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'Best of luck on your journey to healing': A corpus-based discourse analysis of an online forum for withdrawing benzodiazepine users

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Abstract

In many countries, including Belgium and the Netherlands, dependence on benzodiazepines (BZDs) is a medical and social issue, and, for long-term users who want to taper off, doing so remains a personal challenge. For these users, online contexts such as forums can be a place to discuss this experience and look for practical and moral support among former users and fellow users trying to reduce or stop BZD use. This paper aims to shed light on the discourses of a Dutch-language benzodiazepine withdrawal forum, examining 133 forum threads (41,516 words). We take a corpus-based approach that combines frequency analyses with qualitative discourse analysis. We explore how the users extensively share lived, experiential knowledge of using and reducing medication and, in doing so, engage with domain-specific biomedical jargon. As such they discursively construct specialised expertise and a medical(ised), health professional-like expert identity, both in relation to their own situation, but also in interaction with other forum members, as advisors to each other. The forum thus not only serves as a site for emotional peer support, but also as a site for detailed informational support on tapering, which is traditionally offered by health professionals. This is especially pervasive, as many forum users also express indignation about the medical establishment and its lack of institutional knowledge support in the process of tapering off.

Keywords: Benzodiazepines; corpus-based discourse analysis; expertise; online discussion forum; tapering; withdrawal

1. Introduction

Dependence on benzodiazepines (BZDs) has become a silent and often underestimated problem ever since their earliest marketing in the 1960s. This class of psychoactive medications is generally used to treat sleeping problems and anxiety, ideally only for short periods of time. Once treatment exceeds the recommended duration of two to four weeks, the benefits of using BZDs are highly debatable (Dell'Osso and Lader 2013). Long-term, habitual use is not recommended, due to adverse effects such as tolerance, physiological, psychological and behavioural dependence and rebound symptoms, even when used in low and constant doses or for a short period of time (Soyka 2017). Eventually, the effects of habitual BZD use might be difficult to differentiate from original symptoms. Cessation can be a physically, psychologically and emotionally disturbing experience (Fixsen 2016; Fixsen and Ridge 2017), with possible persisting cognitive effects (Barker *et al.* 2005).

Moreover, dependence on BZDs has been shown to lead to withdrawal syndrome following attempts to quit (Ashton 2005; Liebrenz *et al.* 2015). Dependent users are often unable to achieve long-term abstinence via recommended community-based discontinuation strategies such as gradual tapering-off completed in primary care, or assisted by community pharmacists (Wall *et al.* 2018). Nonetheless, multiple studies point to a lack

of institutional and medical recognition of BZD withdrawal difficulties (Parr *et al.* 2006; Canham *et al.* 2014; Vampini and Gallelli 2014). As such, many habitual prescription drug (ab)users who wish to withdraw seek informal support through online chat rooms and forums (MacLean *et al.* 2015). Yet, little is known about the discourses produced in online communities for BZD cessation, aside from the pioneering studies of Fixsen (2016) and Fixsen and Ridge (2017). With this paper, we therefore aim to answer the following research question: *How do forum users discursively (co-)construct their experiences on using and tapering off of BZDs, both individually and collaboratively in interaction with one another?*

In what follows, we summarise the relevant literature on digital health and on discursive construction of expertise (Section 2). Subsequently, we describe our dataset and our corpus-based discourse analytical approach (Section 3). Section 4 contains the results, which is followed by a conclusion (Section 5).

2. Literature review

2.1. Digital health and the shift in patients' epistemic status

Since the emergence of Internet 2.0, new patterns of digital health-information seeking such as online support groups and communities have challenged the traditional distinction between experiential, patient or lay knowledge (generally acquired through the lived experience as patient) and clinician, learned or professional expertise (gained from professional training and practice) (Sarangi 2001; Hartzler and Pratt 2011; Orton-Johnson and Prior 2013; Lupton 2012, 2016, 2017; Oborn *et al.* 2019; Nettleton 2021). This blurring of boundaries was illustrated for instance by the emergence of the hybrid concept of the 'lay-expert' (Prior 2003) and the growing understanding that patients' epistemic status – the status of having knowledge relevant to their condition – is changing. This is described by some as the beckoning of a paradigm shift (Fage-Butler and Anesa 2016).

