in a bad dream that I couldn’t waken up from:”

> It felt like I was watching the world through a distorted lens, objects looked like they were moving or floating a little, and also while talking to another

person, I knew they were real, but felt I was imagining them or watching them through a weird screen.

Time and time again, users describe perceptions of being confined to an alien landscape. Metaphors about being trapped, stuck or imprisoned were used to describe withdrawal. One anonymous user describes benzodiazepine withdrawal as “like being locked in jail . . . and having the jailer walk by rattling his keys” or “like being a prisoner in a sick brain.” Another person said it was as if other people “lived in a different world and we were separated by a transparent screen with distortions in it . . . weird and scary.” Above all, users describe the “benzo” state and withdrawal as a strange, isolating experience; “It was like I was speaking a different language whenever I tried to speak about it to anyone.” The moment-to-moment awareness of one’s own suffering and the “endless looping existential intrusive thought(s)” accompanying benzodiazepine withdrawal can create an on-going existential distress. As one user expresses it; “what is the meaning in all this suffering . . . I am stretched to my limit with this ongoing trauma. Really struggling to see any possible silver lining.”

Physical distress

Symptoms of benzodiazepine withdrawal can be physically as well as psychologically painful or distressing; e.g. “vision went wacky again yesterday which scares me” ; “I’m extremely weak, chills, sweats, bodily pains (following Xanax withdrawal).” The physical sensations accompanying withdrawal are compared to forms of torture or hell, and metaphors used to describe them include acute burning, wildfire, acid, electricity, knifelike pain, crushing and so on; e.g. “excruciating burning sensations

in all the muscles of my body. Sometimes I just STAND STILL AND BURN!" ; "gas, pain and diarrhea . . . electric feeling in my heart and every beat was amplified torture . . . I was too ill to stand . . . agony."

Acute and heightened sensitivity to outside stimuli and events is a well-documented feature of benzodiazepine withdrawal; "The slightest stress . . . can easily throw me into confusion and ramp up sxs [symptoms]. We are just very sensitive right now." Many users experience a profound state of exhaustion, often linked to chronic insomnia, one describing it as a "mean beast accompanying benzo withdrawal."

Anger and remorse

Even though users can feel completely immersed in their psychological and physical suffering, a sense of their experience being chemically induced and shared by others can help people to maintain to sense of selfhood separate and distinct from their harrowing experiences. On Internet blogs, people use expressions such as having a "chemical lobotomy," and a "poisonous little whore of a pill" to describe the overpowering effect of benzodiazepines. Benzodiazepine users on Internet posts frequently express remorse at taking the pills in the first place, but also direct disappointment and anger at the professionals who they feel have failed them e.g., "Why does nothing happen to the psychiatrists who mis-prescribe these drugs indefinitely and who give no indication that the drugs are addictive? I don't think anything could be done. Are there any standards or rules against it?"

Waves and windows

Jumping from (finally stopping) benzodiazepines is rarely the end of the story. Emerging from benzodiazepine withdrawal can be a slow and uneven process, with ups and downs following every dose reduction. The drawn-out nature of a "safe taper" (reducing medication very gradually) can feel tedious and difficult for users:

> I'm 10 months out from a horrific c/t (cold turkey) w/d (withdrawal). I constantly (like ALL day) contemplate life, my existence, my death, generations that have been before . . . These thoughts make me shake and consume me with fear . . . Do they really ever stop?

Classically, there is a "roller coaster" quality to withdrawal, with exacerbations (waves) and ameliorations (windows) occurring apparently randomly, mimicking or exaggerating an individual's pre-existing conditions. As they cycle between hope and hopelessness, people in withdrawal use blogs and discussion threads to share and discuss the existential questions concerning their suffering and the feasibility of "100% healing." Questions such as "will I ever be my old self again?" are met by reassurances that "healing does happen!!" yet symptoms can take months or years to completely abate.

