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**‘I’m Not Waving, I’m Drowning’: An Autoethnographical
Exploration of Biographical Disruption and Reconstruction
During Recovery From Prescribed Benzodiazepine Use**

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Abstract

Benzodiazepines are group of drugs used mainly as sedatives, hypnotics, muscle relaxants and anti-epileptics. Tapering off benzodiazepines is, for some users, a painful, traumatic and protracted process. In this article I use an autoethnographic approach, adopting the metaphor of water, to examine heuristically my experience of iatrogenic illness and recovery. I draw on personal journals and blog entries and former users' narratives to consider the particular form of biographical disruption associated with benzodiazepines and the processes involved in identity reconstruction. I emphasize the role of the online community in providing benzodiazepine users such as myself with a co-cultural community through which to share a voice and make sense of our experiences. I explain how the success stories of former users provided me with the hope that I, the "medical victim", could become the "victor" and in the process construct a new life and fresh identity.

Keywords

Autoethnography; diaries/journals; healing; recovery; self-help; social identity; stories/storytelling

Prelude

It began with a dream. It was simply this; I was staring at the closed eyes of a childlike figure submerged under water. I tried to reach out to save it but my fingers could not grasp the body. When I awoke it was with the sense that something terrible could happen. It was the water that revived me though. Nine months later I was lying face up to the sky in a warm sea. It was my first “trip” away since my iatrogenic illness, and my first experience of something other than painful physical sensations. For a few moments I reconnected with the external world and with life itself. Recently I had another dream. It was a moonlit night and I was on the clifftops watching the crashing waves below. There was a sense of danger, but I was not afraid. I am no longer the captive; I have escaped from my watery grave.

In this article I explore my own and others’ experiences of medically prescribed benzodiazepine dependence, withdrawal and recovery. Using the metaphor of water I analyze my personal journals, and blog entries, and narratives of former users, to construct a heuristic theoretical framework of recovery from what is a medically induced mental and physical condition. I examine the particular form of biographical disruption (Bury, 1982) associated

with benzodiazepine dependency, and the process of identity reconstruction and empowerment which can arise from a “successful” taper. I consider the various strategies and mechanisms offering hope and support during the lengthy and often frightening process of drug withdrawal; in particular the validation and sharing of experiences and narratives with others. Finally, I adopt the concept of the “muted group” (Ardener, 1975; Orbe 1996), in this case benzodiazepine users and ex- users, to examine the co-cultural language and symbols employed to provide a “shared voice” and make sense of user realities (Ardener, 1975; Orbe 1996).

Literature review

If any drug over time is going to just rob you of your identity [leading to] long, long-term disaster, it has to be benzodiazepines. Dr John Marsden, Institute of Psychiatry: London, 2007.

In this section I review the literature on benzodiazepines and withdrawal, which falls largely into three categories: medical research studies, sociocultural and media reports, and former users’ autobiographical and self-help literature. In the six decades since the discovery of benzodiazepines, numerous medical articles and clinical trials have recorded their effects, yet only a handful of studies examine the withdrawal experience from patients’ perspectives. By focusing on withdrawal from the users’ viewpoint, I aim to give voice to the largely silent and geographically dispersed group of people who have experienced - or are experiencing- the effects of benzodiazepine withdrawal. Although this article focuses primarily on withdrawal from prescribed use of benzodiazepines, the highly physiological symptoms of benzodiazepine withdrawal syndrome are similar for both clinically prescribed and illicit users, and I do not attempt to distinguish between these two groups in terms of symptoms. In

keeping with the phraseology of benzodiazepine users, I use the term “withdrawal” rather than the more recent medical term “discontinuation” in the article.

Benzodiazepines are a group of structurally related drugs used mainly as sedatives/hypnotics, muscle relaxants and anti-epileptics (Reed et al., 2011), which directly or indirectly affect virtually every aspect of brain function (Ashton, 2002, p. 7). Gamma-Amino Butyric Acid (GABA) is the main inhibitory neurotransmitter in humans. Benzodiazepines calm and sedate brain and nerve function by acting through specific GABA_A receptors, potentially hijacking the mesolimbic reward system (Tan, Rudolph, & Lüscher, 2011). Tolerance of and physiological dependency on benzodiazepines can develop rapidly, leading to an array of withdrawal symptoms, which include depression, depersonalization, anxiety, suicidal ideation, aggression, agoraphobia, muscle pain, and kinetic and perceptual disturbances (Ashton, 2005; Lader, 2012)

Despite repeated recommendations and guidelines to limit use to two to four weeks, benzodiazepines are still widely prescribed for chronic conditions (Witton et al., 2011). This is largely because of their rapid efficacy, relatively mild side effects, and the lack of comparable alternative medications (Cloos & Ferreira, 2009). Prescriptions for benzodiazepines in Europe have only marginally reduced in the last decade (Rosman, Le Vaillant, & Pelletier-Fleury, 2011), while in United States they increased by 12.5% between 2002 and 2009 (Science Daily, 2014). Short-term benefits are often rapidly offset by physiological dependence, which can develop within a matter of weeks (Lader, 2011). By far the majority of benzodiazepine-dependent patients are long-term users who have unintentionally become dependent after regular repeat prescriptions (Ashton, 2005). Once dependency occurs, withdrawal can be a protracted and distressing process (Ashton, 2005; Lader, 2012; Spiegel & Bruce, 1997).

Benzodiazepines are known to cause over-sedation, reduced coordination, cognitive impairment (Barker, Greenwood, Jackson, & Crowe, 2004), increased risk of accidents and development of dependence (Lader & Petursson, 1981; Lader, 2012). The user's judgment, insight, memory, perceptions, and ability to plan are frequently impaired (Lader, 2012). Long-term users of benzodiazepines often develop new symptoms while taking the drugs, many of which mimic mental health problems. These include dysphoria, depersonalization, malaise, dizziness, anxiety, mood swings, suicidal ideation, agoraphobia, muscle pain, parasthesia and perceptual disturbances (Ashton, 2005; Lader, 2012). In one study, nearly a third of long-term users (more than one year) were diagnosed with depression and between a third and half reported a current physical illness (Rodrigo, King, & Williams, 1988; Zandstra et al., 2004). Prenatal exposure to benzodiazepines led to subsequent dysmorphic features in the children of users, including cleft palate and mild to severe mental retardation (Oberlander et al., 2008; Viggedal et al., 1993). Long-term effects of these drugs are still being revealed, but include reduced cognitive performance persisting well beyond cessation (Barker et al., 2004) and increased risk of dementia in the elderly (Billioti de Gage, Begaud, Bazin, & Al., 2012). A high proportion of benzodiazepine users are older than 65 (Petitjean, Ladewig, Meier, Amrein, & Wiesbeck, 2007), which makes cognitive function of particular concern.