In the earlier, more static conceptualisation of lay knowledge, patients were seen as being able to provide emotional support to one another or share practical advice on dealing with their illness on a daily basis. Clinicians, in contrast, were perceived as the source of informational support on the diagnosis and the management of illness (Pols 2014). However, against the background of a growing contestation of the legitimacy of medical authority and the emergence of patients as reflexive and critical consumers in late modernity, such a strict boundary and power asymmetry between medical experts and lay patients has become untenable (Sarangi 2001; Henwood *et al.* 2003; Britten and Maguire 2016; Declercq *et al.* 2021; Nettleton 2021; Romeyer 2021). Experienced or expert patients are now equally considered as providers of informational support based on their lived illness experience (Collins and Evans 2007; Eyal 2013), which sometimes surpasses practitioners' biomedical knowledge (Fage-Butler and Anesa 2016). Today, online health communities are visited exactly for their combination of informational and psychosocial peer support, as offered by expert patients (Davison *et al.* 2000; Morrow 2006; Nambisan 2011; McDonald and Woodward-Kron 2016; Kingod *et al.* 2017; Rueger *et al.* 2021).

2.2. The discursive construction of expertise

In line with sociological and linguistic social constructionist traditions (Milani 2007; Carr 2010; Eyal 2013; Jaspers 2014; Ekström 2016), we therefore define expertise as a dynamic and multidimensional construct that becomes meaningful when negotiated interactionally in a given discourse (Barton 1996: 299). As such, we see expertise as 'open to contestation and negotiation' (Milani 2007: 102). Discourses are the vehicle through which expert and other identities are articulated; interactants in a discourse must somehow mark and reveal they have relevant expertise, which interaction partners can then challenge or confirm (Kotthoff and Wodak 1997; Candlin and Candlin 2002; Sarangi and Clarke 2002; Weiste *et al.* 2016; Declercq *et al.* 2021; Weiste *et al.* 2022). This does not happen in a vacuum: the construction of expert identities is ideological, themselves constructing and reflecting what is considered valued and legitimised knowledge (Carr 2010).

Online health communities of patients suffering from chronic conditions and of peer groups in recovery from different types of addictions have both been studied as sites for sharing different

forms of expertise and for constructing and negotiating different (expert) identities. In addiction care in general, offline peer support is well-established as sharing a lived experience and is recognised for its critical role in the recovery process (Knight 2021), and Fixsen and Ridge (2017) have focused on the hermeneutic value of online cessation groups.

We add to this limited literature by exploring the dynamic construction of health-related knowledge and expertise in the context of a user forum on BZDs. BZDs form an interesting case, because of their widespread use and the institutional medical recognition of withdrawal difficulties. The insights gained help us understand what kind of expertise and identities (former) BZD users construct discursively while interacting on this forum, and to what end. In the next section, we describe an online support forum that thematises BZD cessation and withdrawal, uniquely in Dutch.

3. Data and methodology

3.1. Data and context

The corpus for the present study comes from an online forum which is hosted by a Dutch organisation for addiction treatment that offers services (including online programs) for people with different types of addictions falling within the legal realm (e.g. gambling, smoking, alcohol). One of their webpages provides an online treatment for BZD dependence. This page also contains an open forum for (former) users to discuss their 'experiences, knowledge and opinions', and it features content from users in the Netherlands and the Dutch-speaking part of Belgium. The data for the current paper were collected as part of a larger multimethod netnographic study on habitual use of BZDs. The overarching research project gained necessary approval from the Ethical Committee of the Faculty of Political and Social Sciences of Ghent University. The data were collected after obtaining informed consent from the website's administrator and the hosting organisation.

Following guidelines for analysing online support forums developed by Smedley and Coulson (2018), multiple measures were taken to protect posters' privacy, such as anonymisation by removing potentially identifying information. Furthermore, we deliberately chose not to include the literal original Dutch excerpts as this would make it possible to 'track' the quotes online and potentially reveal the identity of the posters. In this, we follow recent guidelines on safeguarding privacy and confidentiality when studying online discussion forums and communities for health research outlined by Shaw (2020). The data were extracted from the website in May 2020 (by the first author). A total of 133 discussion posts – initiated between 2016 and 2020 – including 2477 postings written by 161 different pseudonyms were collected for closer analysis.

