FEDERAL RESEARCH PROGRAMME ON DRUGS

BENZONET

Perception, habitual use and cessation of BENZOdiazepines: a multi-method NETnography

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LIST OF ABBREVIATIONS

BCFI/CBIP: Belgian Center of Pharmacotherapeutical Information

BELPEP: Belgian Psychotropics Expert Platform

BZD/Z: Benzodiazepines and Z-products

FAGG: Federal Agency for Medicines and Health Products (FAMHP)/ Federaal Agentschap voor Geneesmiddelen en Gezondheidsproducten (FAGG)/ L’Agence Fédérale des Médicaments et des Produits de Santé (AFMPS)

FEDITO: Federation of Institutions for Drug Addicts/ Federatie van Instellingen voor Verslaafden/ Fédération des Institutions pour Toxicomanes

FOD: Federal Public Service, in this report to refer to the FPS Health Food Chain Safety and Environment

GLEM: Groupe Local d’Évaluation Médicale (accredited by RIZIV-INAMI)

GP: general practitioner

LOK: Lokale Kwaliteitsgroep (accredited by RIZIV-INAMI)

MFO: medical pharmaceutical councils (‘Medisch Farmaceutisch Overleg’)

1. INTRODUCTION

Despite various prevention campaigns and initiatives by the federal government, the long-term use of sleeping pills and tranquillisers, in particular benzodiazepines and Z products (further referred to as BZD/Z) remains alarmingly high in Belgium. According to the most recent national Health Survey from 2018, 12% of the Belgian population had been using at least one prescribed tablet in this class of sedatives, hypnotics and anxiolytics, in the past two weeks. This makes Belgium one of the leading consumers in Europe and even worldwide. Treatment with this medication is recommended for two to a maximum of four weeks, since with longer use, the benefits do not outweigh the disadvantages. Notwithstanding one in three users in Belgium still takes these medicines after eight years.

Such long-term use - more than four times a week for more than six consecutive months - is not recommended because of various negative effects such as tolerance and physical and psychological dependence. Moreover, it is often difficult to distinguish the effects of long-term use from the original symptoms for which the medication was started. In general, both benzodiazepines and Z products have a high potential for misuse and abuse.

Until now, research in Flanders on the one hand has mainly focused on the experiences of care providers in primary and secondary care such as pharmacists, nurses and general practitioners and on the other hand on the perspectives of patients who are prescribed the medication for the first time. In addition, various prevention campaigns are also primarily aimed at potential and starting users. How long-term users experience their use has not been mapped before, nor has there been any research on the experiences of habitual, long-term users who have tapered off and stopped taking this medication.

BENZONET aims to address this gap. This two-year interdisciplinary study (2019-2021) was carried out by the research group Hedera (Health and Demographic Research), Faculty of Sociology of Ghent University in collaboration with the Department of Clinical Pharmacology, with the financial support of BELSPO.

BENZONET is a qualitative study on 1) the experiences and perspectives of individuals who have used or are using long-term sleep medication and tranquillizers more specifically benzodiazepines and Z products (hereafter abbreviated to BZD/Z), and 2) the role of online forums in tapering off, withdrawing and cessation.

The project aims to provide new insights in the sociology of health from the perspective of patients and experts by experience. They are further referred to in this report as (former) habitual or long-term users. We employ the word user in the most neutral sense of the word: someone who is taking medication (regardless of context).

2. BENZONET

2.1. AIMS AND RESEARCH QUESTIONS

The aims of this study are trifold:

(1) to understand how habitual long-term users perceive their medication use, what meaning they attribute to these drugs, and how this is linked to their personal health identities through their personal medication narratives;
(2) to explore the broader discursive backdrop of the contemporary normative imagery of the use of BZD/Z against which individual user narratives are formed;
(3) to explore how online resources such as health communities contribute to the (cessation of) BZD/Z use

2.2. OVERVIEW - WORK PACKAGES AND TIMELINE

WP1 consisted of a preparatory phase during which the advisory committee was invited to a start-up meeting. Prior to its start, the project was granted ethical approved by the Ethics Committee of the Faculty of Political and Social Sciences of Ghent University. Furthermore, recruitment procedures were refined and practically organised. The semi-structured interview topic guide was developed, pilot tested, and extensively validated by the advisory committee. Finally, an online research protocol was developed. WP2 consisted of two online case-studies, the collection and analysis of digital data. WP3 entailed a series of in-depth interviews with (former) habitual users and narrative data analysis. WP4 entailed the integration of the results of WP2 and 3 in an intermediate report, which served as a departure point for the development of the focus group protocol. WP5 involved a series of validating focus groups (with relevant stakeholders: health care practitioners, pharmacists, patients, stakeholders in the field of drug prevention. Finally, WP6 contains the concluding dissemination activities, during which we aim to present results to professional audiences (e.g. presentation at Grey meeting, a publication for a broad professional audience (see VAD website) and a final dissemination workshop for relevant stakeholders). This exceeds the strict timing of the project and is an ongoing activity the team is pursuing.

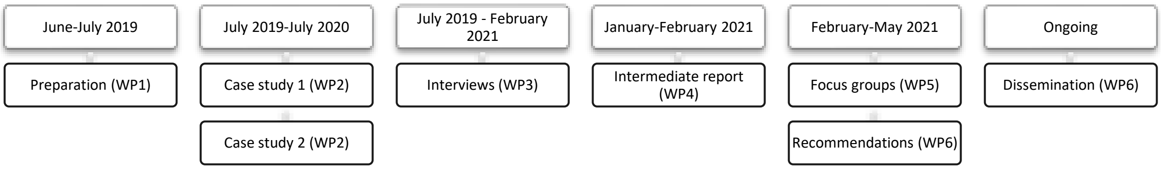

Figure 1 Timeline

2.3. OVERVIEW OF THIS REPORT

Chapter 3 serves as a broad introduction and background to this study by providing a concise literature review with the latest and most relevant statistics and insights on habitual users' perspectives on BZD/Z use in Belgium and Flanders, both before and during COVID-19. For a brief literature review on the state-of-the-art of nethnographic research and online communities related to BZD/Z we refer to chapter 4 and 5. In these chapter, we present the results of the two online case studies, to understand the role of online health communities in acceptance, use and cessation of BZD/Z. Chapter 4 explores how users of a Flemish forum for people over 50 discuss BZD/Z, to explore broad discursive trends and perceptions of BZD/Z in an age group in which the consumption of BZD/Z is typically higher than in the rest of the population. In chapter 5 we then further zoom in on a specific group of withdrawing and former users, by exploring the language used in an online peer support forum. This chapter came about in collaboration with Prof. Jana Declercq of the University of Groningen and allows to further expand upon the role of online communities in cessation. In chapter 6 we present the insights from the in-depth interviews with current and former habitual users. This chapter this provides insight into medication narratives, motivation and meanings of habitual use, into perceptions of cessation, pitfalls and leverages, as well as into habitual users' opinions of current prevention campaigns. Based on these results, we present a set of policy and practice recommendations in chapter 7.

3. STATE OF THE ART

3.1. BENZODIAZEPINES AND Z-DRUGS USE IN BELGIUM: SOME FIGURES

According to the latest national Health Survey from 2018, 12% of the adult Belgian population reported using a BZD/Z in the two weeks prior to the survey (Gisle et al. 2020). These figures indicate a slight decrease in BZD/Z use compared to the national Health Surveys from 2013 (13%) and 2008 (18%), which probably indicates an effect of the ongoing efforts of the federal government to reduce the consumption of BZD/Z. Zoomed in on those who had been using a BZD/Z in the 24 hours prior to the survey, results show that 4,3% of the Belgian population had been using a benzodiazepine and 1,2% a Z-product, of which the majority reported long-term habitual use, respectively 93,4% for benzodiazepines and 90,7% for Z-products (Van der Heyden et al. 2020). Generally, the use of BZD/Z is higher among women and people over 65, while there is also a remarkable peak in use around retirement age especially among men (van de Straat et al. 2018). Furthermore, BZD/Z usage is especially troublesome among people over 75, with 37% of all women and 28% of all men using BZD/Z in this age group (Gisle et al. 2020). As a result, BZD/Z are considered one of the most common 'potentially inappropriate medications' for these older age groups (Bourgeois et al. 2012, Anrys et al. 2018). Chronic use of BZD in specific in people over 65 is estimated at 112 per thousand persons, which is more than three times the OECD average. As such Belgium ranks indisputably high in international comparisons, not only for older age groups but for younger age groups as well. Gisle and colleagues (2020) state that Belgium is probably one of the countries with the highest (over)consumption of these medications, with a daily delivery of 1,260,034 daily doses (DDDs) of BZD/Z by Belgian pharmacies in 2016 (according to figures of APB). But how has the recent pandemic influenced the use of BZD/Z? Between February and May 2020, more than 800 patients (recruited through their dispensing community pharmacist) participated in an online survey organised by the Federal Agency for Medicines and Health Products (FAMHP or FAGG in Dutch) on the use of benzodiazepines and related drugs in sleep disorders. The survey revealed that most patients reported overconsumption (84% were using BZD/Z for 6 months or more) and that more than one in three patients showed signs of psychological dependence (measured through the Severity of Dependence Scale).

3.2. COVID-19, SLEEP AND THE USE OF MEDICATION

The 5th COVID health survey (held in December 2020) -the most recently available at the time of writing this report- reveals that the majority of the Belgian population (73%) suffered from sleeping problems, which is an extremely high number (Sciensano 2020). This number was similar to the outcome of the previous survey held in June-September 2020 (72%). Sleeping problems included: sleep disturbance in terms of falling asleep, waking up too early or having a restless night. In line with research from pre-COVID times, women reported more sleeping problems than men (78% versus 68% respectively). Contrarily to previous research (pre-pandemic) however, people over 65 suffered less frequently from a disturbed sleep, as compared to the active working population. These patterns of increased sleeping problems can be attributed to the anxiety and stress caused by the pandemic, a change in work-life balance and lifestyle in general, such as decreased physical activity, increased screen time, decreased exposure to daylight (especially in winter) and a disruption of the wake-up and sleep routine. In line with the prevalence of sleeping problems, the survey also showed an alarming increase in anxiety and depression symptoms, which are reported by respectively 23% and 22% of the population. These latest figures are even higher than percentages reported during the first COVID-19 wave.

Furthermore, overall 21% of the respondents used a BZD/Z, of which 42% indicated having started or increased their use since the beginning of the crisis. In the age group between 18 and 24 years 75% of those who use BZD/Z indicated that this use started or increased since the start of the pandemic. Accordingly, the sale of sleeping medication has risen considerably. The sale of medication without prescription such as melatonin and herbal preparations has risen in 2020 with 10-11% according to Febelco, the largest wholesaler-distributor of medicines in Belgium (source: VRT news). When zooming in on the month December this increase was even larger (41%) compared to December 2019. In addition, the sale of BZD/Z has increased with 3,4% in 2020 compared to 2019. This comes down to around 200.000 extra units sold on an annual basis. Given the already skyrocketing consumption of BZD/Z in Belgium, this is quite alarming.

The stagnation and even slight decrease in BZD/Z use that was marked in the 2018 national Health Survey has now been reversed. Given that it has been estimated that one in every three users who starts BZD/Z in Belgium still takes these medicines after eight years (Christiaens et al. 2018), there might be a unignorable number of new users who will potentially develop chronic use and dependence.

3.3. WHAT DO WE KNOW ABOUT THE USERS' PERSPECTIVES IN BELGIUM SO FAR?

Over a decade ago, Anthierens and colleagues conducted a series of qualitative studies that led to key insights on the perceptions and motivations of first-time BZD/Z users (Anthierens et al. 2007b) and prescribing GPs (Anthierens et al. 2007a, Anthierens et al. 2010) in a Flemish setting. These studies showed a tension between an awareness of general negative effects of BZD/Z use, and a pivotal need to deal with distress, both in prescribers and first times users. In the latter group this is illustrated in a twofold discursive strategy, in which problems are magnified and usage is minimised, while in the former group, this leads to ambiguous feelings about showing empathy by prescribing, which is often seen as the lesser evil. Furthermore, these studies also revealed that both prescribers and patients tend to avoid discussing or questioning possible long-term consequences of habitual BZD/Z use, desired length of use, related health risks and alternative treatments therapies.

Habitual users' points of view are sporadically also taken into account in studies that focus on deprescribing in general practice (Van der Eecken 2016, Kint 2017). For example, habitual users were also involved during different stages of the Big Bird study, which assesses the effectiveness of a blended care approach, combining face-to-face consultations with a GP together with web-based self-learning by the patient for the discontinuation of chronic BZD/Z use for primary insomnia in general practice. Long-term BZD/Z users were participating in a focus group to provide feedback on the overall feasibility of the patient activities and tools of the study (Coteur et al. 2020).

However, no further research has been conducted explicitly on the perceptions and perspectives of habitual users. Other Belgian studies mainly focussed on the perspectives of health care providers and did not specifically focus on the patient's perspective.

Mehuys et al. (2012) for example conducted a survey among home-dwelling older adults who used medication chronically, of which over a third were habitual BZD/Z users. The study recruited participants through 86 Flemish community pharmacies. The outcomes of that study included recommendations for community pharmacist intervention in medication management and suggested that chronic BZD/Z use could be improved by pharmaceutical care services through applying a minimal intervention strategy to reduce chronic benzodiazepine use (i.e. through a discontinuation letter).

In a study on the perceptions of GPs on polypharmacy, older patients' strong belief in their sleeping medication has been reported as a major barrier in deprescribing (Anthierens et al. 2010). Anthierens and her team (2009) also focussed on residential care. This study with nurses mainly revealed that habitual use of BZD/Z in residential care is generally not considered to be problematic, and motivated in light of working towards the comfort of the elderly patient. BZD/Z are seen as an easy option, with relatively few side-effects. Ever since, several projects have been implemented to work on deprescribing in Flemish nursing homes (Azermai et al. 2017).