Trying to tapering off benzodiazepines can be a painful, traumatic and protracted process (Lader, 2012). Unsurprisingly, the relapse rate is substantial (Morin, B elanger, Bastien, & Valli eres, 2005). Unpleasant physical and psychological symptoms (muscle pain, depression, anxiety etc.) are frequently experienced, sometimes for months or years after quitting benzodiazepines (Barker et al., 2004). While many of these symptoms mirror those of extreme anxiety, others such as perceptual disturbances and extreme light and noise sensitivity are more specific to benzodiazepine withdrawal. Even so, patients who do withdrawal successfully report significant improvements in health and wellbeing after doing

so (Ashton, 2005; Vikander, Koechling, Borg, Tönne, & Hiltunen, 2010). Strategies for cessation are expected to start with primary-care practitioners, who are the main prescribers (Lader, Tylee, & Donoghue, 2009); many, however, are ill prepared for this role. In Pittman et al.'s user study (2013), less than 20% of users were forewarned by their GP or psychiatrist that benzodiazepines were addictive. In general, GPs lack the expertise and time required to withdraw long-term prescribed patients from benzodiazepines (Ashton, 2011), while prescribed patients are usually denied access to secondary health care services offered to abusers of hard drugs.

The bizarre and often prolonged nature of benzodiazepine withdrawal symptoms has led to decades of debate and misunderstanding concerning their authenticity. Common withdrawal symptoms include anxiety, depression, panic, insomnia, hallucinations, hypersensitivity, suicidal thoughts, tachycardia, agitation, muscle tension, tremor and tinnitus, although the full list is far more extensive (Busto et al., 1986; Lader, 2012; Olajide & Lader, 1984). The reported incidence of withdrawal symptoms varies from around 30% to 100% (Ashton, 2005; Rickels, Schweizer, Case, & Greenblatt, 1990), although a World Health Organization (WHO) report urges that such statistics be read with caution, because they could include false or exaggerated withdrawal symptoms (WHO, 1996). Published and online users' stories often portray truly horrifying accounts of withdrawal, particularly where it is immediate ("cold turkey") or rapid (Gordon, 1978; Kellagher, 2006; Johns, 2012; Samet, 2013). Clinical and user studies report cases of protracted benzodiazepine withdrawal syndrome lasting for several years (Lader, 2012). More than 50% of participants declined to participate in, or dropped out of, withdrawal studies (Ashton, 2005). This symptom complex was reported in users with no psychiatric history, for instance when the drug had been prescribed for back pain (Pittman, Youngs, & Karle, 2013).

Speaking on a BBC radio interview and without distinguishing between medically prescribed and illicit users, leading expert Prof. Lader declared it ‘more difficult to withdraw users from benzodiazepines than it is from heroin’ (BBC Radio 4, 1999). Severity of withdrawal has been associated with prolonged or high-dose use and short-acting potent benzodiazepines, although this is not necessarily the case (Ashton, 2005). Ashton points out that a proportion of long-term benzodiazepine users can withdraw with few ill effects (2005). Nevertheless, in one of the few user studies, long-term medical users disliked taking the drugs but feared withdrawal, regarding continued use as “an evil necessity” (Gabe & Lipshitz-Phillips, 1982).

Because of the potential severity of withdrawal, individuals who wish to discontinue benzodiazepines are advised to do so gradually and incrementally (American Psychiatric Association, 1998, Ashton, 2005; Lader et al., 2009; NICE, 2013). “Cold turkey” or rapid withdrawal can lead to fevers, acute psychotic states, seizures and even death (Ashton, 2005; Hu, 2011). Rapid detoxification in medical settings is rarely recommended and often requires the use of adjunct medication (Gerra et al., 2002). Most users are encouraged to undertake a steady taper in their own homes (Ashton, 2005) over a period of weeks, months or years, depending on dose and length of use (Ashton, 2002; Bristol and District Tranquilliser Project, 2013). If carefully managed and with adequate psychological support in motivated patients, the success rate for stopping benzodiazepines can be good (Ashton, 2005; Voshaar, Couvée, van Balkom, Mulder, & Zitman, 2006; Voshaar, Gorgels, et al., 2006). Shorter-acting benzodiazepines such as alprazolam, oxazepam and lorazepam are reputed to have more immediate and aggressive withdrawal symptoms (Ashton, 2005). Users are generally encouraged to switch over to an equivalent dose of diazepam and slowly taper off from this (Ashton, 2005).

Personal and Sociocultural Perspectives

Studies of recovery from serious illness or trauma highlight the importance of considering the subjective experiences of individuals coping with and recovering from their problems (Frank, 2013). Published autobiographical narratives and interviews of “survivors” of benzodiazepine withdrawal can make dramatic and sometimes terrifying reading (Gordon, 1978; Hobson-Dupont, 2006; Johns, 2012; Samet, 2013). Johns describes the acute stage withdrawal, where “every part of my body hurt, tingled, burned, twitched”, followed by an alternating pattern of “waves” (exacerbation of symptoms) and “windows” (alleviation of symptoms), which went on for years (Johns, 2012). In a media interview recalling her experiences of withdrawal, singer Stevie Nicks describes her 45-day hospital “detox” from Klonopin as if “somebody opened up a door and pushed me into hell ”(Johnson, 2009). Hobson-Dupont recalls his slow taper as “emerging from a long, strange dream, having inhabited for so long a time a grotesque nightmare world I could never have thought possible in my darkest imaginings” (p. 218). Samet tells of being “driven to madness by withdrawal . . . all the while being told the insanity was my own” (Samet, 2013; p.7). He describes his withdrawal as being in a social vacuum, affecting not only his personality but also his entire “social interface” (Samet, 2014).

People in the media can glamorize drug addiction and withdrawal, but individuals who are dependent on prescription drugs face many difficulties, including feeling cut off from “normal” society (Thompson, Rew, Barczyk, McCoy, & Mi-Sedhi, 2009). The addiction profile associated with drug dependence and the mental health symptoms accompanying withdrawal can result in perceived and actual stigma (Anthony, 1993). Patients can be regarded as neurotic malingerers by their GPs [BBC, 2011] or be might be deprived of opportunities for self-determination and employment (benzo.org.uk; Hobson-Dupont, 2006; Johns, 2012). Benzodiazepine users, I contend, are a social group without influence or voice; or a “muted group.”

Developing out of cultural anthropology, “muted group” theory describes the unequal

communication and social representation patterns of groups within society. Because of the privileges enjoyed by dominant groups (Ardener, 1975), the voices, opinions and experiences of non-dominant groups are muted and remain segregated from mainstream society. Known predominantly for its use as a feminist critique on male domination including avenues of communication (Kramrae, 1981), muted group theory has been extended to other non-dominant groups (Orbe, 1996), but so far not to medically defined groups. Orbe's co-cultural communication theoretical model focuses on how people traditionally marginalized in society communicate within dominant societal structures. He uses the term co-culture to avoid the negative or inferior connotations of descriptive terms such as subculture for groups whose experiences are often made invisible by the pervasiveness of the dominant culture.