3.2. Corpus-based discourse analysis

The data were analysed according to the principles of a corpus-based discourse analysis (Baker 2006, 2010; Partington *et al.* 2013; Baker and Levon 2015; Hunt and Harvey 2015), which is a data-driven approach using corpus techniques to detect trends in data in a bottom-up fashion. With this approach, discursive trends are observed for instance based on frequency analyses. Corpus-based discourse analysis allows analysts to plough through large datasets and obtain a quantified overview of the most frequent and repetitive linguistic patterns, which can then be further examined using a qualitative discourse analytical perspective (Harvey *et al.* 2007). In the latter, the lines in which a particular word of interest appears are read through manually, and, if relevant, further coded until saturation is reached. This is thus a fundamentally mixed-methods approach: a key goal of a corpus-based discourse analysis is to gain qualitative understanding of those trends in-depth and in-context (Baker 2010). This approach allows a focus on non-obvious meanings (Partington *et al*. 2013), while in a purely qualitative discourse analysis the analytical categories would be coloured more by the researchers' initial expectations about the data. We thus employed this corpus-based approach as 'a gateway' into the large dataset. The tools used for this analysis are outlined below.

3.3. Analytical procedure

Prior to analysis, the 'raw' dataset (consisting of 448,913 words) was pre-processed to allow for corpus analysis. Lay-out, buttons and texts from the forum interface (e.g., the cite button)

were deleted, and the corpus was tokenised. This resulted in 41,516 words for analysis. The data were analysed using the corpus software package WordSmith, version 8 (Scott 2020). The reference corpus used is the Dutch section of the Dutch Parallel Corpus (DPC), a Dutch-language corpus for written Dutch consisting of literary, instructive, administrative and journalistic texts, as well as external communication (Macken *et al.* 2011). This is because the forum data are mostly formatted as letters, and thus follow the conventions of written language more than oral discourse.

Our analysis started with a keyness analysis, to examine the relative frequency of the words in our corpus compared to the relative frequency of words in the selected more general reference corpus, using the log-likelihood test with an alpha of p<.01 and a cut-off value of 15.13 (Rayson *et al.* 2004). This yielded 579 keywords, or words and terms where the relative frequencies between the target corpus and reference corpus were statistically significant. We focused on the 30 items with the highest log likelihood score (see Table 1). After globally examining the first 60 items, we systematically examined the top 30 for reasons of scope, and because the most important trends in the data observed in the first 60 words were all present in the first 30 ones.

Further, both authors conducted a concordance analysis of how the top 30 items or words occur in context and a collocation analysis to explore how and which of these words co-occur most in the corpus. Thus, while the former looks into the immediately surrounding words of a term, the latter explores how words are usually observed together or in close proximity (Haider 2019). The

Table 1. *Keyness analysis (first 30 words)*

#	Keyword in Dutch	Translation in English	Frequency	Log_L
1	IK	I	1713	5500.27
2	JE	YOU(R)	762	2173.86
3	HEB	HAVE	394	1623.55
4	BEN	AM	311	1341.67
5	DIAZEPAM	DIAZEPAM	139	1268.65
6	AFBOUWEN	TO TAPER OFF	129	1150.56
7	AFBOUW	TAPERING OFF (N.)	91	802.35
8	NU	NOW	288	730.70
9	OXAZEPAM	OXAZEPAM	74	722.56
10	MG	MG	195	691.68
11	MIJN	MY	258	563.65
12	PSYCHIATER	PSYCHIATRIST	66	554.40
13	MAAR	BUT	443	533.48
14	*USERNAME*	*USERNAME*	54	527.27
15	SLAPEN	(TO) SLEEP/SLEEPING	78	520.24
16	WEL	INDEED/CERTAINLY/WELL	226	489.78
17	KLACHTEN	SYMPTOMS	86	477.66
18	AFGEBOUWD	TAPERED OFF	57	466.01
19	*USERNAME*	*USERNAME*	47	458.92
20	BENZO	BENZO	45	439.39
21	HEEL	VERY	175	422.58
22	ONTWENNING	WITHDRAWAL	43	419.86
23	WEER	AGAIN	156	404.37
24	ME	ME	156	381.61
25	MIJ	ME	118	353.52
26	LORAZEPAM	LORAZEPAM	38	340.21
27	OOK	ALSO	405	339.93
28	NOG	STILL	261	324.15
29	DAG	DAY	130	314.95
30	GAAT	GOES	156	312.94