3.4. BELGIAN POLICY INITIATIVES

As an implementation of the Federal Policy Note on Drugs from 2001 which stipulated that there should 'be a prevention campaign to make the population aware of the dangers of benzodiazepines (also including driving risks)', the Federal Government has launched several campaigns to raise awareness among the population of the dangers of the overuse of sleeping pills and sedatives. The first campaign was implemented in 2002 (see annex 1). This initial campaign was a general information campaign on sleeping pills and sedatives, aimed at the entire population (distributed via TV, radio and brochures).

Subsequent campaigns (see annex 1) focused mainly on the personal interaction between healthcare providers (GPs and pharmacists) and patients and lead to the creation of leaflets and posters distributed to all GPs and pharmacists to use in their waiting room or pharmacy, a resource book for GPs and pharmacists with information about sleep and sleep sedatives, alternative treatments, medication tapering and motivational interviewing (aimed at behavioral change) and an interactive training module for GPs.

Since 2013 the coordination committee of the Belgian Psychotropics Expert Platform (BELPEP) – a platform established by the then federal Minister of Public Health - aims to promote a more rational and adequate use of psychoactive medications, including benzodiazepines, psychostimulants, antidepressants and antipsychotics. The platform unites experts from various disciplines such as GPS, psychiatrists, geriatricians, psychologists, pharmacists and federal services (e.g. FOD, FAMPH, Sciensano).

The main tasks of this interdisciplinary platform are sensitization through campaigns, development and implementation of guidelines, scientific advice and an active support of monitoring and research. The platform consists of three working groups, focussing respectively on adequate use amongst adolescents, non-institutionalised adults and institutionalised elderly. In 2014 a global vision paper and action plan of the different working groups was published in which the background and history of the federal campaigns was described (https://www.health.belgium.be/nl/belpep-globale-visienota-en-actieplan).

4. CASE STUDY 1: ONLINE TALK ABOUT SLEEPING MEDICATION IN A FORUM FOR OLDER ADULTS

4.1. INTRODUCTION AND BACKGROUND

It is estimated that in Belgium, one in every three users who starts benzodiazepines and Z-products (from here on referred to as BZD/Z) for sleeping problems, stress and anxiety still takes these medications after 8 years (Van Hulten et al., 2003; Christiaens et al 2018). Long term, habitual use (more than four times a week for more than six months continuously) is not recommended due to adverse effects such as tolerance, physiological and psychological dependence and withdrawal and rebound symptoms, even when used in low and constant doses (Kurko et al., 2015; Soyka, 2017; Smith and Farrimond, 2019). With figures ranging from 13% to 17% of the total population -depending on the time frame- the consumption of sleeping medication and sedatives in Belgium is widespread (De Donder, 2017). As such Belgium ranks indisputably high in international comparisons. Generally, the use of BZD/Z increases with age, while there is also a remarkable peak in use around retirement age especially among men (van de Straat and Bracke 2015). People within the age range of 50-59 just before retirement age have also been found to be more prone to sleeping problems than older cohorts and tend to medicalise sleeping problems more (van de Straat et al 2018) especially if they need to engage in work-related responsibilities. BZD/Z usage is especially troublesome among people over 75 with 37% of all women and 28% of all men using BZD/Z in this age group (Gisle et al., 2020).

The heterogeneous group of older adults or people over 50 currently also forms the fastest growing group of Internet users in Flanders (Huisman et al., 2019). Digital activities such as searching and sharing health related information have increased steadily, especially in the age group between 50 and 65 (Huisman et al., 2020a). The increased sharing of medical(ised) information on the Internet and provision of support through online forums allow users to connect to peers in similar situations (Fox et al., 2005a, 2005b; Williams et al., 2008; Fixsen and Ridge, 2017; Lewis et al., 2018; Huisman et al. 2020b). Some BZD/Z users prefer such online communication channels over seeking face-to-face help, because of the anonymity of online sites, a reduced risk of social embarrassment, and an increased possibility to exert choice over what they say and with whom they interact (Fixsen and Ridge, 2017).

In addition, the accessibility of such digital channels regardless of time and geography might also be particularly important for less mobile older adults. Users of these digital forums often act as expert consumers who use online information to actively make individual choices about their health apart from the supervision of their physicians (Declercq et al., 2018). Online forums thus open up new avenues for studying lay understandings of BZD/Z use. In this chapter we present results of a discourse analysis of online posts on BZD/Z use gathered from the most widely used online Flemish forum for people over 50 to analyse a) how the use of BZD/Z is discursively negotiated within an online community of older adults and b) how these older adults describe, justify or oppose the use of BZD/Z in online talk.

As such we aim to provide additional insights into a relatively underexplored field, as very little qualitative research has been conducted on how long term users understand and negotiate the habitual use of sleep medicines (Gabe et al. 2016) even less so in online settings. Yet, talk in Internet discussion forums is markedly different from both casual conversations as well as from therapeutic interactions between health professionals and patients, as those who interact with each other do so anonymously or through pseudonyms and know little to nothing about one another's identities and backgrounds (Morrow, 2006). As such our research aims to fill an important gap in the existing literature.

4.2. METHODOLOGY

4.2.1.ETHICS

Data were collected after obtaining written consent from the administrator following guidelines for analysing online support forums developed by Smedley and Coulson (2018). Several measures were established to protect posters' privacy: 1) anonymization by removing all potentially identifying information, 2) paraphrasing, 3) using composite analytical accounts of multiple messages without direct quotations and 4) fragmentation of translated quotes that are discursively relevant (Sugiura et al., 2017; Smedley and Coulson, 2018).

4.2.2.ONLINE DATA COLLECTION

For this case study data were gathered from the most popular and well-established Flemish website for active over-50s and its open-access public forum. With nearly half a million unique visitors monthly and a history of almost 20 years (started in 2001) this online community is of particular interest because of its wide range and broad audience in the entire Dutch speaking area (in Belgium and the Netherlands). As such, this case study offers a unique insight into how people in the age group that is known to use most BZD/Z-drugs negotiate the use of these medications in online interactions.

In a first phase this forum was systematically screened for relevant accounts on BZD/Z use (of both users and former users) as well as general opinions on sleeping medication and tranquillisers. In addition a more detailed search was conducted with specific keywords related to sleeping medication, tranquillisers, sleeping problems and dependence to avoid missing relevant posts. A total of eight discussions -initiated between 2013 and 2019- including 165 postings were collected. These data were gathered by manual copy-paste function into a Word document after which they were raw-peeled in a second phase (Salzmann-Erikson and Eriksson 2012). Raw peeling of the forum data resulted in downsizing from 58 pages (18 413 words) to 45 pages (15 642 words) (12 pt text, single spaced). After removing identifiable data, these text files were uploaded in NVivo for analysis.

4.2.3.DESCRIPTION OF DATASET

The selected posts were written by 54 different pseudonyms. Posting frequency by pseudonym varied between 1 and 14 posts (av:3, m:2). A total of 21 pseudonyms pertained to female posters, an equal number to male posters and 12 pseudonyms could not be assigned to a specific gender. Regarding the use of BZD/Z a third (18 posters) positioned as current habitual users of BZD/Z, among whom two persons clearly expressed a wish for cessation. In addition, six posters identified as former habitual users of BZD/Z who tapered off and quit using BZD/Z. Contrastingly 15 posters presented themselves as fervent non-users. An additional number of 15 posters only offered general advice to their peers without revealing whether they were using or had ever used BZD/Z. Over half of the posters (n=29) clearly expressed having sleeping problems, and only four explicitly stated not having any sleeping problems. Another 21 posters did not explicitly mention any type of sleeping problem.

Not all habitual users mentioned their type of medication. The types of BZD/Z mentioned are: zolpidem/ Stilnoct® or Zolpidem EG® (n=5), bromazepam/Lexotan® (n=4), lorazepam/Serenase® or Temesta® (n=3), lormetazepam/ Loramet® (n=1) and alprazolam/Xanax® (n=1). In addition, some forum members mentioned taking medications for their sleeping problems that do not pertain to the class of benzodiazepines, especially trazodone/Trazolan® (n=5) but also prothipendyl/Dominal forte® (n=1).

4.2.4.DATA ANALYSIS

4.2.4.1. THEORETICAL FRAMEWORK

Discourse analysis of naturally occurring speech and text on Internet forums is a fairly new means to explore and understand health behaviour (De Simoni et al., 2014). We adopted a critical social-psychological framework (Wetherell and Potter 1988, Potter 1996, Potter 2004, Goodman 2017) for its focus on talk and text as social practice. This strand of discourse analysis is commonly applied to understand how language is used to create and enact health activities such as the use of medication for sleeping problems, as people make sense of their health choices by drawing on and reconstructing social representations that are embedded in everyday language (Starks and Brown Trinidad 2007, Ceuterick and Vandebroek 2017).

The main conceptual pillar within this type of discourse analysis is built around the notion of interpretative repertoires. Interpretative repertoires are recurrent discursive patterns and culturally coherent ways of talking about certain practices -in this case medication use-, drawn on to enable and legitimate those practices. Thus, interpretative repertoires are the discursive building blocks for constructing versions of medication use and health-related choices. Each repertoire contains a restricted range of stylistic and grammatical modes and is made up of a central set of recognizable themes, metaphors, commonplaces and tropes (Wetherell and Potter, 1988; Wetherell 1998; Wood and Kroger 2000; Goodman, 2017). A repertoire enables its users to place their accounts of -their or others'- medication use in relation to socially normative ways of being. Repertoires -or in Wheterell's (1998: 400) words 'culturally familiar habitual lines of arguments'- have been explained to have a metaphorical 'off the shelf' character like books in a library that are known to all and publicly available to be borrowed when needed (Jolanki et al., 2000). Yet, just as library collections are not endless, there is no unlimited freedom of choice with regard to the repertoires that can be taken up, as these are governed by culturally available resources (Juhila, 2009).

4.2.4.2. ANALYTICAL PROCEDURE

The data analysis procedure was developed by the first author and revised by the other authors in an iterative process (see also Dew et al. 2014). Initially the dataset was coded based on recurrent themes, including statements about sleeping problems and anxiety that offer insight into how medication choices are made, tacit rules of inclusion and exclusion which prescribe what can be said and thought in relation to BZD/Z and the emergence of opposing argumentations both within and between different discussions and over time. To identify interpretative repertoires, the dataset was subsequently scrutinized for recurrent linguistic patterns of argumentation and rhetorical tools, including the organisation of talk around contrasts, repetition of words and grammatical structures, metaphors (Wetherell and Potter 1988), micro narratives or brief narrative fragments (Recuber 2015) and other discursive devices described by Wood and Kroger (2000). In the next phase, posts from different discussions were reorganised per pseudonym to explore tendencies in individuals' accounts. To connect emerging repertoires to types of users, this reordered dataset was analysed afresh based on the emerging framework of interpretative repertoires. This final coding was performed independently by two different researchers to increase the reliability of our results. Diverging interpretations were discussed until consensus was reached. To illustrate the observed patterns, selected excerpts were translated into English and paraphrased for privacy reasons.

4.3. RESULTS

Our analysis revealed five different interpretative repertoires, used to account for BZD/Z use by older adults who contribute to the forum discussions. In the following part, each repertoire will be described. Overall, over the years a debate is unfolding between on the one hand adepts of non-medicalised solutions who deconstruct the idea of sleeplessness in ageing as a disease and rather describe it as a natural feature of the ageing process to be treated with natural remedies (by drawing on the risk and addiction, alternative pathways and cessation repertoires), and to a lesser extent advocates of a medicalised solution for age related sleep problems (who retreat to the emotionalisation or rationalisation repertoire).

Repertoire	**Bottom-line**	**Discursive devices**	**Explanatory model on sleeping problems**	**Type of BZD/Z user**
Risk and addiction	BZD/Z are harmful, addictive and provide side-effects	Biomedical vocabulary (neutrality effect) Category entitlement (fact construction) Metaphors and hyperboles (stressing the negative effects of BZD/Z)	n.a.	Nonuser (without sleeping problems) Nonuser (with sleeping problems) Former
Alternative pathways	BZD/Z can be avoided, other solutions for sleeping problems are possible	Micronarratives (fact construction) Hedging	Psychological Biological	Nonuser (with sleeping problems) Former
Emotionalisation	I deserve BZD/Z to help me	Metaphors and hyperboles (stressing the negative effects of insomnia)	Psychological	Current habitual (no contemplation)
Rationalisation	BZD/Z are beneficial and I use BZD in moderation	Diminutives Metaphors and euphemisms (stressing the moderation of their use) Comparisons and trade-offs Sophisms (disengagement beliefs) Recognizing truth (‘argument of control’) Corroboration (support by GP) Active voice (first person agency)	Biological	Current habitual (contemplation)
Cessation	BZD/Z use can be stopped without major issues even after years of use	Active voice (regarding tapering off, cessation agency) Passive voice (regarding previous prescriptions, divert responsibility) Metaphors (stressing negative aspects of BZD/Z) Micronarratives (fact construction)	n.a.	Former

Table 1 Overview of different interpretative repertoires on BZD/Z use

4.3.1.RISK AND ADDICTION REPERTOIRE

The first repertoire contains multiple warnings against the use of BZD/Z. The emphasis lies on negative aspects and inherent risks of habitual of BZD/Z use. In this repertoire BZD/Z are considered harmful. Posters who rely on this repertoire, emphasis both physical and psychological addictive properties, a risk of habituation and underline side-effects of BZD/Z as serious health threats.

> *'You can get side-effects, hallucinations, strange thoughts…'*

This repertoire is used by both fervent non-users and former users, and is applied with the aim of warning others for the pitfalls of long term use of BZD/Z, to either dissuade them from starting or persuade them to cease. The tone of this repertoire is cautionary. '*My motto is: DO NOT TOUCH IT ☺', 'It is best to avoid'*.