Peer-to-peer electronic support groups (ESGs) are now a ubiquitous feature of illness experience, although the appropriate theory and method through which to explore them remain contested (Ziebland & Wyke, 2012). Studies suggest that ESGs not only offer people opportunities to exchange information and help them take some control of their illness (Broom, 2005), but also encourage people to share their stories and experiences (Ziebland & Wyke, 2012), which might be particularly important for those with illnesses that are socially or medically contested (Bülow, 2004) or stigmatized (Berger, Wagner, & Baker, 2005).

ESGs are widely used by benzodiazepine users and ex-users, and their families. In this article I examine my own personal experience of being an active member of an online benzodiazepine forum. I suggest that support forums can not only empower individuals through the provision of information (Broom, 2005; Barker, 2008; Hobson-Dupont, 2006) but hold the potential to create a "virtual community" which, by sharing user stories, can instill hope and engender a sense of heroism into what is otherwise a largely frightening and lonely experience.

Method

Used in a variety of disciplines including education, psychology and anthropology, autoethnography is a particular form of critical narrative enquiry that entails the practitioner undertaking narrative analysis concerning a particular phenomenon (Mcilveen & Queensland, 2008). There are variations to the autoethnographic approach (Wall, 2006); for the purposes of this research I interpret autoethnography as a means of personal and sociocultural inquiry, linking my own experience of benzodiazepine use and withdrawal to information and concepts derived from sociological, medical and self-help literature. The autoethnographic approach has been criticized for its introspection, self-indulgence and lack of scientific or social perspective (Holt, 2003; Wall, 2008). Evocative personal writing can be seen as relying too heavily on the emotional response of the reader, rather than offering objective analysis and methodical rigor (Duncan, 2004; Wall, 2008). I would argue emotions are an integral part of human experience, just as passion is a motivating force driving the commitment required in research (Polanyi, 1967). I see expressive language as a way of articulating experiences of phenomena generally assigned clinical diagnostic terms (such as social anxiety syndrome and depersonalization). In addition I employ metaphor as a vehicle for the interpretation of the inner world of feeling. Metaphor is a form of comparative imagery (Anderson, Bresnahan, & DeAngelis, 2014) that can convey meanings that plain language fails to do, thus capturing the essence of an experience in a concise and memorable package (Lawley & Tompkins, 2001). An established part of many healing traditions (Witztum, Hart, & Friedman, 1988), when used to describe illness and trauma, metaphor can create an abstract world, separate but related to the “ordinary” world (Winslow, 2004).

There are few set rules concerning the framing of an autoethnographic narrative analysis, because the meaning of the story is seen as more important than particular conventions of scholarly production (Mcilveen & Queensland, 2008). To structure the various stages of my analysis I used the heuristic method first developed by Moustakas

(1990). This method, described as “psychologically applied” heuristics (Sela-Smith 2002), invites the conscious, investigating self to surrender to the feelings in an experience, carrying the researcher to unknown aspects of self not normally known in the waking state of consciousness (Sela-Smith, 2002). The heuristic methodology developed by Moustakas has been described as a form of autoethnography (Wall, 2006); I would argue that its uses are broader than this. As an explorative method, heuristic inquiry has a long history in philosophy and natural sciences, and more recently has been used in certain branches of psychology, anthropology and sociology. Heuristics are a means of accessing deeply embedded or tacit knowledge (Polanyi, 1966) of any chosen phenomenon not normally available to our conscious awareness (Moustakas, 1990; Sela-Smith, 2002). While personal experience might be the research focus (Sela-Smith 2002), the interpretation can be of situations and experiences in which one was neither a first-hand participant nor an observer (Fixsen & Ridge, 2012). Nevertheless, the heuristic researcher does not shy away from their involvement with the research subjects and fully acknowledges the personal subjective exploration of phenomena (West, 2001).

Although a subjective process, heuristic inquiry is also focused and disciplined (West, 2001). A six-stage approach is suggested to guide unfolding investigations and inform research design: initial engagement; immersion in the topic; incubation; illumination; explication; and culmination of research into a creative synthesis (Moustakas, 1990). The process of engagement involves clarifying what it is I want to research, which might also involve formulating a question or hypothesis. While most researchers formulate some question, Moustakas regards the process as one of self-dialogue and inner searching, which should not be hurried (West, 2001). In heuristic research, one is creating a picture that portrays the qualities, meanings and essences of unique experiences (Moustakas, 1990, p.13), and as such it is an excellent method for developing insights and new theory concerning the

phenomena under investigation. As the researcher consciously searches for and surrenders to the feelings of the experience, new understanding arises, resulting in self-transformation, with social and transpersonal implications (Moustakas, 1990, p.15). Following this method will encourage me to make best use of my emotional and cognitive learning throughout and subsequent to the research process.

Data Collection and Analysis

My personal journals, emails and blogs composed at the time of benzodiazepine use comprise most of the raw data for this study. For 18 months, the effects of “benzos” and withdrawal from them became the daily focus on my life. Generally a reluctant journal writer, during withdrawal I felt compelled to write extensively about my experiences, although I sometimes censored my expressions for fear of discovery. I note that a number of pages that recorded my more acute moments of pain have been torn out. Once I began to recover, my writing grew bolder. Not only did I write more candidly, I blogged and conversed online with other benzodiazepine users daily. All these conversations have been archived, and provide a rich source of data on withdrawal. For ethical and confidentiality reasons I have used only my own blog entries for this study.

Ethical Issues

There are a number of published stories written by benzodiazepine users about their withdrawal experiences. I have studied these accounts both for personal interest and research purposes, and include extracts and examples to illustrate themes and for comparison. There are also numerous videoed accounts of benzodiazepine withdrawal available on the Internet, but I have excluded these and draw only on published literature. While I have little doubt of the reliability of most stories, there are potential consent issues, and I am mindful that some users might not wish their private worlds discussed for research purposes, even anonymously.

Like me, they may have entered a different phase in their lives by now, and wish to put the past behind them.

The ethics of using autoethnography to convey the “messiness” of personal trauma have also been questioned (Tamas, 2009). Personal narratives that describe traumatic or catastrophic events can be viewed as a type of self-therapy, or even catharsis (Riordan, 1996; Ullrich & Lutgendorph, 2002). Whether or not this proves to be the case is not the main focus of this article. The self-revelatory nature of this research has at times led me to question the advisability of this process. It takes courage to write an honest account of your weakest and darkest moments, and to cast it to one’s potential critics (Smith, 1999). I am however deeply grateful for the opportunity of adding to the “collective story” (Smith, 1999) of psychotropic drug withdrawal and recovery, in what I hope is a constructive and considered way, and with the critical support of experienced research mentors and colleagues.

Personal Narrative

Falling

April 2013. Journal entry: ‘DIARY OF A SOMEBODY.’ This is my journey through the foggy places that drugs can take you. I am three months into withdrawal from diazepam, and experiencing the odd glimmer of hope every so often. Karma (Sanskrit=karma) is what takes us to where we are, but how those experiences shape us and how we deal with them can make the difference. I began by losing myself after an acute psychoneurological drug reaction to the antibiotic clarithromycin . . . I had no idea I was about to fall off a cliff . . .