Table 2. *Categorisation of first 30 keywords*

	Category	Translation	Items Dutch
1	First-person and second-person personal pronouns	I, you(r), my, me, me	*ik* (#1), *je* (#2), *mijn* (#11), *me* (#24), *mij* (#25)
2	First-person and second-person singular verb forms of auxiliary verbs	have, am	*heb* (#3), *ben* (#4)
3	Items that relate to using medications: the active compound, and the unit indicating dosage, the overarching term	diazepam, oxazepam, MG, lorazepam, benzo	*diazepam* (#5), *oxazepam* (#9), *MG* (#10), *lorazepam* (#20), *benzo* (#26)
4	Lexical items in the semantic field of tapering off; symptoms	to taper off, tapering off, tapered off, withdrawal, to sleep/sleeping, symptoms	*afbouwen* (#6), *afbouw* (#7), *afgebouwd* (#15), *ontwenning* (#17), *slapen* (#18), *klachten* (#22)
5	Psychiatrist	psychiatrist	*psychiater* (#12)
6	Adverbs of/nouns relating to time	now, again, still, day	*nu* (#8), *weer* (#23), *nog #28)*, *dag* (#29)
7	Booster	very	*heel* (#21)
8	Other, including two usernames	but, (well), goes, also two usernames	*maar* (#13), *wel* (#14), *gaat* (#16), *ook* (#19), two usernames (#27, 29)

30 items were then grouped based on similarities in meaning or use, resulting in eight categories (Table 2). Specific additional analyses were done of the collocations, cluster frequencies (or multi-word units) and concordances by both authors. While doing so, the meaning and relevance of the keywords were explored and discussed by both authors together, as well as how to interpret them and compare them to relevant literature and related research. Further qualitative analyses included the coding of full posts, for example in the section of the corpus where health professionals were discussed, for positive or negative sentiment, to assess their recurring themes, and for the messages' tone.

4. Findings

4.1. The lived experience of benzodiazepine reduction

A first exploration of our keywords provides a picture of *what* is mainly talked about on the forum. It is clear from the list that the users extensively share and discuss their own experiences of tapering off. This thematic focus of the forum discussions is for instance visible in Category 4: 'to taper off' (*afbouwen*, #6), '(the) tapering off' (*afbouw*, #7) and 'withdrawal' (*ontwenning*, #22). The two most important reasons for starting this medication – '(to) sleep' (*slapen*, #15) and 'anxiety' (*angst*, #32) – appear in the top 30 or right after. Other clearly thematic words in the top 30 are 'symptoms/problems' (*klachten*, #17), as well as some of the most commonly taken benzodiazepines: 'diazepam' (#5, generally recommended as a substitution during tapering-off), 'oxazepam' (#9) and 'lorazepam' (#26).

More specifically, the forum members discuss their current and past uses of BZDs, current and past withdrawal symptoms and their strategies and tricks to deal with them, as well as their past and future visits to health professionals. As Examples 1 and 2 show, the other thematic keywords listed above ('sleep', 'anxiety', 'withdrawal') or related words and forms ('withdrawal symptoms') are also discussed within the same sentences or posts, as

it is the relationships between reducing dosages and the symptoms that follow that are discussed.

Example 1

I have taken alprozolam for a year 0.25 twice, was allowed to **taper off** to one pill in the morning for five weeks, unfortunately too many **withdrawal** symptoms.

Example 2

Yes we all know **anxiety** and lability here, I do in any case, and I still have to further **taper off** quite a bit. Taking it day by day hoping it will get better slowly, sometimes having some respite, but also regularly plough on.