Post that pertain to this repertoire are formulated either in a more factual way (when sec information on side-effects and addictive properties are stressed) or in a more moralizing way (containing blunt anti-drugs statements). The discursive devices linked to this repertoire include firstly the use of a seemingly objective biomedical vocabulary on risk and harm. This includes statements about potential physical addictive properties: *'Sleeping medication is addictive'*, *'There is a risk of addiction', 'These are drugs', 'Sleeping pills are drugs and many people are addicted to them'* as well as statements about psychological dependence: *'It's all in the mind', 'It's the idea', 'It's in your head', 'It's a placebo, the idea that you have taken it offers peace'*.

Secondly, to justify their claims and build up factuality users of this repertoire rely on category entitlement, a tool based on the idea that certain categories of people are considered knowledgeable about a specific domain (Wood and Kroger, 2000) and thus offered credentials to make statements about BZD/Z/sleeping issues.

> *'Anything is better than those addictive benzodiazepines. I recently met someone who had been admitted several times for an addiction to these drugs… so no laughing matter. If you don't stop in the short run, then you will always need more. And if you use it with alcohol, then all bets are off.'*

Thirdly, metaphors and hyperboles or stylistic exaggerations are used to stress side-effects (such as drowsiness) or to embellish accounts of negative effects

> *'If I'd take them I'd sleep three days straight.'*
>
> *'Sleeping medication is as unhealthy as smoking, and creates holes in your brain.'*
>
> *'I prefer to live without all that sedation.'*
>
> *'When I use bromazepam for a while, I can hardly eat, with every bit that I swallow I become nauseous. Nothing tastes good anymore and my stomach feels so chemical.'*

4.3.2.ALTERNATIVE PATHWAYS REPERTOIRE

The second repertoire is built around the idea that BZD/Z can be avoided as other solutions for sleeping problems are possible. This repertoire contains myriad nonpharmaceutical alternatives packed in different accounts of experiential knowledge on natural sleeping aids. As shown in annex I, the range of user-shared instructions to treat sleeping problems is broad and can be subdivided into advice based on a biological explanatory model of insomnia (in which distorted sleep is seen as a disease with a physiological basis) and a psychologized explanatory model of insomnia (in which distorted sleep is seen as a treatable underlying symptom of another problem). Based on the former vision, suggested sleeping treatments include sleeping aids of 'natural' origin such as prominently discussed melatonin preparations and herbal remedies. The latter model on the contrary supports an array of psychological recommendations on sleep hygiene and bedtime rituals, lifestyle changes that might positively influence sleep and psychosocial advice. The overall tone of this repertoire is positive and allows a comforting recognition of the possible impact and burden of sleeplessness, sleep disruption and deprivation, while simultaneously presenting less harmful solutions. All of these solutions are experiential, informal ways to treat sleeping problems. Posters who rely on this repertoire did not recommend consulting a general practitioner or other health care professionals.

Type of advice	***Examples***
Natural sleeping aids	Melatonin
	Herbal remedies (Bach Blossom, valerian, chamomile, lemon verbena)
	Home remedies (fresh chamomile, celery, cherry juice, hot milk)
Psychological advice	Autogenic training
	Focusing on relaxing
	Not worrying
	Acceptance or adjusting expectations regarding sleep
Sleep hygiene and bedtime rituals	Reading
	Taking a hot bath before bedtime
	Avoid daytime napping
	Avoid going to bed too early
	Avoid using electronic devices in bed
	Avoid falling asleep in front of the tv
	Avoid watching thrillers or action movies just before bedtime
	Avoid staying in bed when waking up during the night
Lifestyle changes	Eating habits (avoidance of drinking coffee at night, dining late)
	Screen time
	Physical exercise
	Outdoor activities (gardening, camping)
Psychosocial advice	Seeking social contact (joining a club, volunteering)
	Other meaningful activities (adopting a pet)

Table 2 Overview of peer advice in the alternative pathways repertoire

This repertoire is drawn on by non-users and former users alike, as well as by current users who are (actively) preparing to stop. Two types of discursive devices mark this repertoire. Firstly, micronarratives on personal successful experiences with non-pharmaceutical alternatives are used to subtly dissuade others from using medication. As such they serve to underline the usefulness through discursive fact construction.

> *'A warm bath in the evening helps to relax. I also read in bed every night until I fall asleep. When I wake up at night, I read and quickly fall asleep. With reading you avoid worrying about what keeps you awake.'*
>
> *'I just wait until I fall asleep. The more you focus on the fact that you are supposedly not sleeping well, the worse it gets. Every night is different. Usually after one or two sleepless nights I sleep much better the next night. I think sleeping for four hours continuously is quite an achievement. Usually I wake up*

> *because of the pain, but this will pass too. So for the time being, no pain relief, if it can be done differently. And certainly no sleep medication!'*

This repertoire is further characterised by the use of hedging, a discursive technique in which claims are subtly weakened to safe face, mainly through the use of conditionals. Examples include: 'If it does not benefit, it will not harm', 'You can take Rescue night Bach blossom', 'Valerian might help too, it calms and relaxes'. Posters thereby simultaneously prevent negative feedback (in case the recommended approach would not work), while also preventing to come across as pedantic.

4.3.3. EMOTIONALISATION REPERTOIRE

In this repertoire BZD/Z use is supported and motivated based on emotionalized arguments. Posters who rely on this repertoire maximalise the severity of either the circumstances that initially lead to the use of BZD/Z (loneliness, psychological suffering due to loss of a loved one, physical suffering due to severe illness or damaged biorhythm due shift work) and/or suffering as a result of sleeping problems. In this repertoire, the detrimental impact of sleeplessness and the impact of the lack of sleep on one's normal functioning is highlighted and magnified to justify the habitual use of BZD/Z. Discursive devices that are used to underline the severity of their personal situation, include metaphors and hyperboles:

> *'Lying awake in bed is hell.'*
>
> *'A lack of sleep turns me into a zombie.'*
>
> *'Sleep absenteeism, obstruction and deprivation are used as means of torture…'*
>
> *'The minister who wants to reduce BZD/Z use should experience what it feels like not sleeping for three days, like a zombie, exactly!'*

This is sometimes further amplified by stressing the lack of understanding from health care professionals ('doctors don't know how bad my situation really is') by which posters implicitly demand not to judge them, as even professionals cannot understand their situation. This repertoire was only used by habitual BZD/Z users, remarkably mostly people who sought advice on starting more potent BZD/Z medication and in one instance also when opposing a federal prevention campaign.

In this repertoire, sleeping problems are presented as psychological in origin. Although this idea also occurs in the alternative pathways repertoire, possible solutions differ considerably. Sleeping problems are portrayed as unsolvable by alternative means and the underlying cause of sleeping problems is presented as something unrestorable, thereby further justifying a permanent need for BZD/Z. By magnifying the severity of underlying causes or consequences of sleeping problems, users of this repertoire present themselves as deserving of their medication. This idea of irreversibility clearly also indicates a denial of personal agency.

4.3.4.RATIONALISATION REPERTOIRE

A fourth repertoire was also uniquely used by current habitual users, who unlike users of the emotionalisation repertoire also showed an awareness of the potential negative aspects of BZD/Z use. As such this repertoire contains myriad rationalisations to ease the apparent conflict or cognitive dissonance between the use of BZD/Z and prevailing norms and knowledge on potential negative effects. In this repertoire, the (risk of) BZD/Z use is minimalised and presented as beneficial when used rationally and controlled. Posters who rely on this repertoire thereby protect their self-esteem and neutralize self-blame by employing linguistic devices to convince themselves and others that it is acceptable in their current situation to use BZD/Z. Doing so, they discursively negotiate the stigma of addiction and actively resist being positioned as addicted. Either directly by saying that 'addiction is a choice', or more implicitly by using seemingly more objective or rational(ised) reasons. This stands in strong contrast to the emotional reasons and tone in the previous repertoire.

Posters who rely on this repertoire seem to constantly negotiate the negative aspects of BZD/Z use either implicitly or more explicitly, often through a combination of multiple discursive devices. A typical tool uniquely used in this repertoire are trade-offs. The potential benefits of longer and better sleep is said to outweigh the (known) risks and users who rely on this repertoire tend to prefer the option of risk management. Examples include: *'Better to take a pill every now and then, to get a good night's rest than to lay awake every night', 'insomnia is a heavy burden on our daily lives'* or this more metaphorical and implicit formulation: *'sleeping healthily is a dream for many'*.

This repertoire is further exemplified by the use of myriad minimisation techniques. Diminutives are employed to underline the moderateness of the use or dosage, such as *'a little pill', 'a little relaxant before bedtime', 'a little Trazolan®', 'a tiny half', 'mother's little helper'*; metaphors and euphemisms: *'a relax pill', 'it is not a sleeping pill but a pill to fall asleep', 'it is an additional sleep aid'*. Another minimisation technique involves minimalizing the dosage or frequency of use: *'I have been tapering down from 1 to ½ pill', 'I only need them at night', 'I take half a pill every evening', 'one little tablet for the entire night'* or stressing the limited need *'I only need a pill to fall asleep not to continue sleeping through the night'; 'I use it when I haven't been sleeping well for a couple of nights in a row', 'I do not use them daily', 'I only use them to rest at night and to be alert during the day'*. Comparisons of personal medication to medications that are considered to be more harmful serve the same purpose (especially Z-drugs are considered less harmful than benzodiazepines).

Furthermore, sophisms or false arguments around prolonged use or age serve to make motivations appear rational and are so-called fact constructing techniques: *'if you take it for that long, it can't be bad'* and *'starting with something at our age is often not as harmful as when you start at a young or middle age', 'at our age it is necessary to take pills'*.

Another technique used in this repertoire to render one's own position reasonable is recognising truth in other positions on the negative impact of BZD/Z:

> *'An addiction, especially to sleeping pills, is something you are in control of, rather than the (little) pills themselves.'*
>
> *'It is not because you use sleeping pills that you become addicted.'*

Moreover, corroboration techniques are used to avert negative comments and avoid responsibility: *'upon advice of my pharmacist', 'under the supervision of a GP'*, as well as tropes that underline the freedom to decide on one's health choices: *'I am old enough to choose wisely with the support of my GP', 'third agers are capable of deciding for themselves', 'everyone has a personal sleeping story, and it's hard to account for someone else'*.

Positive metaphors and emoticons were also used to underline the benefits of BZD/Z: *'and we slept happily ever after ☺👍'* (smiley and thumb up). Such expressions are used to limit further discussion about the possible negative effects all together, and are specific to online forms of interaction in which a discussion can be closed with one such reply.

In the rationalisation repertoire insomnia and sleep distortion are further portrayed as medical issues related to ageing or an imbalance in hormones. This medicalised framing of the underlying reason for using BZD/Z as a biological imperative clearly limits possible treatment options and thus implicitly serves to justify the use of medication. Habitual users also relate their sleeping problems to other inherent traits such as one's personality, genetically inherited traits or to age (*'short sleeper', 'perfectionist', 'already as a child', 'continues to determine your sleep for the rest of your life'*).

4.3.5.CESSATION REPERTOIRE

In the final repertoire, the use of BZD/Z is presented as something that can be stopped relatively easily. This repertoire is used by former users, who successfully stopped. Tapering off (stopping gradually) is recommended and presented as something that can be achieved easily, even after years of habitual use. Possible difficulties related to cessation are therefore minimized. The tone of the repertoire is mild, non-judgmental and positive and therefore encouraging for users who contemplate to stop. The repertoire emphasises personal agency and self-determination, mostly reflected in the use of the active voice regarding tapering off and cessation:

> *'You can easily get rid of benzodiazepines such as Trazolan® (sic). The problem is rather the fear of not being able to fall asleep and thinking I am not sleeping yet or lying awake, waiting to fall sleep. Think of fun moments from the past when you could still fall asleep without sleeping pills and focus ONLY on those memories, if necessary on childhood memories. For me this works fine....'*

Contrastingly, this repertoire is also exemplified by the use of the passive voice when referring to the initial prescription, thereby diverting responsibility and avoiding agency regarding the initiation of BZD/Z use. *'It was prescribed to me by the doctor as a sleep regulator', 'I once had to take something to be calm and sleep well. Yet, in the long run, I wanted to quit because I didn't want to abuse pills.'*

Additionally, micro-narratives serve the purpose of fact construction:

> *'After losing a beloved one, I took pills for six months and got rid of them again effortlessly'.*

Moreover, former users do not explicitly mention help from health care professionals when tapering off. This omission further emphasises their personal agency in the decision to quit, which is also illustrated in the use of the first person singular. Personal reasons for stopping are mostly described as self-directed, inspired by a decreasing effectiveness or out of fear for side-effects (*'I did not want to abuse medication'*). Discursive devices that are used to underline this include some metaphors that negatively portray BZD/Z: *'I just stopped with that chemistry'*.

These arguments partially overlap with the risk and addiction repertoire. Yet the cessation repertoire stands out, as it is something that only recovered former users (as peer experts) can claim, while the risk and addiction repertoire is also used by fervent nonusers to reject and judge the use of BZD/Z. On the other hand the cessation repertoire also includes psychologized advice to focus on an acceptance and normalization of sleeping problems related to ageing, which are ideas that align with the alternative pathways repertoire.