The routes to benzodiazepine dependency are various. My introduction to benzodiazepines began with an extreme and prolonged reaction to the antibiotic clarithromycin in early

October 2012. After a busy, productive but stressful three months I came down with pneumonia-like influenza, for which the antibiotic was prescribed. Within one day of taking it I began to develop a strange nervous excitability, a racing pulse and strange leg pains. At first I was unable to distinguish between my viral illness and the new side effects, but on the third night I became acutely unwell. My main symptoms were catastrophic fear, tachycardia, insomnia, nightmares, depersonalization, burning and crawling skin, muscle twitches, nausea and constant urination. To my horror I realized that all these symptoms are listed as potential side effects to this antibiotic. By the fifth evening I was pacing the floor, weeping and wringing my hands. I contacted the GP who advised me to stop the drugs and reassured me that this would pass, but after a week there was still no change. In desperation I rang a private doctor who prescribed a short course of lorazepam.

As with other benzodiazepine users who have struggled with insomnia, anxiety or pain, the first doses of lorazepam brought a sense of sheer relief. There were no immediate side effects, indeed the pills were so small and pleasant tasting that, despite the warnings on the packet concerning the risk of dependency, it was hard to regard the drugs as anything other than benign. Desperate to ease my extreme symptoms, for the first month I clung to the drugs, at the same time recognizing them for the precarious lifejacket they were. After a month, the GP suggested I stop the lorazepam, and try zolpidem (a z-class drug) instead. Immediate withdrawal from benzodiazepines is never recommended, but in fairness to the doctor I was on a very small dose. The combination of withdrawal and sleeping pills put me in a hell-like state for 48 hours, after which I was frightened that I would end my life. Another GP suggested I switch to diazepam, which is considered easier to taper off (Ashton, 2002). Whereas lorazepam brought some peace for a few hours, the effects of diazepam were slow and insidious, and akin to being submerged in thick, grey mud. My physical processes slowed down, I developed amnesia and was generally unable to think. I regularly dreamt of

animals disappearing into grey mud, or being lost in thick fog. I woke with night terrors and with black shapes in front of my eyes.

Drowning

I have only painful and sad memories of those early months on diazepam. On the prescribed dose I was mentally disabled and in physical torpor, unable to function at all if I took a dose during the day. After 35 years avoiding alcohol and drugs I believed myself completely drug dependent. Yet the GP had been warned not to try reducing the pills yet, and I kept to my daily schedule.

May 2012. Blog entry: I find it boggling to think I survived the first few months of this illness. My mind was so disturbed that I was unable to do much at all and hardly went outside the village except for medical appointments. There was no imaginable future except being drugged up or dead. When my husband bought two packs of anything I would feel agitated that I probably wouldn't be around to use them. The idea of being normal again seemed impossible. At the same time as being beside myself with anxiety I was in deepest emotional pain. The pain was made worse by being unable to cry for days because of the effects of the diazepam. My only relief came from cooking for the family but there was no joy then, only perpetual misery. Life was agony. At times it still hurts but I know I am doing many of the things that were then impossible.

More urgent than my concerns about drug dependence was my fear of living with the constant gut-wrenching anxiety. Anxiety was no longer something from which I just suffered, it seemed to threaten my very existence.

December 2011. Journal entry: I don't see this as anxiety, it's more fundamental. Like the wires on my brain/nervous system have become twisted. The diazepam works for

the evening and night to some extent, but the time it works is getting less. At the same time I am more and more physically agitated.

My experiences of anxiety were twofold: strange and uncomfortable neurological symptoms (including palpitations, shaking, dizziness) and bizarre intrusive thoughts. Nighttime was the most terrifying, because along with the nightmares came suicidal imaginings. Even months into a slow and meticulous taper, anxiety was a frequent visitor:

May 2012. Journal entry: Shaking life a leaf inside. What has happened to the world I have built myself? Emotionally it is like being a teenager but without the good bits – all I want to do is cry half the time. I thought I was quite a mature human being once upon a time . . . I would like to sleep and wake with it all better, all sorted.

Locked In

There is ample evidence linking benzodiazepines to cognitive impairment. Side effects including amnesia, loss of balance, poor judgment, and inability to concentrate are all well documented. In addition there can be loss of interest, numbness and an inability to express normal emotions. While I could perform manual tasks such as cooking, I found it impossible to plan or make decisions. I could no longer relate to others which, combined with a total absence of joy or imaginative thought, led me to believe I must be autistic. Most bizarre of all to me was my complete inability to look other people in the eye, which made intimate social contact virtually unbearable. Simple visualization exercises (which I usually enjoy) became impossible, as did any form of hypnotherapy or progressive relaxation. I was a prisoner in a tortured mind and body, my only relief coming (along with memory loss, slurred speech and a headache) for an hour or so after a dose of diazepam. The payback came some hours later, when I woke in a state of doom-laden fear.

May 2012. Blog entry: My experience of switching over to Valium is that it is a real depressant and emotionally strangles you. I was screaming inside when I took 10mg for a while, but unable to connect with anyone at times. I couldn't read a book or watch a movie as it was like a foreign language and hence deeply disturbing. As I have reduced I am relieved to feel more normal emotion, and cry buckets (mostly poor me, this is misery, etc.).

June 2012. Blog entry: Our natural expressions have been and are being suppressed by this drug. This can be helpful in a crisis for a while, but our inner vital force/chi/energy is not able to throw off the symptoms it would if we were not being "gagged". We lose much of our REM sleep for instance. We are literally not ourselves.

During this time I was full of guilt and remorse at the change within and its effects on my family. I saw myself as a walking time bomb and was in constant fear of destroying myself and bringing shame on others. For once completely out of my depth, I placed my hope in the health professionals whom I had spent most of adult life avoiding. I religiously attended my weekly visits to my general practitioner, who listened with a mixture of concern and disappointment. Commenting on my lack of progress, he concluded that I was "treading water" and needed to take antidepressants. This message was reiterated by at least three other health professionals. Reading the possible side effects of a number of brands, I rationalized that, with my obvious drug sensitivity, this could be a quick route to a worse hell, and that what I needed to do was get off the benzodiazepines. The problem was I had no idea if my symptoms would improve or worsen should I do so. Nevertheless, after four months of continual use I began a slow and painful process of tapering off diazepam.

May 2012. Blog entry: I have learned to be suspicious of well-meaning medical advice I am offered because some of it has not proved helpful and may have prolonged or deepened the problem. The important thing is not to apportion blame or feel let down by those whose desire to save me short-term pain has backfired... At my last OH (occupational health) assessment I confessed my miserable state, assuming an understanding ear. The doc refused to acknowledge (that) my problems were predominantly drug induced. It made me quite outraged to be labeled with major depression.