However, the top 30 also provides insight into how this thematic focus is being discussed. The forum users abundantly use first-person pronouns when they talk about tapering off. 'I' (*ik*) is the number 1 keyword, and 'me' (*me*, *mij*, #24) and 'my' (*mijn*, #11) are also present. Other relevant keywords are 'have' (*heb*, #3) and 'am' (*ben*, #4). In Dutch, these verb forms can be used only with first-person pronouns or with second-person pronouns in questions. However, a frequency analysis of the clusters shows that in this dataset they are mainly used with 'I', as 'I am' (*ik ben/ben ik*, 209 occurrences) and 'I have' (*ik heb/heb ik*, 248 occurrences). These are also the most common two-word clusters. Like in English, the Dutch verb forms '*am*' (*ben*) and 'have' (*heb*) can function both as main verbs, with similar meanings in English, and also as auxiliaries in perfect tenses, and, in the case of 'am' ('*ben*'), in passive constructions. In our dataset, most examples are active verb constructions, which indicates that the users mainly discuss their own states and actions, as in Examples 3 and 4.

Example 3

I have used oxazepam for 3 months and have tapered off.

Example 4

For eight days, **I** am now on 4 x 5mg diazepam and **I** cannot handle it any longer, **I** already was heavily depressed and panic attacks and anxiety and have serious chronic pains, and migraine and cluster headaches.

In the concordance lines surrounding 'I', a wide range of aspects of reducing the use of BZDs appear. The concordance lines furthermore show that the pronoun 'I' (*ik*) often appears in more emotional statements on withdrawal symptoms (Example 4).

Other keywords provide further insights into *how* the personal experiences of BZD users are described to peers on the forum. Another common element is the intensity of that experience, reflected in the keyword 'very' (*heel*, #21). Like in English, this is an adjective or adverb that modifies the following word. So, we specifically looked at its two right collocates to find out what it boosts or intensifies in our dataset. The most frequent words are mainly other modifiers and boosters that further modify 'very', and a range of adjectives, such as 'good' (*goed*), 'long' (*lang*), 'slowly' (*langzaam*), 'gradually' (*geleidelijk*) and 'well done' (*knap*). The concordances of 'very' bring up more adjectives, but point to the same direction as the most frequent right collocates, e.g., 'cold' (*koud*), 'calm' *(kalm*) and 'strong' (*sterk*). The adjectives in this subset of data are thus often evaluative, sensory or relating to time. Consequently, they all clearly reference the experience of tapering off and withdrawal, and again do so in a wide array of ways: highlighting the duration, the bodily experience and the emotions or mental impact of withdrawal.

Besides sensory and emotional intensity, a number of keywords in Category 6 further highlight the temporal aspect of the users' experiences, which is also visible in some of the adverbs discussed above: 'now' (*nu*, #8), 'still' *(nog*, #28) and 'again' (*weer*, #23). Additionally, concordance lines and collocation analysis show that the noun 'day' (*dag*, #28) occurs as either 'all day' (*de hele dag*) – mostly underlining the severity of withdrawal symptoms – or 'per day' (*per dag*), indicating a more pragmatic description of daily taper doses (see also Section 4.2, on collocates of 'mg'), and related forms. These adverbs of time and frequency show how the users emphasise the duration of tapering off. This clearly distinguishes BZDs from other substances (like alcohol or cocaine).

This first set of keywords thus indicates that the forum mainly thematises tapering off from BZDs, with a focus on the intensity of bodily/sensory and emotional aspects, and the duration and slowness of the process. Although this may seem obvious, it is an important finding as such: forum websites like this potentially also contain discourses legitimising use and/or resisting reduction. Other aspects of using and reducing BZDs, such as

stigma or complications regarding social relations or professional lives, are not discussed extensively. The focus rather lies on individual difficulties in tapering off according to a standardised scheme, which shows that a one-size tapering schedule does not fit all.

Moreover, when talking about these experiences, the users do so from their own personal perspective using first-person pronouns and active constructions. This indicates that the users thus heavily thematise their own experiential knowledge and lived experience. Furthermore, these trends also show how the forum members medicalise the consequences of long-term BZD use and the withdrawal process. This process of automedicalisation (Pickersgill 2012) is crucial for the forum members in asserting the right to act as an expert *patient* with lived knowledge rather than as a recovering addict. References to addictive behaviour are remarkably absent.

4.2. The experience as medical: Speaking like a health professional

A number of keywords specifically illustrate how the process of tapering off is discussed in extensive technical detail, using specialised language and medical jargon, especially summarised in Category 3. An interesting keyword is 'mg', in both English and Dutch short for 'milligrams'. The concordances of 'mg' illustrate the technicality of the forum users' discourse, as well as the dosage often being discussed specifically in the context of reducing it (Examples 5–6).