4.3.6.COMBINING REPERTOIRES

The majority or a bit over one third of all posters (31%) relies on the alternative pathways repertoire, while 23% on the other hand relies on the rationalisation repertoire. The risk and addiction repertoire is employed by 10%. The emotionalisation repertoire is used by 8%. Almost a quarter of all posters (23%) relies on a combination of repertoires (see table 3). This shows how repertoires can be selectively drawn upon and reworked (Potter 1996). For instance, the cessation repertoire which is uniquely used by former BZD/Z users, is always used in combination with the risk and addiction or the alternative pathways repertoires to underline the necessity of cessation (through displaying negative effects) or to illustrate the feasibility of cessation (though alternative means). Habitual users who actively contemplate to taper off through alternative means often rely on a combination of the rationalisation repertoire with elements from the alternative pathways repertoire. Furthermore, the combination of repertoires by one poster is not always condensed in one post or discussion but also evolves over time. For example some users moved on to actively seek help after contemplating to taper off, while others went through a rebound phase after cessation.

Type of user	**Repertoire(s)**
Non-user	Risk and addiction and/or alternative pathways
Current habitual user (no contemplation)	Emotionalisation
Current habitual user (contemplation)	Rationalisation
Former user	Cessation and/or risk and addiction and/or alternative pathways

Table 3 Overview of possible repertoires per type of BZD/Z user

4.4. DISCUSSION

Like other online health communities, the forum offers both informational and social support, (Nimrod, 2010; Nambisan, 2011; Potter et al., 2016). Technical or 'how-to' information (for example on a stepwise method to taper off or on combining melatonin with BZD/Z) and practical knowledge or often personalized and experiential advice (for example on improving sleeping habits) are discernible in the alternative pathways and cessation repertoires. Emancipatory knowledge or inspiration is discernible both in the cessation repertoire (e.g. in the form of empowering personal micronarratives on cessation) but equally in the rationalisation and emotionalisation repertoires (in posts that plea for a guiltfree use of BZD/Z). As such, the forum also seems to function as a moral compass. All repertoires depart from the -often tacit and implicitly accepted- idea that habitual use of medication for sleeping problems should be avoided. In the risk and addiction repertoire this norm is accepted, and often discursively magnified. In the alternative pathways repertoire this norm is also accepted yet often implicitly. In the rationalization repertoire on the other hand, this implicit norm is acknowledged yet discursively renegotiated. In the cessation repertoire, emphasis lies on how to overcome the use of BZD/Z and as such the norm is implicitly accepted as well. Only in the emotionalisation repertoire the awareness of this norm is more subtly present in that the necessity to use BZD/Z is magnified in such a way that health arguments are overruled all together. Thus, overall, the idea that long-term use of sleeping medication is unfavourable seems to be broadly accepted, even by most habitual users on the forum.

This message has also been spread by the Belgian Federal Government in recent years (for example through the prevention campaign of 2018 directed at first time users). Furthermore, the wide range of non-pharmacological (often personalized) strategies presented in the alternative pathways repertoire is clearly in line with the advices promoted by the government in the mentioned campaign and distributed by the umbrella organization of general practitioners (Cloetens et al. 2018). Nevertheless these campaigns are never explicitly mentioned as a source of information by posters. Posters firstly self-position as experts by experience, rather than as passive recipients of official health advice.

This normative view of BZD/Z is in line with the current healthicisation view on sleep (Hislop and Arber 2003; Gabe et al., 2016; Cheung et al. 2017; Coveney et al., 2019). Healthicisation emphasises the importance of sleep for health, well-being and even public safety, as 'an obligation of every responsible citizen through appropriate lifestyle choices and principles of 'good' sleep hygiene' (Williams et al., 2008: 251). Hence, healthicisation rejects medicalised solutions for sleep management and refers to 'interventions to improve sleep hygiene and encourage healthier sleep-wise or sleep-smart lifestyles' (Coveney et al., 2019: 282). Foresightedness, individual responsibility and asceticism are core values within this discourse (Potter et al. 2016). The ethos of healthicisation thus holds individuals responsible for their actions as they are expected to make the right healthy choices, which is a common element in discourses on active, healthy and successful ageing (see also Bülow and Söderqvist, 2014).

Contemporary ageing discourses generally focus on avoiding ageing and age associated discomforts -such as a decreased sleep quality and quantity- and thereby create a moral framework on how to age well (Liang and Luo 2012, Van den Bogaert et al 2018). Sleep has become a key aspect of 'fashioning the self' in later life (Marshall, 2015), which has to be tailored by the ageing individual. Ageing persons thus have to take sole responsibility for their health and (healthy sleep) choices. Through the myriad examples in the dominant alternative pathways repertoire, peers offer advice (in a very positive friendly atmosphere). Likewise the cessation repertoire is also used to express positive regard and solidarity with those contemplating or struggling to stop. Yet both repertoires also set the tone for what is considered most desirable: a non-pharmaceuticalised sleep. In the alternative pathways repertoire, this leads to the rather contradictory situation in which posters present a plethora of natural (non-pharmaceutical) solutions to resist the decrease sleep quality or changed sleep patterns that come with ageing. Through the imperatives of healthy and successful ageing by not using medication but other alternatives, they also implicitly seem to put forward an ideal of resisting ageing all together. A decreased need of sleep is often feared, resisted and not accepted as something natural. This fear equally occurs in BZD users who opt for a pharmaceuticalised solution and fervent non-users who problematise the issues at hand as well, yet with other solutions. As such they both seem to be susceptible to the contradictory phenomenon of 'post-ageist ageism' (Marshall, 2015). Otherwise put, by constructing ageing and the associated sleep problems as something undesirable, negative ageist stereotypes are reproduced. In fact, only very few posts within the alternative pathways repertoire actually plea for merely accepting a changed sleep pattern in later life (see table 2).

Furthermore, a fear of unhealthy ageing is also discernible in the risk and addiction repertoire, used by both former users and what Gabe and colleagues (2016) have coined 'noble non-users' to warn for the negative health consequences of habitual BZD use. The use of these warnings also leads to very explicitly moralising positioning of the posters. Clearly, using medication with a negative health impact is not quite in line with the moral ideal of successfully dealing with the sleep consequences of ageing. Deviance from this norm is considered morally inacceptable and therefore renegotiated by habitual users, who are also participating in the forum. Users of BZD/Z on this forum seem to feel a need to justify their use (either towards their peers or for themselves in an effort to save face) for which they either retreat to the emotionalisation or the rationalisation repertoires (with the latter being the second most used repertoire). To avoid moral commentaries they either present themselves as 'deserving' or 'responsible' users, a trend that has been documented before (Anthierens et al 2007b, Gabe et al., 2016).

Our findings on the discursive positioning of BZD/Z users confirms much of the identity work that has been presented on the basis of interviews with elderly users of BZD/Z (post-retirement age and oldest-old) in Britain (Smith and Farrimond, 2018) and Finland (Lumme-Sandt, 2000), as well as in focus groups with different age and professional groups (Gabe et al., 2016). Our study adds to this literature on the sociology of sleep, as we use data based on online interactions between elderly, while our data show identity work vis-à-vis peers, in an anonymised setting (and not vis-à-vis a health practitioner or researcher). As such our results illustrate how the forum is a site of moral debate in which those who do not age successfully -by taking medication for their sleep problems- are assisted with 'good' advice, experiential expertise and sometimes moralising and unintendedly ageist and thus stigmatising warnings.

4.5. CONCLUSION

The posters on this forum might not be representative of the entire heterogenous population of people over 50. In Flanders more Internet users over 50 are male and higher educated, although women are catching up (Huisman et al. 2018). This possibly influences the health literacy of the posters in this forum. The discerned healthicisation trend might thus be set by a higher educated segment of technologically literate older adults. Nevertheless our results show a broad range of opinions held by different types of medication users and reflect the possible variation in discursive negotiations of BZD/Z use among this age group, which is theoretically relevant beyond our sample. Even more so since our findings provide additional insights and nuances to previous empirical studies (e.g. Gabe et al. 2016). The fact that the majority of posts relied on the alternative pathways repertoire, also shows that our results could be indicating an ongoing change in mentality on BZD/Z in older adults at large. The older adults active online might be both the early adopters of technologies and changed societal perceptions of medication use and seem to be setting the tone for changing perceptions on BZD/Z use by the majority of older adults.

5. CASE STUDY 2: THE IMPORTANCE OF PEER SUPPORT DURING CESSATION

5.1. INTRODUCTION

Dependence on benzodiazepines (here further referred to as BZD) 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 BZD are highly debatable (Dell'Osso and Lader, 2013). Such long-term, habitual use is not recommended due to adverse effects like tolerance, physiological, psychological and behavioural dependence, withdrawal and rebound symptoms, even when used in low and constant doses or for a short period of time (Soyka, 2017). Eventually, effects of habitual BZD use might be subtle and difficult to differentiate from original symptoms. Moreover, dependence to BZDs have 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 (Wall et al., 2018; Coteur et al., 2020). These strategies include gradual discontinuation completed in primary care, or assisted by community pharmacists. Furthermore, very few users find their way to appropriate residential care (Liebrenz et al., 2015). International studies show that many habitual benzodiazepine and other prescription drug (ab)users who wish to withdraw seek informal support through online chat rooms and forums instead of seeking professional care (MacLean et al., 2015; Fixsen, 2016; Fixsen and Ridge, 2017). Some prefer online communication channels to connect with fellow users rather than face-to-face help, because of the anonymity of online sites. They come with a reduced risk of social embarrassment, and an increased agency in what they say and with whom they interact, in addition to the increased accessibility, unbound to time and geography (Fixsen and Ridge, 2017). Yet, little is known about these forms of help nor about the support, function and role that digital communities play for recovering long term BZD users (MacLean et al., 2015), especially from a discourse perspective (Fixsen, 2016).

In general, online health communities are visited for both the informational and psychosocial support they offer (Davidson et al., 2000; Morrow, 2006; Nambisan, 2011; McDonald and Woodward-Kron, 2016; Rueger et al., 2020). As such, online health communities offer specific forms of expertise. In the existing literature on health and illness, a distinction is often made between experiential, patient or lay expertise (acquired through the lived experience as patient) and clinician, learned or professional expertise (gained from professional training and practice) (Hartzler and Pratt, 2011; Oborn et al., 2019). In this more static conceptualisation, patients are believed to provide emotional support to one another, while clinicians are seen as the source of informational support, or information on how to manage an illness. Experienced patients are equally considered as providers of informational support through their lived illness experience. However, in line with the existing social constructionist and discourse analysis literature we see expertise rather as dynamic, contextual and constructed in discourse and interaction (Armon, 2016; Carr, 2010; Ekström, 2016), and 'something people do rather than something people have or hold' (Carr 2010, p. 18).

Given the described lack of knowledge on informal support for BZD withdrawal, in this chapter, we explore how (former) users talk online about the process of tapering off or reducing BZD, and what kind of expertise they discursively construct in doing so. More specifically, we analyse an online support forum, unique to the Dutch-speaking area, that thematizes benzodiazepine cessation and withdrawal, by relying on a corpus-based approach to discourse analysis. With this approach to discourse analysis, discursive trends are observed based on frequency analyses. This corpus-based approach allows to plough through large datasets and obtain an objective overview of most frequent and repetitive linguistic patterns, which can then be further examined using a qualitative discourse analytical perspective (Harvey et al., 2007). This approach considerably decreases possible researchers' bias (Hunt and Harvey, 2015).

Moreover, our method adds new insight to the field, as to the best of our knowledge, only one study has addressed how English-language digital forums on BZD cessation create co-cultural online communities in which users can share a voice and make sense of their withdrawal experiences (Fixsen, 2016; Fixsen and Ridge, 2017). This study, however, employed a narrative inquiry of autobiographical and online withdrawal accounts focussing further on cessation metaphors.

5.2. METHODOLOGICAL FRAMEWORK

5.2.1. CORPUS-BASED DISCOURSE ANALYSIS

The data was analysed according to the principles of Corpus-Assisted Discourse Studies, also CADS (Baker, 2010, 2006; Baker and Levon, 2015; Hunt and Harvey, 2015; Partington et al., 2013), a data-driven approach using corpus techniques to detect trends in data in a bottom-up fashion. Often, CADS starts with a keyness analysis, which examines the relative frequency of the words in the specific corpus under scrutiny compared to the relative frequency of words of a more general corpus, also called a reference corpus. Taking this list of keywords as a starting point, the keyness analysis is then complemented by other corpus analyses such as other frequency analyses (looking at absolute frequencies of words or word clusters); dispersion (how words are distributed in a text); collocation analysis (how and which words co-occur in the corpus), concordance analysis (how words appear in context). The latter form is a (more) qualitative one, in which the lines in which a particular word of interest appears are read through manually, and, if relevant. CADS thus is a fundamentally mixed-methods approach; a key goal of CADS is to gain understanding of those trends in-depth and in-context (Baker, 2010). In line with this, we undertook a keyness analysis as well as the qualitative analysis of browsing concordances and reading through the corpus..

5.2.2. DATA AND CONTEXT

Data were collected after obtaining informed consent from the website's administrator and hosting organisation. Following guidelines for analysing online support forums developed by Smedley and Coulson (2018), multiple measures are taken to protect posters' privacy (such as anonymization by removing potentially identifying information). For this reason the original Dutch quotes are not added to the manuscript. The data was extracted from the website in May 2020 (MC). A total of 133 discussion posts -initiated between 2016 and 2020- including 2477 postings by 161 different pseudonyms were collected. This resulted in 41516 words for analysis.

The forum is hosted by an organisation for addiction treatment that offers services (including online programs) for people with different types of addictions. One of their webpages provides an online treatment programme to reduce or quit the use of benzodiazepines. This page also contains an open forum for both users and recovered users who act as peer support workers, which is visited by people from the entire Dutch-speaking area (the Netherlands and the northern part of Belgium). The forum has a specific function to order the discussion topics in order of popularity in terms of either the number of times a discussion topic was viewed or by how many answers a topic received, as summarised in table 4.