The Lonely Struggle

March 2012. Journal entry: Physically feeling complete CRAP. Idea that I wouldn't get dependent was sheer ROT. Been on it merely months, and coming off even a little is HELL. Yes, I feel very unhappy. I feel I have lost my life, and could lose my job, everything. Some really heavy kamma (Sanskrit=kharma) came along. Absolutely wrapped up in the moment.

The early days of withdrawal were very tough. Despite the love and care of my family and close friends, I felt completely alone in my struggle, and in daily despair. When people told me I would get better I never believed them. I had no idea how to withdraw and made random erratic dose reductions, which undoubtedly increased the psychological and physical withdrawal symptoms. I looked into every alternative therapy, and consulted at least four different practitioners. Every day different withdrawal symptoms seemed to appear, sometimes disappearing hours afterwards. With every small cut in diazepam I experienced a new assortment of symptoms:

April 2013. Journal entry: Over 7 months of being ill, no wonder I'm fed up with it, sick to death in fact. Today I'm intolerant as new symptoms appear – or old ones reappear – facial twitching, pins and needles, palpitations, etc. A week into this new taper and it's tough.

Guidance and a measure of reassurance came from contacting a local tranquillizer project. Speaking about my experiences with someone who understood and whose advice I could generally trust was a blessed relief. The counselors' advice to "take your time" and "keep distracting yourself" was eminently sensible. Being told "it will be the most difficult thing you ever have to do," but "you will get through it" made me think I was possibly not the worthless wretch I had come to imagine myself. I etched their messages in my head and when courage failed me, repeated them over and again as a mantra.

June 2012. Blog entry: One of my lifelines has been a local tranquillizer support charity. The volunteers all have personal experience of benzo withdrawal, or supporting a loved one going through it. They are very understanding and also good at reassuring me that once I come off the drugs I will get my life back. They also said post-benzo recovery can take up to a year. At present that seems impossibly long but I know that these withdrawals make me impatient, anxious, even frantic at times.

I regard myself as an independent and fairly single-minded person, and drug-dependency never sat well with me. Seeing my old identity being stripped away was painful and humiliating. Up to this point all my energies had been consumed with getting through the day "successfully". The original reassurance from my doctor that I "was not an addictive personality" was no longer proving true, and the frustration of those around me that I was certainly no better was becoming more evident. "Can't you find someone to sort you out?"

was the articulated or implied sentiment of the bewildered friends and relatives who still bothered to call.

Anger and frustration can be destructive responses, but in the case of drug withdrawal might be more effective than acceptance and inertia. One day, in a fit of tears and frustration, I jumped into a car and drove into town. It proved to be a turning point. High on adrenalin after this breakout from my self-imposed imprisonment, I experienced an overdue revelation. If I was the one who must save myself, then I needed methods to cope with withdrawal. The urge to self destruct began to diminish and was replaced by a dogged determination to build on any small progress I perceived; shopping in the local supermarket, talking to the doctor without crying and so on. Normal distraction activities, such as watching TV, listening to music or visiting friends were too painful or stimulating, so I took to self-help techniques. I made a more regular attempt at meditation, cooked cakes for my local community center and, despite my exhaustion and bodily pains, tramped across the fields every day. I caught the first glimmers of spring after the barren coldness of that long winter, and believed that life without constant fear might be possible:

May 2012. Journal entry: At times, such as this morning, I can feel quite bright, energetic, and the (physical) pains are quite bearable. The changeability makes it bearable, but the unpredictability make the situation scary and feeds an obsessive worry about my health and wellbeing.

One particularly useful practice was the Emotional Freedom Technique (EFT) technique I learned from a YouTube video. Day after day I repeated the positive affirmations out loud, like a child warding off monsters. Following the advice of Johns (2013) I tried to dissociate the “withdrawal me” from other aspects of myself:

April 2012. Journal entry: The “withdrawal me” is like a child who is having a painful wound dressed. The “rational parent me” has to be one step ahead with clever distraction techniques. We just have to do whatever it takes to get us through and makes you feel better for a while.

The Raft

For the first four months into withdrawal I had been searching for a source of constructive support. At seven months I tried cognitive therapy, but my mental state was so changeable that keeping to any plan was impossible. My diary entries are a reminder of how anxious and preoccupied I was at this time and how distressing and changeable were my symptoms. Tapering “safely” proved to be a very slow, solitary and frightening process, while on the surface I attempted to live a “normal” life. One’s experience of normality can become distorted of course, when one’s main preoccupation for months and even years is the size and frequency of one’s drug reduction.

Still in the process of recovery, Hobson-Dupont (2006) felt compelled to describe his two-and-a-half year taper from high doses of prescribed benzodiazepines and the strange and myriad isolating physical and psychological withdrawal symptoms he coped with daily. Reading his unassuming and honest account of withdrawal (the first book I read in eight months) provided me with the right mix of humility and courage to reach out to others going through withdrawal. I joined a forum, started a blog and engaged in daily dialogue with my new friends. In our diminished worlds and feeling somewhat unlovable, we gave each other nurture. We were no longer mere medical victims and anxious neurotics, but anonymous heroes to one another by virtue of our ability to withstand suffering and express compassion to one another. We shared advice on “benzo-friendly” foods, supplements, self-help techniques, music and books, and rejoiced in one another’s achievements. The distinctions

between dependent, addict, short-term and long-term user were less important than our camaraderie and sharing of stories. Most important were our warnings to each other not to give up the fight, but to focus on the Holy Grail of healing and wellbeing described at length by ex-user pioneers in their blogs and books. These success stories were devoured, and I almost memorized the best parts. Initially I was reluctant to be in the club, and keen to get out as soon as possible, but discovered in the forum a pool of cognitive, emotional and practical resources that fed my daily need for hope. Many of the symptoms users were describing pointed to a common experience. At times I could hardly believe the pain some members had to endure, but it was very good to hear the success stories.

July 2012. Blog entry: I have learned so much since joining the forum. In particular I have learned about the resilience of the human spirit, and the generosity that others can display even through adversity. I love reading people's stories, especially the successes of course, but also the journeys that people have had. It is a humbling experience and I realize how fortunate I have been. For whatever reason, I am in a much more positive place than I was when I joined, even with all the tricky symptoms which play around with our minds and bodies as a result of these drugs.

As I came closer to my goal, my desire to share any relative successes with other users experiencing difficulties grew. I urged my anonymous friends to hang on in there, reminding them (and myself) that we are on the road to recovery.

August 2012. Discussion thread: As a more recent "benzo" dependent I know that these weird thoughts and emotions associated with drug use and withdrawal are not related to a personality disorder. Most people on the drugs are by definition highly sensitive and hence landed there in the first place! . . . So sorry you are having a tough time. This process seems to take forever but the key is a lot of patience and

courage. Take each day at a time. Tick them off. Stay focused on the goal. You can do it!!!