Example 5

I now have 12,5 **mg** a day (coming from 25), that is practically nothing. It can be that your body gives those vibrations because you are switching between your quetiapine.

Example 6

I have 2 **mg** alprazolam imipramine antidepressants 125 **mg** and use 25 **mg** quetiapine to sleep. Was allowed to only reduce a quarter per 4 weeks but stubbornly went to 1 **mg**.

Similarly, the collocates of 'mg' confirm the extensive and technical discussions of the procedural nature of the reduction of the dosage: 'per' (*per*, always followed by an indication of a time span, e.g., day or week) being the most frequent collocate, while the other top collocates are the prepositions 'from' (*van*) and 'to' (*naar*), used to discuss the original and decreased dosages, as well as 'day' (*dag*).

The users thus also use the forum as a site for reporting exactly how they are tapering off, in extensive technical detail about which medications they take and in what dosages. The examples show this is also done in combination with other markers of an expert identity: in Example 5, the user employs the phrase 'that is practically nothing', which is an assertive, non-mitigated assessment of the dosage, which is followed by an explanation of why another user experiences a particular withdrawal symptom. In Example 6, the user refutes the reduction schedule of their health professional in favour of a personal approach. Other examples of technical language and medical knowledge or resources are the references to the *Ashton Manual* (Ashton 2002), a patient guide or protocol on withdrawal written by a British general practitioner which is mentioned in Example 7.

Example 7

Personally, **I** would advise **you** to slowly (25% per week) replace the lora with an equivalent diazepam, 1 mg of lora is between 10 to 15 mg diazepam. Then **you** would be on about 40/50 **mg** of diazepam with two **mg** of lora. Just read the Dutch **Ashton Manual**.

Here, the last phrase alone 'Just read the Dutch Ashton Manual' can serve multiple sources in constructing the user's expertise: first, it is a piece of advice – a reading recommendation –which as such projects a high level of expert identity that is further strengthened in its explicitness through the use of an imperative form. Second, it may reflect a typical scientific/biomedical practice, i.e., of providing a source for their claim. Third, it at the same time legitimises preceding claims on how exactly dosages must be reduced, and the background/explanation the user gives when comparing lorazepam and diazepam. The first section of the example also reflects the user's positioning in the medical domain, through using percentages. The assertive comparison between two BZDs similarly assumes pharmacological expertise and constructs a clear expert identity. However, there are also some mitigating elements, such as the

hedging in the adverb 'personally', and the modal verb 'would', which assume and reflect more the tone of peer support.

The highly technical language in which the forum users discuss the withdrawal process and give each other advice shows they are familiar with a particular, medicalised body of expertise on BZD use, and, more importantly, also actively and assertively incorporate it into their forum contributions. In doing so, they also engage with medical discourse and put their experience firmly in the biomedical domain (instead of addiction recovery), and construct an expert identity. This is also illustrated by the referral to active compounds (instead of brand names or generic names), in the meticulous mentioning of dosages and in the myriad references to the *Ashton Manual*. This technical vocabulary also serves to accomplish authority and legitimacy by the posters. As such they perform identities as 'expert patients' but also as '(lay) doctors' or experts (Prior 2003); they employ 'not only relevant medical labels but also "medical reasoning" to endorse' their point of view (Sarangi 2001: 4).

Hence, to become a member of this virtual community, one needs a fair degree of medical literacy to understand the specific language that is used. Membership thus seems to be delineated by certain tacit rules of conduct, anticipating at least some degree of medicalised knowledge and vocabulary.

4.3. Sharing lived experience and expertise

The forum is also a place for dialogue and emotional support, which co-occurs but also goes beyond mere professional-like specialised and technical knowledge. The first indication of this in the keyness list is the second keyword 'you(r)' (*je*). In Dutch, *je* is both the second-person personal pronoun 'you' and second-person possessive pronoun 'your'. The concordances show that it is used in both ways, and in a range of contexts. The users ask each other questions, for instance about what BZDs others are currently (still) using, but also how they are doing in general and what specific symptoms or medical problems are like at the moment. They explain aspects of withdrawal to each other, give advice and wish each other a successful recovery (Examples 8–10).