Healing

During the difficult process of recovery, Internet users offer each other support, encouragement and self-help tips; "Listen to your body and adjust your taper rate to suit your individual tolerance. Learn non-drug techniques to help you deal with your underlying issues . . . meditation, yoga etc." One coping strategy is to accept the on-going suffering and to have faith that; "HEALING DOES HAPPEN . . . That's the

words you need to have Faith with." Users and ex-users urge each to "keep in mind the real healing comes after you jump, when you are no longer feeding the beast." Those who do make it through the withdrawal journey, and "turn their backs on the pills" often express a sense of triumph, and feel compelled to share their successful, and at times heroically constructed story with others. Going cold turkey (c/t) or quitting benzodiazepines abruptly can be dangerous, and is not recommended (NICE, 2013). Internet posts on cold turkey suggest that plenty of users (through ignorance, poor advice or choice), have stopped in this way, yet the sheer hell of surviving a "c/t" can attract some online admiration; "To my c/t warriors!!! You are my heroes. This is the hardest test- this is walking through fire. And we're DOING IT!!! " Nevertheless, quitting benzodiazepines can prove too difficult for users; "Failed on my last taper because I underestimated how difficult it would be. I also was hospitalized when I tried cold turkey."

Renewal

Inevitably, many people in recovery wish to put their troubling experiences behind them and stop posting on support forums. Other people remain active members or become site moderators, using their acquired understanding to reassure, educate and inspire new and existing members. Those who do succeed and go through recovery write encouraging messages to others not to give up hope, even if they need more than one attempt at withdrawal: "This was my third time trying to get off . . . you can always try again." Success stories from beyond withdrawal spread the hopeful message that life after "benzos" can be better than ever; "It has been 22 months and I'm like new." After the numbing and disturbing effects of benzodiazepines, recovery or "healing" can be a deep experience, likened to a spiritual rebirth by some;

“Yesterday . . . was my first benzo free day in over six years! A time of rebirth!!! . . . Wish me luck. I'm on my way.”

Discussion

People who post on YouTube or benzodiazepine support sites represent a small proportion of benzodiazepine users worldwide. What users have to say about their experiences however is of considerable importance to researchers and practitioners wishing to understand benzodiazepine withdrawal. As with other experiences outside the “normal” frame of reference, the distress associated with benzodiazepine withdrawal may be impossible to fully describe or imagine, even with the use of metaphors, unless it has been experienced for oneself (Johns, 2012; Hobson-Dupont 2006). We identified seven major themes of user stories: hell and isolation; anxiety and depression; alienation; physical distress; anger and remorse; waves and windows; and healing and renewal. From these accounts we interpret the “essence” of benzodiazepine withdrawal as feeling stuck, trapped or imprisoned in a hell-like dimension, separated from the “normal world” and people around you. More of a roller coaster than a state, benzodiazepine withdrawal is punctuated by symptom changes and fluctuations that can test the sufferer on a daily basis. Nevertheless, there are increasing glimpses of wellbeing as withdrawal progresses. As such, a common online model for user withdrawal involves users trying to step out of their experience and look at it for what it is, that symptoms are chemically induced; that withdrawal is hard, isolating and can be prolonged; but that others have been through this “walk through fire” and are there to encourage and support you. Healing and recovery is portrayed as a gradual process, but with it can come a sense of achievement and even rebirth.

To check the validity of our interpretations we cross referenced and compared these Internet accounts with professional accounts (Ashton, 1991, 2005; Lader, Tylee, & Donoghue, 2009; Reconnexion, 2010). We believe our definition of "benzo distress" and recovery encompasses what many users describe as central to their experiences. Not all users experience symptoms and for some withdrawal symptoms are mild or short lived. Those who suffer most are often long term users or users who stop benzodiazepines abruptly. Those posting stories are more likely to have experienced particularly disconcerting symptoms, while a high percentage of users fail to complete the first taper or reinstate (restart) benzodiazepine use after doing so (Pittman et al., 2013).

The role of benzodiazepine support forums and videos

On-line health support groups are part of a growing body of lay communication systems, which challenge the former hegemony of expert-based information systems. Their positive impact on healthcare has been widely examined (Berger, Wagner, & Baker, 2005; Broom, 2005; Ziebland et al., 2004), including as a source of lay knowledge (Broom, 2005; Hardey, 1999) in relation to patient empowerment (Mo & Coulson, 2014; van Uden-Kraan et al., 2008). Their relationship with the mainstream medical establishment is complex as some forums and blogs offer information which could be viewed as inaccurate, risky or subversive (Gavin, Rodham, & Poyer, 2008; Mo & Coulson, 2014). The reliability of YouTube as an information source been questioned (Morahan-Martin, 2004) and some of the videos on benzodiazepine withdrawal are particularly disturbing and frightening[1] [2] ,

[1] https://www.youtube.com/watch?v=uDbPnAQ-c1o&t=2s
[2] https://www.youtube.com/watch?v=MlA-qMeyJFw