Back to the Surface

Benzodiazepines alter the basic chemistry of the brain; they, dull the senses, influence neurons in the body, and even populate the adipose tissues (Ashton, 2002). Withdrawing from these drugs is like a waking up, but as the senses come alive, the results can be disturbing and painful. Fortunately for me, the resurfacing of my imaginative self brought with it relief from the stark realities of withdrawal:

June 2012. Blog entry: As we come off the drugs paradoxical things happen. Our vital energy begins to spring back to life, and this is liberating. For me it happened gradually – first I could start to enjoy music, and recently I have been able to read novels. I remember the first time I really laughed at something funny again – how great it felt to see the lighter side of life! Since I got below 4 milligrams (of diazepam), I am also having some “normal” dreams, as opposed to all weird drug dreams. I can meditate again without feeling in such a fog. In that sense I know I am healing . . . I have taken to dreaming of things I will do when I am well, places I will go to, projects I will pursue. It doesn't really matter if some of these things do not happen.

Six months into withdrawal I plucked up the courage to drive to the seaside with a friend. At this point I was still swimming through mud, but with glimpses of the world out there. This experience proved to be an absolute tonic.

July 2013. Blog entry: How I love the sea and swimming in it! It made me feel good for the first time in 11 months. I even woke yesterday feeling quite upbeat . . . The

physical tension, pain and hypersensitivity are still there, but there is more brightness to the world. Now at least I feel more part of the world, and can . . . feel some peace.

I have painted a bleak picture of my medical care, but around this point I had a lucky break. To satisfy work requirements I visited yet another occupational health consultant. In the past this doctor had worked with many patients struggling to get off benzodiazepines and verified that my symptoms were common in withdrawal. His praise for my “sensible approach” to tapering was a huge morale booster. On the occasions I walk past his office to work I silently thank the good doctor for his vote of confidence in my recovery.

“Waves” and “Windows”

On my final “benzo” visit to the chemist, the pharmacist loudly queried if I was “still reducing”. I made an instant pact with myself that this prescription would be my last. Yet despite my tapering progress, I lived in dread of the “next cut”. Even a slight reduction could lead to waves of depression, hypersensitivity and pain. The trick was to taper very slowly, but that required precision and planning. Many of my online conversations now concerned withdrawal effects and the technical details of cutting and weighing increasingly minuscule fragments of pill.

August 2012. Blog entry: I have just dropped to 1mg. Also considering daily trituration but I feel I need the two-week holds to recover. For me it is no worse cutting now than from 7mg, just different. It’s always like jumping into the unknown. At the moment I feel and look more like my old self, but am very “revved up” at times. The best part is that my motivation to do things is much higher . . . the most tricky part has been emotional turmoil at times, and, now I near the end, believing I can survive this ordeal sans (without) the drug.

As the effects of the drugs wore thinner, waves of emotions flooded in. I grieved for my lost year, my fellow sufferers, for the loveliness and pain of life:

October 2013. iPhone note:

Sometimes life is like watching a beautiful film

But is a devastating film nonetheless

I've got the emotions of a mixed up teenager

I weep like a ragged child

It upsets me that I feel so damaged.

Rebirth and Reconstruction

As consciousness returned, so old motivations and skills began to reappear. I took on a short-term writing project to occupy myself and discovered to my relief that this mental work was enjoyable. I bought a dress and went to my first family lunch party, determined to reveal my still fragile but emerging self. After such an ordeal, going back to "old me" was never an option. I held on to the possibility of becoming a more vital and authentic version of myself. I wrote in my journal about being "so happy to be getting my brain back again!" To me it felt like "slowly opening your eyes. Every moment, every day is a rebirth. It's happening to everybody, but usually we don't notice."

August 2012. Discussion thread: One user who c/ted (cold turkeyed) told me it was like being reborn when he emerged from withdrawal after 18 months. That's too long for any human being to suffer, but I liked the imagery of a new and better start. Maybe our CNS (central nervous system) will grow extra strong and the old problems will die away.

I discovered that, for me, the key to self-reconstruction was to capitalize on any signs of improvement or happiness when I saw or felt them, and to ignore the nagging pains and voices telling me to doubt that I could change. I gained a sense of empowerment from willing myself to keep going forward, all the while carrying out my benzodiazepine taper plan with military precision. I wrote in a personal email that I was “clawing my way back. Reducing these drugs is the hardest but most empowering thing I have ever done. Miles to go yet, but I am optimistic (most of the time).”

Aftermath

After my “jump” from benzodiazepines I had one memorable experience. On the third “benzo-free” night I awoke audibly gasping for air, as if I had been holding my breath for a very long time. Otherwise, I felt a mixture of relief and anticlimax from passing the taper finish line. The long life of diazepam (compared to shorter-acting benzodiazepines) softens but also lengthens the withdrawal process. The general time for clearing the cells and tissues of diazepam is estimated at around three months, while recovery can take much longer. All I could do at this point was to wait and see if I would eventually “heal”.

November 2013. Discussion thread: It’s been nearly three weeks since I quit. I don’t miss the pills one bit but it would be nice to feel a bit more even. I’ve been working a lot, partly to keep my mind focused on factual stuff. Doing a lot of writing. Sleeping okay. Walking every day. Morning blues around 10am when I can’t see what’s what. Generally improves as day goes on. Then the shakes [come] in the evening. All very character building, ha ha. The good news is that it’s certainly not worse than tapering so far.

Some months later, I experienced feelings I recognized as happiness.

December 2013. Blog entry: Physical withdrawals are now pretty mild and only when I am overtired, ill or stressed. Mentally mostly good, for which I feel incredibly grateful. Of course there is so much trauma to get over, but I have also gained a lot of inner strength from this ordeal . . . I feel different from before all this happened but it's not all negative. My nervous system is still more sensitive but I can stop myself from getting worked up about things that used to bother me. I am more aware of my limitations, but at times my motivation is quite high. I don't cry that often and can appreciate beautiful things more.

Many times I have punched the sky with sheer elation, amazed at my lucky escape:

February 2014: iPhone note:

On a note of gratitude:

'I'm so f—g lucky . . . I so nearly disappeared for years into a series of drug-induced illnesses. I escaped with raw knuckles but a thankful heart.

Discussion

For my narrative I have adopted the metaphor of water to heuristically explore my “embodied experience” (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010) of iatrogenic illness and recovery, using the following headings to describe the sensations and direction of this process: falling, drowning, locked in, the lonely struggle, the raft, back to the surface, “waves” and “windows”, and rebirth and reconstruction. What I have described is a frank and distinctly personal account of prescribed benzodiazepine use and withdrawal. The severe psychoneurological reaction I suffered from clarithromycin was unusual, but not unique. In one study, 38 cases of clarithromycin-induced neurotoxicity were reported, with psychiatric disorders listed as the most common morbidity. Of these cases, 58% were treated with

benzodiazepines and neuroleptics in the acute phase (Bandettini Di Poggio, Anfosiso, Audenino, & Primavera, 2011). Most recorded cases will have been hospital admissions, so the true number of people experiencing these symptoms will be more. In my case, no doctor suggested that my original symptoms be reported, and the diagnosis on my medical records was “extreme anxiety and depression”.