Example 8

Taper off of 20 mg in five weeks (4mg per week) really is too fast. 1 mg per two days is also fast, probably too fast and that can explain **your** heavy withdrawal symptoms really well.

Example 9

[users are discussing the globus sensation] **You** can't not think of something, that is a trap I always fall in as well. **You** have to accept that you feel something and that there is still nothing. That is tremendously difficult but I think it's still the only way. I have been doing that for months and still cannot fully reassure myself, but I write down what went well and what didn't go well every day. That has to help eventually, I hope. Best of luck to **you** on **your** journey to healing!!

Example 10

Pay attention to **your** own signals and especially, read page 1 of the Manual and make sure that the doctor who is guiding you understands and agrees if possible. In short: **your** motivation, **your** pace, **your** body, **your** process.

The examples here show the different kinds of health-related expert identities and expertise the users construct. Examples 8 and 10 are similar to Examples 5–7 in their projections of medical expertise through assertive assessments of others' tapering off strategies, the shortened reference to the *Ashton Manual*, the use of imperatives to give explicit advice and the advice to become your own expert patient by learning to monitor yourself ('pay attention to your own signals'), and by focusing on personal agency ('your motivation […], your process'). Example 9, however, addresses the psychological consequences of withdrawal symptoms, but constructs advice and expertise by sharing lived experience from a personal perspective ('a trap I fall into as well') while also acknowledging the difficulty and complexity of the situation, both for the user themselves and the user being addressed.

When examining further the concordance lines of 'you' (*je*), it is also clear that this word appears in posts in which the forum users express empathy, and further recognise how difficult the process of tapering off benzodiazepines is (Examples 11–12).

Example 11

I am happy you made the effort to share your story, although I understand the superstition to wait with it for a bit – please keep doing it.

Example 12

I wish **you** a lot of strength.

The interactional nature of the forum context is also further reflected in the fact that two usernames appear in the keyword list. These are in our corpus because the users respond to each other by tagging each other. Beyond the top 30 (i.e. #31–60), we also find keywords that are used solely for interactional purposes, like greetings, such as 'hey' (*hoi*), 'dear' (*lieve*), 'hello' (*hallo*) and 'take care' (*liefs)*. These keywords and the corpus trends point to the fact that the forum provides a site for the users to discuss complexly their experience as a patient who is trying to reduce or taper off and as someone who is dealing with physical and mental problems that impact their daily life.

Sometimes, the interactional nature is also implicit, in ways that cannot show up in the keyness analysis. For instance, the dataset contains a lot of direct questions, sometimes with a question mark (Example 13), but also without (Example 15, below).

Example 13

Is there somebody who, after **tapering off** of benzos, can **sleep** again because that is what my psychiatrist says. I can hardly believe that. And do you experience vibrations in your body?

Hence, the forum users' experiential and medical knowledge is utilised not only to inform one another but also to offer one another support on a more psychological level by normalising the difficulties of the process. In doing so, they become each other's supporters on their paths towards recovery. Discursively, this is illustrated by interactional features such as politeness forms and informal greetings, but also by myriad posts with reassuring and comforting messages, sometimes combined with personal stories. Through sharing experiences, reflecting about possible solutions and providing support during rough (relapse) episodes, the forum users build a safe (virtual) community of peers, similar to offline peer support groups in addiction treatment (Mudry and Strong 2013) and patient support groups (Hartzler and Pratt 2011).

4.4. Us versus them: Expertise on and experiences with healthcare providers

Next to the users themselves and their fellow forum visitors, a third stakeholder that emerges from the keyword list is 'psychiatrist' (*psychiater*, #12). Psychiatrists are either presented as ally or 'culprit' of an iatrogenic dependency, as in Examples 14–16.

Example 14

Ultra-short tapering schedule pushed down my throat. The GP also remains behind the **psychiatrist**. I was quite upset about it.

Example 15

(on withdrawal symptoms) Why is that so underestimated by a **psychiatrist** or doctor, incomprehensible.

Example 16

If my **psychiatrist** had not retired I would still be on alprazolam.

In these rather negatively voiced posts, the users criticise a lack of recognition (mainly of withdrawal and rebound symptoms or complaints when tapering off) or express a feeling of not being heard as a patient (e.g., with regard to a preference for certain methods for quitting, the pace of tapering off, or a preference for non-pharmaceutical withdrawal methods), while some also blame the prescribing psychiatrist for their dependence.