	Most visited discussion topics (number of views)	*Most answered discussion topics (number of answers)*
1.	Is this relapse? (n= 24369)	Is this relapse? (n= 839)
2.	Tapering off with lorazepam or diazepam (n= 20728)	Tapering off with lorazepam or diazepam (n= 164)
3.	Years of using 40 mg diazepam (n= 4884)	Listing five positive feelings, that is doable (n=123)
4.	Am I physically addicted already? (n= 4578)	How to convert diazepam (n= 79)
5.	Which withdrawal symptoms did you have, and how did you deal with them? (n= 4415)	I've tapered-off clonazepam, but now I'm in a frenzy (n=73)

Table 4 Most visited and answered discussion topics (at time of data extraction May 2020)

5.2.3. DATA ANALYSIS

Before analysis started, this dataset was pre-processed to allow for corpus analysis (JDC). Lay-out, buttons, and text from the forum interface (e.g. the cite button) were deleted, and the corpus was tokenized. Data was analysed using the corpus software package Word Smith (Scott, 2020).

A keyness analyses was performed first using the log-likelihood ratio test with an alpha of p<.01 and a cut-off value of 15.13 (Rayson, Berridge and Francis, 2007). In our case, the keyness analysis yielded 579 keywords. The reference corpus used is the Dutch section for the Dutch Parallel Corpus (DPC), a Dutch-language corpus for written Dutch, consisting of literary texts, instructive texts, administrative texts, journalistic texts, and external communication (Macken et al., 2011). When browsing the forum data[1], we noticed it is mostly formatted as letters, and thus closest to written language, in our case. We therefore selected the written section of the DPC for our analysis.

In our case, we focused on the items with the highest log likelihood score. We globally examined the first 60 ones, and systematically examined the top 30. We chose to focus on the top 30 because of reasons of scope, and because the most important trends in the data that we observed in the first 60 words were all present in the first 30 ones too.

Of the top 30, both authors first checked the concordance lines globally (how the items occur in context), and, of the most frequent items, also the collocations (the words the items co-occur most with). The 30 items were then grouped together based on similarities in meaning or use, resulting in 8 categories (see table 2), and categories of (primary) interest were chosen (categories 1-7). The categories of interest were then revisited again, more in-depth, and specific additional analyses were done of 1) the collocations, 2) cluster frequencies and 3) 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.

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[1] Forum data is particular in terms of genre conventions. When, for heuristic purposes, dichotomizing traditional spoken and written genres, it holds a place somewhere in between; it is not spoken, but still interactional. In the field of computer-mediated communication, it is not as immediate as chatting, and different in terms of how the audience is addressed on social media.

N	Keyword in Dutch	Translation in English	Frequency	Log_L
1	IK	I	1.713	5.500,27
2	JE	YOU(R)	762	2.173,86
3	HEB	HAVE	394	1.623,55
4	BEN	AM	311	1.341,67
5	DIAZEPAM	DIAZEPAM	139	1.268,65
6	AFBOUWEN	TO TAPER OFF	129	1.150,56
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 5 Keyness analysis (first 30 words)

5.3. RESULTS

5.3.1. THE LIVED EXPERIENCE OF BZD REDUCTION

When generally examining our keywords, they primarily provide a picture of *what* is mainly talked about. In our case, the users extensively share and discuss their own experiences of tapering off benzos. This thematic focus of the forum discussions is first and foremost visible in keywords 6, ‘to taper off’ (*afbouwen*), 7 ‘(the) tapering off’ (*afbouw*), and 22, ‘withdrawal’ (*ontwenning*). Also relevant here is that the two most important reasons to start benzodiazepines, ‘(to) sleep’ (*slapen* keyword 15) and ‘anxiety’ (*angst,* keyword 32) appear in the top 30 or right after it, and the word ‘symptoms/problems’ (*klachten*, keyword 17), as well as some of the most commonly (mis)used benzodiazepines (Votaw et al. 2019): ‘diazepam’ (keyword 5, brand name *Valium* also generally recommended as a substitution during tapering off), ‘oxazepam’ (keyword 9, brand name *Seresta*) and ‘lorazepam’ (keyword 26, brand name *Temesta*).

A few examples of concordances for keywords 6, to taper off, are:

1. *I have been **tapering off** oxazepam for a week now. And since today, I am extremely itchy. Does someone else recognize/know this too?*

2. *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.*

3. *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.*

4. *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?*

More specifically, they discuss their current and past uses of BZD, 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 the examples 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 exactly the relationships between reducing dosages and the symptoms that follow that are discussed.

A number of keywords clearly show that when they talk about tapering off benzos, the forum users’ abundantly use firs-person pronouns. ‘I’ (*ik*) is the number 1 keyword, other first-person pronouns are keywords ‘me’ (*me*, *mij*, keyword 24) and ‘my’ (*mijn*, keyword 11). Other relevant keywords here are 3, ‘have’ (*heb*) and4, ‘am’ (*ben*). In Dutch, these verb forms can only be used with first-person pronouns or with second-person pronouns in questions. However, a frequency analysis of the clusters shows that in this data set 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 respectively the same meaning in English, but also as auxiliaries in perfect tenses, and, in the case of ‘am’ (‘*ben*’) in passive constructions. This means they can be used in many different ways, both grammatically and semantically. This is also the case for our data set, as the collocates and concordances of these verb forms show, although most examples are active verb constructions. This points to the fact that that users discuss their own states and actions.

A few specific examples of the use of the pronoun ‘I’ (sometimes in combination with ‘have’ or ‘am’) are:

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

2. *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.*

3. ***I*** *read here '****I*** *sleep so badly, only five hours or so'. Then* ***I*** *think 'if only* ***I*** *would sleep that much'!*

In the concordance lines surrounding keyword 1, 'I', a wide range of aspects of cutting down on the use of BZD appear, which correspond to the aspects found when browsing through the concordance line of the thematic keywords: their current and past uses of BZD, withdrawal symptoms and their strategies to deal with them, visits to health professionals, and so on. The concordance lines furthermore show that the pronoun 'I' (*ik*) often appears in more emotional statements on withdrawal symptoms (example 2). Users also reflect on what they see and read on the forum, and how this relates to their own situation, as illustrated in example 3 (as we will also show further).

A number of keywords also provide further insights into *how* the personal experiences of BZD users are described to fellow users on the forum. One common element is the intensity of that experience, reflected in the keyword 'very' (*heel)*. Like in English, this is an adjective or adverb that modifies the word that follows, so we specifically looked at its right collocates (R1+R2) to find out what it boosts or intensifies in our data set. The most frequent ones 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)*, 'well done' (*knap)*. The concordances of 'very' bring up more adjectives, , but which point to the same direction as the most frequent right collocates, e.g. 'cold' (*koud),* 'calm' *(kalm)*, 'strong' (*sterk)*. The adjectives in this subset of data are 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 further highlight the temporal aspect of the users' experiences, which is also visible in some of the adverbs discussed above: keyword 8 'now' (*nu*)*,* 28 'still' *(nog),* 23 'again' (*weer*). These adverbs of time and frequency point to the fact the users emphasize the lengthy nature and duration of the process of tapering off. This clearly distinguishes the withdrawal process of benzodiazepines compared to other substances and drugs such as alcohol, cocaine or speed. Additionally, concordance lines and collocation analysis shows keyword 28 of noun 'day' (*dag*) occurs as either 'all day' (*de hele dag*) or 'per day' (*per dag*) (also see section on collocates of MG), and related forms.

This first set of keywords thus indicates that the forum mainly thematizes the tapering off of BZD use, 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 legitimizing use and/or resisting reduction. Other aspects of using and reducing BZDs, such as stigma or complications regarding social relations, professional lives, are not discussed extensively.

Moreover, when talking about these experiences, users do so from their own personal perspective using first-person pronouns and active constructions. This indicates the users thus heavily thematize their own experiential knowledge and lived experience. Furthermore, these trends also show how 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 to usurp the rights to act as an expert *patient* (rather than recovering addict), with lived knowledge. These keywords and corpus trends point to the fact that the forum provides a site for the users to complexly discuss 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 impacts their daily functioning.

In what follows, we fill further explore how these lived experiences are discussed, focusing on how expertise and expert identities are constructed in the forum.

5.3.2. THE EXPERIENCE AS MEDICAL: SPEAKING LIKE A HEALTH PROFESSIONAL

A number of keywords specifically point to the fact that the process of tapering off is discussed in extensive technical detail, using specialized language and medical jargon. This is also already visible and the examples from the previous section, but the top 30 also contains three active compound names of popular benzodiazepines as well as the item 'mg', in both English and Dutch short for milligrams. The concordances of 'mg' illustrate the technicality of the forum users' discourse, as well as that the dosage is often discussed specifically in the context of reducing it:

4. *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.*

5. *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 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, and other top 5 collocates being the prepositions 'from' (*van)* and 'to' (*naar)*, that are used to discuss the original and decreased dosages, as well as 'day' (*dag)*. The users thus also use the forum as a site for extensive and detailed reporting of how they are exactly tapering off, in extensive technical detail on which medications they take, and in which dosages. Other examples of technical language are the references to the so-called Ashton Manual (Ashton, 2002), a patient guide or protocol on withdrawal written by a British general practitioner, often colloquially referred to as the 'bible of withdrawal'. However, the following example (as well as examples 5 above and 7 and 8 below), reflect the technical complexity of the discourse best:

6. *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****.*

The highly technical language showsthat with which the forum users discuss withdrawal process and give each other advice shows they are familiar with a particular, medicalized body of expertise on BZD use, and, more importantly, also actively incorporate it in their forum contributions. In doing so, they also put their experience firmly in the biomedical domain, and construct an expert identity around it. More specific of their expert identity construction in the examples are "that is practically nothing", a strong, assertively formulated evaluation (example 4), or the "stubbornly" in example 5.

Moreover, it at times gives their accounts a factual, objective appearance. This is for example illustrated by the referral to active compounds (instead of brand names or generic names), in the meticulous mentioning of dosages or in the myriad references to the Ashton Manual. In order to become a member of this virtual community one thus needs a certain degree of medical literacy and knowledge on BZD to understand the specific language that Is used. Membership thus seems to be delineated by certain tacit rules of conduct, which seem to expect at least some degree of medicalised knowledge and vocabulary. However, as the next section shows, the forum also is a place for dialogue, and, in that dialogue, more emotional discourses, and subsequent emotional support.

5.3.3. SHARING EXPERTISE AND EXPERIENCE

The forum does not function as just a diary for users to log their personal experience or share the technicalities of tapering off. The forum is a place of dialogue and interaction on BZDs, and thus also for sharing, co-constructing expertise, and providing both informational and emotional support. The first indication of this in the keyness list is the second keyword in the list is *'*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 both ways, and in a range of contexts. Users ask each other questions, for instance on what BZD 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:

7. *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.*

8. (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!!*

9. *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 fact that forum users explain things to one another is also visible in the concordance lines of keyword 17, 'benzo' (*benzo*). These concordance lines show that when benzodiazepines are either used to discuss personal usage , but also in assertive statements on how BZD more generally work, and in which users are explaining something to other users. Examples of this latter general assertive category are the following:

10. *And because a **benzo** relaxes muscles, muscle then tense up in the case of withdrawal*

11. *The symptoms that you have definitely also fit **benzo** withdrawal.*

12. *I am making that comparison consciously, because Oxazepam is a quick **benzo** just like Alprazolam and tapering off of quick **benzos** is more difficult than the tapering off of a slow one like Diazepam.*

These examples also contain a number of markers of authority and expert identities: the causal relation in example 8; the 'definitely' in 9, and the note on consciously making a comparison, also indicating the high degree of expert identity construction in these utterances. When further looking at the concordance lines of 'you' (*je)*, it is also clear that *you* appears in posts in which forum users express empathy, and recognize how difficult the process of tapering off benzodiazepines is:

13. *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.*

14. *What a bummer that **you** are in so much pain.*

15. *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, as these are in our corpus when users respond to each other by tagging each other, and that beyond the top 30, in keywords 30-60, keywords such as ‘hey’ (*hoi*), ‘dear’ (*lieve)*, ‘hello’ (*hallo)*, ‘take care’ (*liefs)* occur. Sometimes, the interactional nature is also implicit, in ways it cannot show up in the keyness analysis. For instance in example 8, the user references someone else’s statement on sleeping 5 hours, to then evaluate their own (lack of) sleep. Moreover, the data set contains a lot of direct questions (sometimes with question mark, but also without, such as example 5).

Hence, the forum users’ experiential and medical knowledge is utilized to offer each other 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 elements 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, 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).

5.3.4. US VERSUS THEM: EXPERTISE OF AND EXPERIENCES WITH HEALTHCARE PROVIDERS

Beyond the users themselves and their fellow forum visitors, a third stakeholder that emerges from the keyword list is ‘psychiatrist’ (*psychiater)*, keyword 12 in the list. Both authors coded the full posts in the section of the corpus where health professionals were discussed, for positive or negative sentiment using a five-point scale, to assess their recurring themes, and the messages’ tone. This analysis showed that extracts containing the word psychiatrist present psychiatrists as either ‘culprit’ or ‘ally’. Examples of the psychiatrist as culprit are:

16. *Ultra-short tapering schedule pushed down my throat. The GP also remains behind the **psychiatrist**. I was quite upset about it.*
17. (on withdrawal symptoms) *Why is that so underestimated by a **psychiatrist** or doctor, incomprehensible.*
18. *According to the **psychiatrist** this is not possible because it would contain muscle relaxants*.
19. *If my **psychiatrist** had not retired I would still be on alprazolam.*

In these rather negatively voiced posts, users criticize 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 a certain methods to quit, 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 on the other hand, psychiatrists are rather 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:

20. *I think I will go from 1.25 lora to 8 dia in 5 weeks. The **psychiatrist** will agree with that I guess.*
21. *My **psychiatrist** is going to read up on the Ashton Manual.*
22. *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 were mostly described from a negative or a neutral perspective. To further contextualize this last keyword, we also examined occurrences of the words *huisarts* (general practitioner) and *dokter* (doctor), which showed similar trends. Here, we also found a smaller group of users was very negative, to the extent they had, or were considering legal action:

23. *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**.*

24. *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 your really sick? […] I would gladly tell my story, **this crap must be forbidden**.*

In addition, the data shows that these forum users also share links to stories from English-language media of people who were not informed well about the dependency users can develop on BZD 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. Although this is a specific group of users, it shows that the forum also provides a place to problematize the role of health professionals and the lack of adequate support in most regular health care context in the process of tapering off. Studies do indeed show that many medical specialists show limited knowledge of BZD dependence and withdrawing treatment (Vampini and Gallelli, 2014; Parr et al. 2006). In sum, in their search for support resulting from the absence of adequate medical help, forum users not only search empathy from likeminded peers who fully understand their situation and suffering, but also create a collective identity based on a shared lived experience. Although it has been observed in other contexts that experienced patients provide each other with expert informational support, our data point to a context in which this happens because of the (perceived) lack of recognition and medical expertise (rather than as an addition to formal care typically offered in other support groups).