My introductory experience of benzodiazepines might be unusual, but the physical and psychological difficulties of withdrawing from tranquilizers are not. An estimated 20% to 50% of benzodiazepine users experience problems withdrawing, and around a third describe their symptoms as very distressing (BBC Radio 4, 2011). Patients can feel physically ill and suffer bizarre symptoms such as extreme hypersensitivity to noise and light, or severe panic. In Pittman’s user survey, around 30% were unsuccessful in their first attempt to withdraw (Pittman et al., 2013), while in other studies this number was greater (Rickels, Case, Schweizer, Garcia-Espana, & Fridman, 1991).

Biographical Disruption

The term biographical disruption emanates from the chronic illness literature (Bury, 1982), but can be useful to describe more transitory states. From the users’ perspective benzodiazepine withdrawal, even when medically supervised, can be a biographically disruptive experience (Bury, 1982; Reeve et al., 2010). There are a number of factors leading to this “narrative disruption”. First, there are the strong sedating and inhibitory effects of the drugs themselves. Benzodiazepines are prescribed to “turn down the volume” of the mind and central nervous system. This, as I discovered, can be relieving for a while, but for me it soon became a physical and psychological straightjacket. One of the most personally disturbing aspects of dependency and withdrawal was being both unable to articulate my bizarre psychological and physical symptoms or to answer my carers and critics. Until I made contact with other users and ex-users, the experience of feeling psychologically “gagged “

was acutely painful. As one ex-user protests, it “wasn’t healthy to mute the world the way benzos do it” (Drugs-forum, 2014). Known as alexithymia, the inability to process or express emotion is a phenomenon reported in drug users and ex-users (El Rasheed, 2001; Lindsay & Ciarrochi, 2009). Lindsay and Ciarrochi found a lack of correspondence between perceived and clinical alexithymia in their study of newly abstinent substance users. Participants reported a lack of emotional processing which did not match their actual ability to process emotion in tests (Lindsay & Ciarrochi, 2009). In my case, I believed myself mentally and emotionally impaired because I lacked the right vocabulary to express the alien thoughts and feelings I was experiencing.

Second, benzodiazepine withdrawal is a strongly “embodied experience” (Reeve et al., 2010). Because of the insidious nature of benzodiazepines on GABA receptors throughout the body (Ashton, 2002; Hobson-Dupont, 2006), symptoms can appear almost anywhere. Many patients with physical withdrawal symptoms fear they are suffering from serious or chronic diseases (Ashton, 2002; Lader, 2012). During my months of withdrawal I attended or was requested to attend a series of urinary, uterine and neurological tests, based on my seemingly abnormal symptoms. All these symptoms diminished or disappeared with time. Thirdly, withdrawal does not follow a linear path; symptoms can appear and disappear in no particular sequence, both during and after a taper (Vikander, 2010). Exacerbation of withdrawal symptoms and ameliorations often occur in what users refer to as “waves” and “windows” respectively, and confusingly can mimic or exacerbate an individual’s pre-existing conditions.

My third point concerns the social isolation that often accompanies prescribed drug dependency and withdrawal. The muteness or “voicelessness” (Happ, 2000) of the involuntary drug dependent is a lonely experience, during which all aspects of selfhood are affected (Bologh, 1981). On top of withdrawal symptoms such as agoraphobia, derealization,

depression, hypersensitivity and fatigue preventing normal social participation, benzodiazepine users face the stigma of drug use and dependency within a society that is widely uninformed about and even hostile to such phenomena. Because of their psychoneurological nature, many withdrawal symptoms mirror those of anxiety (Aston, 1994, 2002), which can confound both patient and health professional. Because symptoms are mostly invisible, benzodiazepine withdrawal syndrome can be a contested “illness” (Barker, 2008), with some authorities expressing suspicions that clinical reports might be fabricated, imagined or exaggerated (Bobrow, 2003; WHO, 1996). Even among trained health practitioners I discovered a surprising lack of understanding about the problems of psychogenic drug withdrawal. Misunderstanding and fear of social stigma can, in turn, prevent sufferers from disclosing their problems or seeking help (Brooks, 2011).

Benzodiazepine users, I suggest, represent a muted group in a dominant society that broadly disapproves of drug dependence. This, along with the drawn-out nature of recovery, means that some individuals may need to take months or years off work, and not infrequently experience marital and family breakdown. While most people make a full recovery, a percentage will suffer protracted withdrawal (Ashton, 2002; Lader, 2012). In a few cases, particularly when a person has been on benzodiazepines for decades, or has withdrawn from several psychoactive drugs, withdrawal can lead to a state of “grave disability” (Rxisk, 2014), with sufferers seeking compensation through lengthy and expensive court cases (APPGITA, 2013; BBC Radio 4 1999, 2011; All Party Parliamentary Drugs Misuse Group, 2008).

In summary, benzodiazepine dependence and withdrawal can lead to profound biographical disruption (Bury, 1982; Reeve et al., 2010). Not surprisingly, those who find themselves dependent on minor tranquilizers can struggle to come to terms with their plight. Users refer to a “blighted life” because of the lack of affect produced by long-term use of the drug and their anger at what they see as faulty prescribing (Blay 2012). Published and online

narratives of former benzodiazepine users (Gordon, 1978; Hobson-DuPont, 2006, Johns, 2012; Samet, 2013) describe feelings of betrayal by medical experts to whom they originally turned for assistance. Hobson-DuPont questions how a medicinal product in widespread usage and reported by his MD to be “safe and effective” could have caused him to become so debilitated and addicted (p.34).

Support During Withdrawal

Not all users will have difficulties withdrawing from benzodiazepines. Some long-term users are simply resigned to taking their medicaments indefinitely, or view the prospect of withdrawal as unthinkable (Gabe & Lipshitz-Phillips, 1982). With increasing evidence of the problems associated with long- and even medium-term use, including brain damage and dementia, health care professionals are under pressure not only to reduce the number of benzodiazepine and z-drug prescriptions, but also to encourage most long-term users to discontinue. According to Kellagher (2006), an effective support system for people attempting to come off benzodiazepines should combine a gradual taper with an appropriate psychological container, comprising of information, encouragement and a belief in intrinsic health. Information is now far more available online, (for example the widely used Ashton Manual, 2002), but sustained psychological support is harder to access. Local support organizations offer on-the-ground support services and meetings, but geographically such facilities are few and far between. Telephone support is available for benzodiazepine users, but these services can struggle to cope with the volume of calls.