Our study indicates that during and after benzodiazepine withdrawal, people turn to forums and seek reassurance, advice and support from other users, sometimes in a state of extreme distress and anxiety. Becoming dependent on benzodiazepines can impact significantly on a persons' life, including distorting the persons' view of themselves. Studies of drug users suggest that people reconstruct self-identity as they move from being drug-dependent to being drug-free (Redden et al., 2013). Long-term users, or anyone experiencing problems coming off "benzos" may find it hard to imagine an identity beyond the drugs, and like other marginalized groups may feel stigmatized and unable to articulate their particular needs and concerns within the dominant medical culture (Orbe, 1998). Despite their limitations, Internet sites like YouTube provide users with an alternative forum from which they can express their particular form of distress, exchange stories and tips, and celebrate their success with others. In a society that broadly disapproves of drug dependence, benzodiazepine users can, via their virtual platforms make contact with a global "benzo" community and share stories with sympathetic others who may be in a position to advise and support them or to learn from them (Fixsen, 2015). Those who recover can hold themselves up as real life examples or role models for other users, potentially extending our understanding of psychophysical distress and healing (Spermon, Darlington, & Gibney, 2013). By communicating their stories, benzodiazepine users give meaning and legitimacy to their world-view (Frank, 2013) and in the process promote better social recognition of their suffering. In this way, isolated individuals find a "shared voice," and language and can benefit from a sense of belonging to a peer (co-) community (Lin & Huang, 2013).

Despite general warnings from the medical and other professions and drug regulatory bodies that long-term use is unjustified both in terms of efficacy and the

risks of long-term usage including dependence, long-term prescription of benzodiazepines continue (Ford et al., 2014). Unlike most studies of side and withdrawal effects, we have made no distinction in distinction in our analysis between prescribed and illicit use, as our interest lies with the lived experience of benzodiazepine withdrawal. This is not to suggest that the two groups of users do not face distinct psychosocial issues, but to reinforce the unavoidable embodied and mental nature of benzodiazepine withdrawal for all those who must go through it. As our study suggests, the distress associated with benzodiazepine dependence and withdrawal can be considerable and is regularly underestimated by practitioners who prescribe them (Sirdifield et al., 2013). Clinical studies suggest that people who taper slowly and receive psychological support are more likely to succeed in stopping benzodiazepines for good (Ashton, 2005; Morin et al., 2004), yet specialized NHS support for benzodiazepine withdrawal remains minimal, with local support groups struggling for adequate funding (APPGITA, 2014). In the absence of easily accessible, free or affordable withdrawal and recovery programs it seems likely that people will continue to turn to Internet forums for reassurance, advice and support during and after withdrawal.

Conclusions

In this article, we have drawn on patient narratives in the literature and on Internet sites to interpret the nature of benzodiazepine withdrawal, and the distress accompanying it, from the user perspective. The experience of benzodiazepine withdrawal is uniquely personal yet shared with a global community. The results in this paper can only represent a proportion of benzodiazepine user stories and experiences. We have focused on the imagery and metaphorical interpretations of

withdrawal, as brought to life through text and spoken word, to interpret the collective experience of benzodiazepine distress and recovery. Our findings indicate that benzodiazepine withdrawal can, according to many user accounts, be a harrowing and distressing experience, that can feel alien, hellish and unending to the sufferer. As an all-encompassing yet socially invisible experience, it is made socially real through Internet forums.

There are a number of limitations to our study. The amount of narrative information on benzodiazepine discontinuation posted on the Internet is immense and we were able to examine only a selection of this material. In addition, our methodology was qualitative and interpretative, thus any conclusions we make are offered tentatively. Further, broader studies of user accounts are required which provide insights into what it is like to undertake and complete benzodiazepine withdrawal.

We believe, nevertheless, that exploring user metaphors in this way has allowed us to examine “benzo” withdrawal and recovery from a user-centred perspective, which can complement existing professional models of BZ discontinuation (Ashton, 2005; Ford et al., 2014; Reconnexion, 2010); help to distinguish these phenomena from other psychologically and drug induced states, withdrawal or syndromes, and is therefore of considerable value to practitioners and researchers. Importantly, models arising directly from consumer/patient experience have the potential to influence and change attitudes to complex medico-social problems and can lead to the introduction of new treatments and support strategies that align more closely with the experiences and day to day needs of the cohort under consideration.

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