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

Table 6 Categorization of first 30 keywords

5.4. CONCLUSION

As with medically unexplained syndromes (Greco, 2012) our data suggest a discrepancy between standard biomedical professional knowledge and lay experiential knowledge on BZD withdrawal. This prominent conflictual dimension of BZD withdrawal has led many struggling (former and withdrawing) users to seek informal online help, where the severity of their symptoms is recognised and their suffering legitimised. This also points to a hiatus in the current professional (biomedical) offer. This is also visible in our data. Consequently, as peer expert patients they provide each other: 1) (what they consider) adequate advice, partially based on experiential expertise presented in a medical-technical jargon and 2) emotional support embedded in motivating language. Our results shows corpus-assisted discourse analysis can yield a profound understanding of the forum users' language, communication styles and discourses. Because of the bottom-up 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. As this method has not been applied to similar datasets, nor in this specific language area where the use of BZD is extremely high compared to other European countries, our results add important evidence to the existing body of research on the role of online health communities in cessation. While previous work, such as the milestone article by Fixsen and Ridge (2017) has focussed on online withdrawal stories and the rich metaphors used to bring these experiences alive, our results zoom in on the specific expertise offered by the forum through the corpus-specific language that is used by the forum members. Our study has a number of limitations and calls for further research. Forum data provides an interesting view in community dynamics, but communities can also be exclusive or cause resistance or tension (Kaufman and Whitehead, 2018), as much as they can be inclusive and provide a site for support. Our findings do not shed light on why some BZD users may not choose to use such online support networks. Moreover, our findings on the users being expert patients seem to point to the users having high degrees of health literacy, and it currently is unclear how literacy level play into forum use for online support. Finally, our Dutch-language data only provide insight in one specific community in a specific context; further research is needed to shed light on similar dynamics in other health care systems, and different languages and communities.

6. IN-DEPTH INTERVIEWS WITH (FORMER) HABITUAL USERS

6.1. METHODOLOGY

6.1.1.ETHICS

All interviewees gave their informed written consent (see annex 4). In addition to the general ethical principles outlined in the consent form, we furthermore we strived to offer participants full agency over their data, given the sensitive nature of the data. We therefore included several forms of post-interview checks. A first oral post-interview check was held immediately after the audiotaped interview to check with the participant whether all that talk had been tape-recorded could be transcribed and thus included as a data. In some specific instances respondents had revealed sensitive information they did not want to be included as data, and which were subsequently not included in the full transcript. In addition an further (optional) written post-interview check was offered to participants. Some were happy to make use of this, and reviewed the transcript of their interview. Sometimes this way the original data was further extended with additional written text of the participant, and in some instances small parts and fragments were removed. In all transcripts were anonymised (hence all recognisable elements were removed). Furthermore, the company to whom most of the transcriptions were outsourced (which were not transcribed by any of the team members) signed a confidentiality agreement. Furthermore, situational ethics included asking participants whether they felt comfortable with certain questions or sharing specific information when they gave signs of discomfort, reassuring them when necessary and offering sufficient background information on the research procedure during and after the interview. As a follow-up care each participant received an information leaflet with references to a myriad of sources they could consult for coping with underlying issues, as well as for withdrawing from habitual BZD/Z use as well (see annex 5), as recommended by the follow-up committee.

6.1.2.SAMPLE DESIGN AND RECRUITMENT STRATEGY

A purposive sample with maximum variation with regard to gender, age and type of use (i.e. current/former, indication sleep/anxiety, type of prescriber) was designed to recruit participants, with the aim of achieving substantive representativeness and theoretical generalization (Mortelmans, 2013). Eligibility criteria to participate in an interview included: a minimum age of 18 years, identifying as a (former) habitual user (using at least one BZD/Z for more than 6 months more than 4 times a week), not residing in residential eldercare or psychiatric care or a detention centre and having offered full informed consent.

By making the project widely known to the general population, we aimed recruit a group of participants as diverse as possible. We used a trifold recruitment strategy. In addition to launching the call through various online (social media, study participants recruitment page, specialised Facebook groups and online forums on insomnia, benzodiazepines use, ageing) and offline channels (posters in strategic places such as the University Hospital Sleep Clinic) (see annex 1), it was also decided to actively recruit through word-of-mouth advertising. This allowed to also included people who might otherwise not be in contact with the call (due to, for example, not being active online) or would not spontaneously choose to participate. We thus avoided that only people with an explicit motivation or reason for participation (for example advocating awareness as a former user) would be attracted.

Eventually through the diversified recruitment procedure, our sample included a cross section of the population covering not only a variety of people in terms of age, gender and type of user, but also in terms of socio-economic status and education (including both low to highly educated people), residency and also general health (from no underlying physical or mental problems to chronic illness).

Recruitment	#
Active recruitment through word-of-mouth	16
Online (webpages and specialised social media)	10
Posters	4

Table 7 Recruitment strategy interviews

6.1.3.SEMI-STRUCTURED INTERVIEWS

A total of 30 semi-structured in-depth interviews were conducted between July 2019 and February 2021 with persons who identified themselves as long-term user or former long-term user of BZD/Z (= more than 6 months more than 4 times a week). This means that one third of the interviews could be organised in person due to COVID19 regulations. The other interviews took place either via telephone or via video call through a secured online platform (depending on the preference of the participant). Conducting remote interviews through both channels did not reduce the amount of information shared by the participants or reduce the duration of the interview, this trend is also confirmed in the literature (e.g. Novick 2008, Irvine 2011, Irvine et al. 2013, Jenner and Myers 2019, Howlett 2020). An additional advantage of this method is that the geographical diversity of our sample increased.

The majority of the interviews (n=20) was conducted by the first author, who is a trained anthropologist and a senior researcher with ample experience in qualitative methods. Two trainees (Ellen Tanghe and Ellen Lagast) conducted each five additional interviews as part of their internship or seminar work, after an online introductory training session to the topic guide and the interview method (with specific attention to probing techniques). To streamline interview techniques as much as possible and to rule out possible interviewer bias, each interview was discussed and reflected upon in an iterative process.

Two types of semi-structured interview topic guides were developed, tailored to either current long-term users and former long-term users. In these guides we focused on the desire to quit and motivation to withdraw, and on facilitating and hindering factors during withdrawal. In order to map the experiences of BZD/Z users, we inquired the medication stories of (former long-term users). What context created the desire to start the medication? Why do people use this medication for longer periods? What added value does this have or had for them? Which negative experiences do they have? What is the role of the prescriber? What causes a tipping point in the direction of phasing out for some and what are facilitating factors in this? Both topic guides were validated by the members of the follow-up committee and piloted. More specifically topics addressed during interviews include: (1) Medical information: medicine brand name, frequency of use, dosage, length of use, method of purchase; (2) Personal data: gender, age, occupation, residency, family situation; (3) Initiation: prescription, reason for starting, initiative, follow-up; (4) Health identity and perception of current use: motivation for prolonged use, role of BZD/Z in personal live, meaning of BZD/Z; (5) Social networks: perception by others, use in social network, impact of use on social relations, experiences with stigmatisation; (6) Online behaviour: online information seeking, participation in online fora,… (7) Health literacy: knowledge of long term use and health effects, personal experiences with side-effects (8) Perception of current prevention and sensitization campaigns and initiatives, points of improvement; (9) Dependence: perception of dependence, assessment of personal dependence; (10) Cessation: experience, reasons, aids and barriers and in current users: willingness to stop (phases of Prochaska and Di Clemente, perceived self-efficacy). For an overview of each interview topic guide can be found in annex 6.

The length of the interviews ranged from 20 to 113 minutes, averaging one hour (66"). After informed consent from the participant, all interviews were digitally recorded and then fully transcribed. All interviews were conducted and transcribed in Dutch. Only the quotes in this report were translated into English. We tried to stay as closely as possible to the original Flemish expressions to capture the tone and voice of the speaker as much as possible.

Participants received a gift voucher of 25 euro (to spend in a well-known bookshop) as a compensation for their participation. The persons that were interviewed online received this voucher via mail.

6.1.4.DATA ANALYSIS

Interview transcripts were coded with the aid of NVivo qualitative analysis software, according to the narrative analysis method of Bissell, Ryan and Morecroft (Bissell et al. 2006, Ryan et al. 2007). This approach makes it possible to gain fundamental insights into the subjective experiences of the participants by mapping the language used by them.

All interviews were coded -iteratively- based on 1) recurring themes and topics (= experiences, type of use) and 2) patterns of argumentation and rhetorical tools (including the organization of conversations around contrasts, repetition of words and grammatical structures, metaphors, analogies and enumerations, etc.) (= medication narrative). This led to the presented typology of user narratives.

The data analysis procedure was developed by the first author and revised by the other authors (see also Dew et al. 2014).

6.2. RESULTS

6.2.1. SAMPLE

The interviewees lived all over Flanders and formed a diverse group in terms of both their education level and age. The youngest participant was 20, the oldest 86. The mean age was 57.6 years. Slightly more women than participated (n = 16) than men (n = 14).

With regard to their BZD/Z use the interviewees can be situated in one of the following categories that are in line with the stages of change set out by Prochaska and Di Clemente’s model of change: satisfied users who do not consider to stop, those who describe themselves as 'recovered' (former users), those who consider quitting, those who are tapering off and those who relapsed after one or multiple attempts to withdraw.

The majority (n=17) identified as current long-term users, while seven identified as former users. Two participants were former daily users who now positioned themselves as sporadic instrumental users. Four interviewees were tapering off at the time of the interview. It is also striking that the majority used or had used BZD/Z for quite some years (Av. 11).

Among the current long-term users, the majority were on zolpidem (n=9) or alprazolam (n=8), which are also the most used BZD/Z in the general population (as results from the national Health Survey from 2018 show). This trend is also confirmed in the FAMPH survey from 2020, where almost half of the patients used zolpidem followed by lormetazepam (23%) and lorazepam (12%).

Gender	Women	16	
	Men	14	
Age	20-30	3	
	31-40	2	
(Av.57,6)	41-50	5	
	51-60	5	
	61-70	8	
	71-80	3	
	81-90	4	
Identified as	Current habitual user[2]	17	
	Former habitual user	7	
	Instrumental user	2	
	Withdrawing[3]	4	
Length of use	Minimum	0,5	
(in years)[4]	Maximum	53	
	Average	14,6	
	Median	11	
Indication	Sleeping problems	20	
	Anxiety	4	
	Combination	6	
Professional status	Employed	9	
	Unemployed	1	
	Long-term sick leave	1	
	Disability	5	
	Student	2	
	Retired	13	
Family and living status	Married or cohabiting	No live-in (grand)child(/ren)	8
		Live-in (grand)child(/ren)	8
	Widowed	Living alone	1
		Live-in caretaker	1
	Divorced	No live-in (grand)child(/ren)	2
		Living with (grand)parent(s)	4
	Single	Living alone	2
		Live-in child(/ren)	1
		Cohousing	1
Residency	East Flanders	16	
	West Flanders	6	
	Antwerp	3	
	Limburg	2	
	Flemish Brabant	1	
	The Netherlands	1	

Table 8 Overview of participant characteristics

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[2] We employ the neutral term ‘user’ for a person who takes BZD/Z, since not each interviewee positioned as a patient, and since some also started and/or withdrew on their own initiative without the help of a medical professional.

[3] All these people where contacted again in January 2021 to check in with their withdrawal process. One person meanwhile completely stopped, one person was tapering off further, one person had retreated to sporadic instrumental use and one person had relapsed. As their interview narratives relate to the specific point in their withdrawal process, we choose to list them as they identified at the time of the interview.

[4] Three participants could not remember how long they had been taking BZD/Z, and referred to the length in vague terms such as ‘for years now’. These were not included in these numbers (hence n=27).

The majority of the respondents in this study used just one BZD/Z (n=21). Six participants used two BZD/ Z at the same time, and three people used three different types of BZD/Z at the same time (of these, only one person had been tapered off and stopped in the meantime). More than 22 participants had never switched brand (including four former users), the others had a history of previously attempting other BZD/Z (usually one different species, but two people had tried two or three other BZD/Z before). Other psychotropic medications that were combined with the use of one or more BZD/Z include: escitalopram (Sipralexa® n=2), trazodone (Trazolan®, n=4), flupentixol/melitracen (Deanxit®, n=1), and sulpiride (Dogmatil® n=1).

Former users had most often tapered off from: zolpidem, lorazepam and, not coincidentally, diazepam as the latter this is used as an intermediate step when tapering off from shorter-acting BZD/Z.