An increasingly popular source of information and support are moderated Internet forums aimed at prescription drug users. The largest Internet benzodiazepine support site, Benzobuddies, currently has more than ten thousand members worldwide. Through these online communication avenues fellow users can and have created a global co-support and co-cultural group with its own vocabulary (Orbe, 1996). Alongside and sometimes deliberately

replacing medical terminology, group members employ “benzo” language to describe and share their experiences and to make sense of their reality. For example, members use the term “healing” instead of recovery, “waves” to describe aggravations, and “windows” for symptom ameliorations. Quitting benzos completely is referred to as “jumping”. Like other marginalized groups, benzodiazepine users and ex-users generally feel unable to articulate their particular needs and concerns within the dominant medical model (Neulip, 2014). Thus they have constructed an alternative pathway and vocabulary through which to express themselves and exchange stories. In this way, isolated individuals find a “shared voice” and can enjoy a sense of belonging to a peer (co-) community.

Medical specialists often advocate a rate of withdrawal that is highly uncomfortable for many users (Kellagher, 2006; Samet, 2013). In the United States and elsewhere, rapid detoxification in specialist clinics is fashionable, but for benzodiazepine users is potentially harrowing and dangerous (Gerra et al., 2002). Part of the ethos of Internet and face-to-face support groups is to offer continuous and extended support during what might be a year or more of tapering off benzodiazepines (Ashton, 2002; Kellagher, 2006; Samet, 2013).

“Microtapering”, for instance, is a method advocated by certain members of the Internet benzo community, but is not mentioned in any mainstream medical literature. To be frequently reassured that healing is simply a matter of time and patience can also be key to sticking to a withdrawal program. Similar sharing of lay health expertise, some of which challenges medical opinion, is described in other studies of health-related ESGs (Barker, 2008), and is associated with a sense of empowerment and greater control of one’s health problems (Broom & Tovey, 2008).

From “Victims” to “Victors”

Recovery from any illness is a unique and deeply personal process meaning different things to different people (Anthony, 1993; Ridge & Ziebland, 2006). Writing from the mental health

perspective, Anthony argues that successful recovery does not mean that the person has changed, nor does it alter the fact that sickness or catastrophe has taken place; just that these factors are no longer the primary focus of one's life (Anthony 1993:4). For ex-benzodiazepine users, however, the situation is complicated by the iatrogenic (medically induced) etiology of withdrawal symptoms. There could be a need to disassociate one's new self from the monstrous "withdrawal me" which one hopes to shed slowly like an old skin and undergo a kind of transformation. Johns uses the term "renewal" to describe her process of healing (Johns, 2013), while Samet describes quitting benzodiazepines as a life-changing experience after which he will "never be the same person again" (Samet, 2014). Surviving any trauma and "moving on" from it (Isakson & Jurkovic, 2013) can be an empowering experience. Strange as it seems to me now, throughout my taper I lived in constant doubt that I would eventually join the ranks of the "heroes" whose success stories I devoured. Similar hero status had been ascribed to other survivors of illness or traumatic experience by fellow sufferers, for instance in cancer narratives. Cancer survivor Lance Armstrong for instance, describes himself as a reluctant hero, with patients eager to hear the story of someone who had beaten "the odds" (Morris, 2013). Nevertheless, I suggest that the bizarre and consciousness-altering nature of benzodiazepine withdrawal is, for those going through it, an experience like no other.

It takes time for the body to recover its ability to utilize GABA_A effectively after withdrawal (Ashton, 2002). Moving on from trauma also takes time, and my "new" biographical construction is a work in progress. Narrating my story might prove to be a "healing" experience but equally could lay me open to criticism for self-preoccupation or bias. There are risks associated with disclosure, but some stories demand to be told. In the describing and analyzing personal experiences with the goal of understanding a wider culture, autoethnography can reveal social and personal injustices, privilege victim and survivor

voices (Spermon, Darlington, & Gibney, 2013) and disrupt prevailing viewpoints (Ellis, Adams, & Bochner, 2010), such as that medical paternalism can serve patients well while still excluding them from decision-making processes (Stan, 2002).

In choosing my journal entries, I have been critically selective. Such was my self-absorption at the time that many sections make tedious reading. In addition, there are aspects of my recovery that have not been explored here for personal reasons. My spiritual beliefs and practices, for instance, proved immensely useful during the lengthy and painful recovery process. Other writers attest to how spiritual values and practices can help people cope with major traumatic events (Isakson & Jurkovic, 2013). On a practical level, mindfulness and meditation can interrupt negative rumination (a significant feature of withdrawal) and promote positive thinking (Ridge, Williams, Anderson, & Elford, 2008). The therapeutic benefits of journal keeping and autobiographic writing area is another topic that could have been explored (Ullrich & Lutgendorph, 2002), as are the benefits to wellbeing of a supportive family and community network.

Nevertheless I regard the above factors as familiar features of my everyday life experience. Becoming a regular member of and contributor to an online support group (my “benzo-community”) remains the most novel and morale-boosting feature of my self-monitored taper program, through which redefining myself became possible. Particularly memorable are the steady flow of success stories posted by ex-users, fuelling my belief that a better life after “benzos” was indeed achievable, and that a medical “victim” could become a “victor” and go on to construct a new life and a fresh identity.

More than four decades since concerns were first raised about side effects and dependency, the use of benzodiazepines worldwide remains huge (Ford, Law, Barjolin, Betterton, & Carnwath, 2013). Benzodiazepines are dispensed to people of all ages, gender

and socioeconomic groups; long-term use however, is associated with being elderly, less educated, having a psychiatric diagnosis, and being socially isolated (Zandstra, Van Rijswijk, Rijnders, Van De Lisdonk, Bor, Van Weel, & Zitman). The above categories contain some highly vulnerable, marginalized members of society, which might explain why the “not very sexy” issue of “involuntary tranquilliser addiction” (Hope, 2013) has only recently been put back on the government agendas. In the absence of easily accessible, free or affordable withdrawal and recovery programs, addressing the specific requirements of those who are involuntarily dependent on benzodiazepines (National Treatment Agency for Substance Abuse, 2012), users will continue to turn to Internet forums for advice and support during and after withdrawal.

For this article I have used the autoethnographical method to chart my journey through troubled waters. Exploring my experiences in this way felt surprisingly natural; once I had started writing the words seemed to slip onto the page, as if possessing an authority of their own. I began this journey largely ignorant of the effects of benzodiazepines and knowing nothing about their impact on people’s lives. A crucial part of my recovery was recording these experiences in order to preserve some sense of identity. The idea of applying my insider’s perspective to generate fresh debate around the dispensing of benzodiazepines, the information and support offered to patients, and commonly held assumptions concerning drug use and addiction, came to me later. Highly interpretive as they are, autobiographical accounts of sickness and recovery challenge more rigid definitions of what constitutes meaningful and useful medical research (Ellis et al., 2010) by insisting that the voices of patients themselves be considered not just valid, but authoritative and essential for change. Using an autoethnographic method has enabled me to explore beyond the personal and to apply established theory, including co-community and muted group theory, to the thorny and largely ignored socio-medical problem of benzodiazepine dependence.

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