In more neutral or positive posts, however, psychiatrists are instead portrayed as 'allies' on the journey towards recovery, if the mentioned needs for recognition and acceptance of one's personal tapering off preferences are met (Examples 17–19).

Example 17

I think I will go from 1.25 lora to 8 dia in 5 weeks. The **psychiatrist** will agree with that I guess.

Example 18

My **psychiatrist** is going to read up on the Ashton Manual.

Example 19

She also indicated that they really do not all protect each other and that another **psychiatrist** might be more open to cooperation and my ideas about tapering off.

In general, psychiatrists are mostly described from a negative or a neutral perspective. The words *huisarts* ('general practitioner') and *dokter* ('doctor') showed similar trends.

A smaller group of users was very negative, to the extent that they were considering legal action (Examples 20–21).

Example 20

I also want to file a **complaint** at the disciplinary committee about my old **general practitioner** and the treatment that went wrong. She kept **stuffing** me, it couldn't be because of the pills while I showed her evidence from the Pharmacotherapeutical Compass and package insert, she did not want to refer me and called me **stubborn**.

Example 21

Who are we going to **sue** indeed, the legal advice office offers free responses to those things. Shall we call them to see what they see, or would that not be worth it? […] Would this then be your question: Who can I see for getting extremely sick of prescribed and approved medication, of which it has been known for 60 years that it can make you really sick? […] I would gladly tell my story, **this crap must be forbidden**.

In addition, the dataset shows that these forum users also share links to stories from the English-language media of people who were not well informed about the dependency users can develop on BZDs when they started using them, and who then struggled with intense withdrawal problems. In doing so, the users (also) seek reinforcement for the idea that they are not responsible for the onset of their dependence and the consequences thereof, which they frame as iatrogenic. In these instances they position themselves as victimised patients. This shows that the forum also provides a place to problematise the role of health professionals and the perceived lack of adequate support in the process of tapering off. Studies do indeed show that many medical specialists show limited knowledge of BZD dependence and withdrawal treatment (Parr *et al.* 2006; Vampini and Gallelli 2014).

In sum, in their search for support resulting from the absence of adequate medical help, the forum users not only seek empathy from like-minded peers who fully understand their situation and suffering, but also create a collective identity based on a shared lived experience. These experienced patients provide one another with expert informational support. Our findings suggest that this often happens because of a (perceived) lack of recognition and medical expertise, rather than as an addition to formal care. The forum is thus a site for both the appropriation and contestation of biomedical expertise. The posters transcend traditional epistemic boundaries (between lived experience and biomedical expertise) due to the technicalities of tapering off and the specialised pharmacological knowledge required to accomplish a taper and the claimed iatrogenic nature of their condition.

5. Conclusion

Our study shows how illness and health-related expert identities complexly intertwine and accommodate one another. The forum users present themselves as patients who (need to) undergo (self-)treatment for their prolonged withdrawal symptoms (rather than as other possible identities such as addicts). They centre their personal, lived experience of tapering off by discussing withdrawal symptoms and other sensory experiences, and the long duration of tapering off by sharing aspects of lived experience, such as the emotional and psychological difficulty of tapering off. In doing so, however, they also report on monitoring and steering that personal experience by building on (advanced) medical expertise and personal research, constructing clear expert identities that at times approximate identities of health professionals yet also challenge medical hegemony. Simultaneously, the forum is also clearly dialogical, and here too, the users respond to and give advice on issues relating both to lived experiences and medical aspects, again while shifting between their identities as expert patient, suffering patient, medical expert, victimised patient and peer available for support. Because of our bottom-up corpus-based approach, we were able to analyse the most common linguistic elements that exemplify the discourses of this specific group of people with a BZD dependence who do not seem to find, or have not found, their way to appropriate medical care and have become their own and each other's health expert.

Our study has a number of limitations, and calls for further research. The studied forum seems to

attract users who are digitally engaged and have high degrees of health literacy. Additionally, our Dutch-language data only provide insight into one specific community in a specific context. Further research is needed to shed light on similar dynamics in other healthcare systems, different languages and communities, for example comparing this corpus to corpus data from a forum focusing on recovery from other substances.

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