Active compound	**Original brand name (in Belgium)®**	**#**
Current use		
Zolpidem	Stilnoct	9
Alprazolam	Xanax	8
Lorazepam	Temesta/ Lorazepam EG	5
Lormetazepam	Loramet/ Lormetazepam EG	4
Bromazepam	Lexotan	2
Brotizolam	Lendormin	2
Prazepam	Lysanxia	2
Chlorazepate	Tranxene	1
Clotiazepam	Clozan	1
Diazepam	Valium	1
Former use		
Diazepam	Valium	3
Lorazepam	Temesta	3
Zolpidem	Stilnoct	3
Clonazepam	Rivotril	3
Bromazepam	Lexotan	2
Flunitrazepam	Rohypnol	2
Alprazolam	Xanax	1

Table 9 Overview of BZD/Z used by participants

6.2.2. MEDICATION NARRATIVES

Two clear trends emerge from the various narratives or stories. On the one hand, we discern the medication narratives of participants who had been using BZD/Z for a long time at the time of the interview. These are often very elaborate medication stories, with many side-lines, sometimes no clear starting point, and an often confused or unclear chronology. Typically, the narrator moves from one point in time to another with no clear introduction or indication of these time lapses. The result is an often long and associative story, which is not organized in an orderly manner over time. On the other hand, we discern the stories of people who have stopped using BZD/Z (sometimes for a long time). These are always clearly delineated stories, with a clear beginning, plot (often the turning point that led to the desire to withdraw) and a clear end point (sometimes with precise start and stop dates).

In the following part, we will discuss the starting point (reason and start of medication and its symbolic value of BZD/Z as a token of concern) as well as the path to long-term, habitual use and the significance of this medication for their users. Subsequently, we will described the experiences of habitual long-term users, who describe themselves as contented/satisfied users as well as those who have a more ambiguous attitude towards their use. Thirdly, we will focus on the stories of people who quit using BZD/Z. What are their reasons for withdrawing? How did it go? What helped and what hindered the process? We will further dwell on these stories of recovery, which in some cases evolved into instrumental use, or sometimes lead to relapse. Finally, the last section further examines the image of BZD/Z. How do long-term and former users deal with the stigma attached to habitual BZD/Z use and the label of addiction? What is the role of the media and specifically that of prevention campaigns in this?

6.2.3.THE ONSET: A BIOGRAPHICAL DISRUPTION

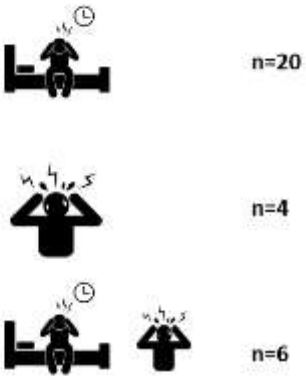

Figure 2 Indications for first prescription

The majority of the participants received their first prescription for sleep related problems (n=20), only a minority for an anxiety problem (n=4) or a combination of both (n= 6). Former users who had tapered off had used BZD/Z for all of these indications (three times for sleep problems, twice for anxiety and once for a combination). None of the respondents started using recreationally, contrary to what has been found in research into BZD/Z use among young people (see Bardhi et al. 2007, Quintero 2009, Pino et al. 2017).

Strikingly, all narratives had a rather similar starting point. Without an exception, all medication narratives, the ported sleep and/or anxiety issues can be directly linked to a major event in the life of the patient, either emotionally (loss of a loved one, child, family problems) professionally (stress due to study or heavy workload, serious incidents at work) or medically (a serious physical condition, unrecognized postpartum depression). These events all caused a sometimes unexpected major disruption or break in the life story of the patient. To restore the negative outcomes of that disruption in the life story, medication was started. Either to be better able to deal with the consequences of the biographic disruption (sudden sleeping problems or anxiety attacks) and to continue 'daily life' as normally as possible and to have as little impact as possible on the regular daily functioning. Usually, the medication is therefore used rather to be able to continue to meet the demands of daily life (for example, to continue to function at work despite sleep deprivation caused by sadness after a break-up) and not so much with what caused these changed sleep patterns or anxiety (i.e. the biographical disruption in itself) (Engman 2019). In this example, it is in fact not the grief about the breakup that the participant wanted to have resolved with medication. In principle, this also means that once the disruption in the life story has been restored (e.g. when the grief has been processed) and daily functioning is in principle no longer hindered, that no medication is needed anymore. On that point, however, many people are already dependent, and cause and effect are often difficult to distinguish. As such, many participants declared to continue to use medication, even when the biographic disruption was restored (for example when retired, when graduated, when recovered from a physical illness, when emotionally recovered from a break-up, etc.)

6.2.3.1. FIRST PRESCRIPTION

The majority (n=25) received the first prescription from a general practitioner (GP). The other interviewees were given a first prescription either by a psychiatrist (n=3), a neurologist (n= 1) or another specialist (n=1). Most of the interviewees explicitly asked for a prescription or directed it themselves (n=18), as is also illustrated in the following quotes:

> *"When I had the feeling that I was no longer sleeping well, I went to the doctor with this question. He prescribed it."* (Man, 84, current use of bromazepam)
>
> *"And then I asked can I get Xanax® because someone recommended it to me. Then my doctor wrote that [prescription] without any problems."* (Woman, 49, current use of alprazolam)
>
> *"It started with my brother, my brother had come-out and that was a huge shock to the whole family (…) yes, I couldn't sleep either. My family doctor was with my parents and I asked please, can I have one too, because I just don't sleep, I lie awake all day. And then I went to see him and he said yes, it is fine, you need your rest, it is difficult and yes, he agreed."* (Woman, 52, current use of zolpidem)

A third of the interviewees (n=10) however, indicated that they had started the medication upon advice of a health care practitioner, sometimes reluctantly as we see in the following examples:

> *"I am always reluctant when they say that you have to take that, because I always said: is that really necessary? But at the time I was so... tired with those panic attacks... because basically I had been taken away with the MUG because I was driving and then I had that panic attack and that was exactly like a heart attack, because I got tingling in the face, pain in the arm, pain in the chest area. So I thought yes, I'm slipping away."* (Man, 29, former use of zolpidem, lorazepam, diazepam, bromazepam)
>
> *"I always have Lendormin®. They have prescribed that from the beginning and I felt good about it (…) My doctor had already said that, I take that too, he says, if I have to get up at night or this and that, hey. That's a little fall-asleep [Dutch: 'inslaperke'], he says. "* (Man, 69, relapsed after withdrawing from brotizolam)
>
> *"When I was pregnant, way back in time (…) And after giving birth to my son then, I went into a bit of a depression and then I was prescribed that. That's how it started. I think that's how it started. Gosh yes that was very difficult. It is only after giving birth that I almost fell into a depression. Exactly that I suddenly couldn't bear anything anymore. Yes, you still hear that people go through depression after they give birth (…) So yes, I started on those pills. Yes, I went to the doctor and he prescribed that medication. Gosh I think it started in 1967, but that was a bit on and off eh. The doctor then said you shouldn't stop (…) I had a hard time and kept on working, but no one has noticed this."* (Woman, 77, long-term use of lorazepam)

Some participants did not have a positive recollection of the first prescription or medical advice, like these people:

> *"They just say ah yes, we are going to give you something that can will enable you to fall asleep well. Voilà. At that time you were actually not informed about it, um, as I say, I was also very young."* (Woman, 41, long-term use of lorazepam)
>
> *"But that was really irresponsible, it was a doctor who prescribed that to me and (…) he said keep taking that, um, and for the rest he didn't say follow a therapy. He said: just take that. "* (Man, 41, long-term use of alprazolam)

> *“I would never take those pills again, I had confidence [in the prescriber] and I didn't want to take cannabis, I didn't want to take any drugs, nothing. Actually, I just felt mislead.”* (Woman, 64, former use of clonazepam)

Furthermore, a few could not remember on whose initiative the first prescription was offered (n=2), while one respondent was given a first prescription as a minor at the explicit request of a parent to the prescribing GP.

> *“I certainly explained my things, my problem of not sleeping. And I think he said then, take a light sleep aid. I think it was. On my own [initiative] I would, I will not have asked. Because I am not .. I have to take medication, but I would not take medication on my own- whereas my husband, he swallows, swallows- If you give him a box, he will take it all. I am more: just the necessary and then stop, eh.”* (Woman, 66, long-term use of zolpidem and lormetazepam)

These findings are in line with the Dutch study by Haafkens (1997) in which 38% (or 19 of the 50) interviewed women were unexpectedly prescribed a BZD/Z and only a third had asked for medication themselves.

It is striking that some interviewees initially started using BZD/Z sporadically through people in their close personal network (partner, (grand/)parent, parent-in-law) often a while before they requested their own prescription from a treating physician (n=4), as illustrated in the following quotes:

> *“I always studied at my grandparents’ place, so I actually got it from my grandmother. I asked her. Yes, but it was only the day before my exam that I took it, once. And only in the last years of my studies. It used to be more a bit psychological: I have to sleep because I have to be fresh tomorrow. It wasn’t so much out of fear of failure, but it was really: I have to sleep, I have to get my hours of sleep to be fresh tomorrow (…) [my grandmother] had been using that for, um, several years. So she had it at home. ”* (Woman, 35, former use of bromazepam and zolpidem)
>
> *“And my mother-in-law always had some kind of sleeping aid in the house. And I have asked a few times, when I was in a period that I thought now I need something, um, a little sleeping remedy/aid, just once a pill or two to take with me. And that, I, yes, I felt good about it, I'll put it this way.”* (Man, 50, long-term use of zolpidem and prazepam)

The story of this young woman stands out:

> *“Well ... to start with ... when I was about thirteen years old in high school (...) I had a bit of a hard time and a little bit difficult behaviour and being unruly eh, and then I got that from my mom eh, because she did that too, was prescribed by the doctor. And that helped her, so she gave that to me too... by the third, the fourth year in high school, I also started using it more regularly. Then it was already through the doctor. But the prescription was not yet in my name… because I was too young, [he] put it on my mama's name, but [the doctor] knew that it was for me and that was also discussed. And then later, in my first or second year in higher education, it was really with the GP and the normal course of events.”* (Woman, 20, former use of prazepam, alprazolam and zolpidem)

6.2.3.2. A TOKEN OF CONCERN

When the medication was recommended by someone else (social network members or a doctor), it is often seen as an empathetic intervention towards the person who is suffering. Passing on, recommending or prescribing medication then becomes a form of care, what Whyte and colleagues (2002) coined a ‘token of concern’. In some cases, this is also felt as such by the participants. When a relative or close acquaintance passes on medication it is experienced as a sign of care. Likewise, a few participants who were asked by people in their close network to share their medication, had a hard time opposing such requests, and in some instances showing empathy won it over from ethical concerns and a correct use of a personal prescription.

For many participants, receiving a prescription from a health care professional is also proof to them that their situation is being taken seriously, is being followed up and that basically, a solution is being offered. For some others, who are more reluctant towards medication in general, this is not the case (see the above quotes of interviewees who did not necessarily want to start medication).

Strikingly, none of the respondents indicated or recalled that their general practitioner or other prescriber discussed alternatives for dealing with the underlying causes of sleeplessness and anxiety. Not even by those who indicated that they did not request the medication themselves. Although the current WOREL guidelines (2018) on the approach to sleep complaints and insomnia in adults in primary care advise to explore and recommend alternative solutions. This finding may be related to the fact that the interviewees had been taking this medication for more than 14 years on average (before this guideline was developed). Some interviewees might also have had a hard time recalling the initial consultation or might unconsciously have omitted that information. Not mentioning that the prescriber provided alternative advice (which was not taken into account) could also be a psychological mechanism to deal with some sort of shame and to avert responsibility.

The role of the prescribing health care professional (GP-psychiatrist) at start-up varies from actively recommending the medication to a great reluctance to prescribe. Sometimes prescribers are put under a lot of pressure to prescribe.

> *"I think it has become a habit somewhere, if I can't sleep, I'm going to see the doctor and I'm going to ask myself something, to be able to sleep, so it's basically so commonplace that everyone does it. I'll just go and ask and maybe I will get it and if I don't get it then I will try to obtain it in another way ... (...) I think that is the case nowadays, that you go to the doctor that it is easy to obtain, and probably already available via the Internet now... so many people also try to obtain it that way."* (Man, 62, former user of zolpidem and bromazepam)

> *"In fact he said I don't really like to give that, and he said you are going to get addicted to it. But I told him I really have to get it or I will go to another doctor. Gosh yes because I slept so little eh. And that helps a bit, so that I can about 6 hours of sleep in total. He didn't like to give it or he didn't like to prescribe it exactly, gosh because he said you're going to get addicted to it, you won't be able to live without it anymore. But I actually have a lot of help from it."* (Man, 86, current use of alprazolam)

> *"I myself had suggested to the doctor whether I could not get a sleeping pill. And he would have said, gosh, a sleeping pill is quickly addictive. I would rather than just give you something little to fall asleep for just a short time. But also not with intention that it would be abused (…) Yeah, we have moved, eh, we have changed [GP] anyway. So now my doctor does prescribe it."* (Woman, 48, long-term use of zolpidem)

> *"And then I went to my doctor once and said that, yes, I was exhausted and that I could no longer sleep after those tasks and she prescribed it (...) I noticed that she was reluctant to do so, because she had written on the label: SOS. She says, only use it temporarily for now, when necessary. Sporadically as SOS…"* (Woman, 35, former use of bromazepam and zolpidem)

In sum, the above results show that a prescription is often the result of a complex interplay between the prescriber and patient, in which the advocate of a medicalized solution (whether it be the physician or the patient) usually seems to draw the longest straw.

6.2.4.THE PATH TOWARDS LONG-TERM USE

Most interviewees indicated that their long-term use became a habit, gradually, and almost unnoticed and unconsciously. This is also the case with the woman from the following quote. Despite the initial cautious attitude of the prescribing physician, she nevertheless continued to use the medication for more than four years:

> *"But I was, well, lucky I guess, that I naturally need less medication, so half [of the standard dosage] was enough for me. So with a box like that I could, yes, take it twice as long as prescribed (...) that happened kind of gradually... I don't remember exactly how it went, but I started to take it much more frequently . Yes, in the beginning I took it every now and then, but then it started to get, um, more chronic (...) It was like I didn't want to risk it anymore to just lie down in bed and wait and... it was there and it was easy (...) I think in the meantime I also asked my [family member] now and then, for bromazepam."* (Woman, 35, former use of bromazepam and zolpidem)

Many interviewees stated that they did not initially intend to use the medication for a long time, as this man:

> *"Yes, I didn't think I was going to take it for that long. But I took it for a few years anyway."* (Man, 62, previous use of zolpidem, current instrumental use of alprazolam)

None of the respondents said they had received or recalled receiving clear information on the long-term effects of BZD/Z use, nor on the recommended limitation of two to maximum four weeks of use. Few interviewees indicated that the prescribing practitioner provided an end date of made explicit for how long they could use the medication. No one indicated that they had received a plan to taper off when the prescription was started. With the exception of a sporadic warning of dependence, the majority of those interviewed did not receive comprehensive information about possible side effects of the medication.

> *"I actually did not receive any advice about this, I did not receive any advice about the duration, or I don't remember it, I did not receive any advice. I do know that it was recommended* [by the GP] *a few times before I actually started taking it."* (Woman, 46, former use of zolpidem)

> *"Actually nothing has ever really been said, that it is quite heavy medication or pay attention or we go for, that he would have said in advance we are going for six weeks and then certainly no longer do something like that, but nothing has ever been said about it."* (Male, 50, tapering off from clonazepam)

> *"I think it should be made clear that this is not just any pill. That it is a pill that has to be watched and dealt with wakefulness. That it also has side effects, as I just told you. I did not know that, yes I was not alert for that, but yes maybe I was alert for that, but I just was not told. Yes I was not told, I am sure. Yes, the other side of the medal should also be mentioned. What are the dangers of that pill? Dangers eh, the dangers! (…) Yes, they should display information very clearly and doctors should display more to their patients. It is actually the work of the doctors as they are the prescribers and need to assist more in monitoring their patients. They are not allowed to just give that at the start for three to four months, but they should evaluate it after a month. And they should be able to reduce if it is not a medical necessity. They should be able to do that, if possible, remove it at start-up. And not let it drag on for a long time, like in my case. Guys you can take it briefly, but you should know that there will also be an end date. And I don't think my GP is strict enough about that either, my GP. Yes and that he doesn't really think about it either. He is not specialized for that either. They have to know something about everything eh. And you shouldn't blame them either. "* (Woman, 58, current use of lormetazepam)

As with the lack of information on alternatives, this finding should be read with some consideration, and could also be at least in some participants a mechanism to avert responsibility or to deal with cognitive dissonance.

Furthermore, no one indicated that the initial prescription was strictly followed by the treating physician. Several participants indicated that their prescription was automatically renewed, often without an actual consultation with the prescriber, in which case they could pick up an extension of the prescription. Some indicated that their prescription was tacitly extended along with other prescription renewals. A few participants experienced more difficulties, but in those instances relied on creative solutions, such as using additional medication from family members, or even changing to another GP.

6.2.5. WHAT DOES THE MEDICATION MEAN TO THEIR USERS?

The reason for long-term use cannot be solely attributed to a sometimes lacking follow-up by prescribers. After all, the significance that the medication has for those who use it is also an important factor. It is striking that even interviewees who had stopped taking this medication also mentioned the personal added value. They talk about "comfort", "help", "support", "convenience". The medication also gives a feeling of "control" and thus security.

Both current and former users described the psychological significance of the medication, which is described as a form of support or aid. Having the medication available provides a feeling of safety and confidence, while for some it allows control over their own sleep (and by extension busy daily schedule).

> *“Yes, I don't think I could imagine myself without this medication. It does make me feel safe. Because yes with that medication my nights are better than without I think."* (Woman, 84, long-term use of bromazepam)
>
> *“Because that is really a yes, I thought it was a great feeling that you take that and set the clock. Twenty minutes later yes, you are sleepy and, half an hour later, you are asleep. And you don't have to worry anymore, you don't have to lie awake anymore, you don't have to wait anymore. So I thought that was a pleasant feeling. It was so, you had control over it. It was, it was, it was actually really easy. You are getting ready to go to sleep, you take it and half an hour later you are sleeping. I was able to time everything much better to get my hours of sleep.”* (Woman, 35, former use of bromazepam and zolpidem)
>
> *“I've always had it at home ever since. Since then there has not been a moment that I have not had it at home. And even to the extent that after a while I just have to take it with me too. Not if I'm going to be with friends, that's another thing. But even when I go to work, it's in my backpack. Just because I know when I have it with me, it is a measure of reassurance in case I should ... err control freak, I've never lost control, but I'm afraid I can lose control of myself."* (Man, 50, long-term use of zolpidem and prazepam)

Usually interviewees appeared to be well aware of this psychological effect. Someone was also literally referring to the medication as a "little psychological pill".

> *“It's all in the mind. It's all in my head. And there is the idea that I need things to relax in the evening to be able to go to sleep.”* (Man, 50, long-term use of zolpidem and prazepam)
>
> *“But on the other hand, I also thought it was an easy solution for myself, so to speak, to take a sleep aid when I went to sleep, knowing that I would then sleep well. So it is partly my only comfort in the evening.”* (Man, 66, relapse after tapering off from zolpidem)
>
> *"You feel, it is a comfort, you go to bed, I sleep my hours."* (Woman, 46, former use of zolpidem)

For many people, the medication offers a sort of mental support, often long after the initial reason has is resolved.

6.2.6.LONG-TERM USE: A LONG AND WINDING ROAD

Although all medication narratives are unique, some major trends can be discerned in this multitude of stories. Two main types can be distinguished in the stories of long-term users. Some of this group does not agree that quitting is a better option. They can be described as "contented habitual users". Another part agrees that quitting would be better, but does not consider it an option feasible.

6.2.6.1. CONTENTED USERS

First, there were people who had been taking the medication for a long time and were quite satisfied with it. The focus of their stories is more on the framing of their life story and the circumstances that lead and motivate their use. These stories are often contained in emotional arguments, intended to provoke empathy: they seem to want to argue indirectly, perhaps even unintentionally, that s/he 'deserves' the medicine or that at least they need the medication. These users did not express any intention to change their use of medication and usually do not see the point of doing so. These contented or satisfied users are mainly going to magnify the reason for their use of the medication in emotional terms.

> *"Tell me, why? Why would you change your wife, if you're fine? Isn't that the same? Why would you push your husband aside, when he does his job, when he does what he has to do? Yes, that's my explanation of it."* (Man, 70, long-term use of lorazepam)

While some slyly dismissed the question of whether they wanted to use the medication differently, as in the above quote, this question also aroused fear or resistance in others:

> *"I don't think I will ever stop taking this (…) I need that medication to get through life, yes. If I didn't have that trazodone and that alprazolam I would be spinning for hours in my bed again. I would not be able to stop my merry-go-round and I would have much less sleep, I would feel very difficult. Because it drives you crazy, if you don't fall asleep. If you, if you can't stop your whirlwind, it really drives you crazy."* (Woman, 49, long-term use of alprazolam)

In Diclemente's and Prochaska (1998) trans-theoretical model of behavioural change, these users would be situated in the pre-contemplation phase (i.e. they do not consider quitting). Experiencing side effects or negative effects is hardly discussed in this group. If negative effects and health problems are discussed at all, they are often minimized or rationalized (benefits are considered to outweigh the disadvantages, which in some cases will of course also be medically motivated and supported).

Within this group, there are several stories of chronic illness, in which the use of BZD/Z is embedded in very complex situations of multiple medication use. These respondents have a very particular ambivalent position with regard to their use of BZD/Z. The woman in the following quote for example is well aware that she might be dependent on the medication, yet in light of the chronic pain she suffers, being pendent on BZD/Z seems a minor issue when compared to the ordeals she goes through.

> *"I realize I am dependent on medication, but I don't mind. In my case, with the medication I'm taking, I don't mind. Because I know if I drop that, then it will be a disaster again and I just don't want that anymore, voilà. There you go."* (Woman, 49, long-term use of alprazolam)

6.2.6.2. AND THOSE WHO DO NOT FEEL ABLE TO STOP

Besides the group of contented users, there is also a group that seemed to be clearly more concerned about the possible impact of long-term medication use on their health, but nevertheless considered themselves unable to change their medication use. Within the circle of change DiClemente and Prochaska (1998) they can be situated within the contemplation phase. They are aware of health risks and also reflect on them. On the one hand they experience their long-term use as problematic, on the other hand they have no intention of taking action. The main reason for this is that these users tended to estimate their chances of success as very low. Hence most were not convinced that withdrawal and cessation could actually work for them.

> *"If I happen to forget one it can be so strange. Imagine being without it for two or three days, it is something quite addictive, isn't it? And yes, I have already tried [to stop], but it doesn't work." Interviewer: what could possibly persuade you to stop? Probably nothing anymore now, at my age… You don't really enjoy life anymore either, you're just alone all day long. I do think I probably need it more now than I used to. You should be all alone every night, it is difficult."* (Woman, 77, long-term use of lorazepam)

Like the woman in the previous quote, some had tried to stop before, but without success. These users generally show a very low self-efficacy when discussing the possibility of withdrawal.

6.2.7. WITHDRAWAL STORIES

The narratives of people who stopped taking BZD/Z show a very similar structure. In these accounts, the initial reasons for starting BZD/Z are quite similar to the reasons of habitual users (i.e. insomnia, anxiety and a combination of both). What stands out is in every withdrawal story, is the precise moment or mental turning point at which someone remembers having decided to taper off and stop the medication.

6.2.7.1. REASONS FOR CESSATION

The main reason for tapering that was mentioned by the respondents is an (often growing) awareness of the negative impact of BZD/Z use on their health and specifically the experience of side-effects. Side effects varied from: forgetfulness, rebound effects (dizziness, hot flushes), dependence (in need of the medication, often in increasing doses), impact on vision and speech, drowsiness/being dazed, changes in personality (aggression, changed perception of reality), reduced sleep quality. The fear of addiction also played a crucial role in many withdrawal narratives.

The impact of one's social network played a less important role. And for some, a combination of factors lead to the ultimate decision to quit. One's close network (partner, children) can sometimes provide the ultimate extra push in the back, especially when they start to notice a negative impact and raise their concern about this. In addition, the authority of a doctor is also important. It is striking that only two people stopped following explicit doctor's advice.

We further illustrate these findings with a few quotes here.

One lady developed memory loss after long-term use of brotizolam and decided to stop out of fear of developing dementia caused by the medication:

> *"So I come to the conclusion that sleep medication has an enormous influence on your memory."* (Woman, 84, tapered off from brotizolam)

Another woman suffered from hot flashes ("vapeurs") for a while and also passed out regularly, at around the same time of the day (6 pm). This bothered her while working. She said the following about this:

> *“I have read about the rebound effect in the package insert. And I have the impression that I actually went through the side effects when the medication wore off. Then I started to see that it was because of that! And now I really have to stop (…) In the long run, when I knew that those complaints were due to that, I sometimes faced a dilemma, what am I going to do now? Lie awake all night?”* (Woman, 35, former use of bromazepam and zolpidem)

A growing fear of developing dependence or addiction was the main reason for several people to quit:

> *"Yes, I think you will eventually -I don't know if that is the case, but I was very afraid that it was- that you become psychologically dependent on it."* (Woman, 46, former use of zolpidem)

> *“I kind of started to have a hard time, because I noticed that it was very addictive very quickly, especially those, eh, sleeping pills. Uh, that you just feel that if you don't use it anymore, you can hardly sleep afterwards. So because of that I started to go against it a bit and tried to hand it off so I would not have to take it. ”* (Woman, 20, former use of prazepam, alprazolam and zolpidem)

> *“Because yes, of course I don't want to stick to it all my life (….) You know that you can fall asleep more easily, that's the solution, that little pill, but it suddenly doesn't work anymore. Or you suddenly don't feel it anymore. So you think come, I want to sleep and this works, you put your confidence in it. And that's what makes it dangerous I think, when you trust that pill and you start to think this is the only thing that works.”* (Man, 29, former use of zolpidem, clonazepam, bromazepam, alprazolam and lorazepam)

> *“I'm a bit afraid of that, that addiction will occur. I'm a little afraid of that. My wife too... It only offers me reassurance. I'm going to try to drop it back now.”* (Man, 69, relapse after tapering off from brotizolam)

The possible impact of long-term use on the brain was also a cause for concern and a reason to attempt to quit for this man:

> *"Knowing that using it permanently will probably have consequences for my brain functions."* (Man, 66, relapse after tapering off from zolpidem)

Another person developed sudden vision problems with his vision, started searching for a possible cause on his own, he attributed these problems as a result of his long-term BZD/Z use. Visual problems in the form of a distorted and blurred vision and changed colours were also reported several times as a complaint after taking the medication, but also during the tapering period (even up weeks after tapering off).

> *“I saw colours very differently. Red was no longer as red as it used to and blue was no longer as blue and green was no longer as green (…) Everything became a bit, like when you are colour blind, everything is a bit more grey.”* (Man, 52, former use of diazepam)

> *“I did not find it frightening, because I was already used to that medication, but sometimes I saw distortions in my image. After twenty minutes [in bed], just between being half awake and almost falling asleep, the colours on the screen of my mobile screen were different. As if it was covered in a specific filter. Yes, things, letters and numbers were kind of mixed up. And when I looked at the wall in my room,*

> *sometimes I saw yes, I can't say- It was all just a little bit distorted, but it wasn't bad enough to be afraid of. "* (Woman, 35, former use of bromazepam and zolpidem)

Furthermore, side effects throughout the day, such as feeling dazed or groggy were also discussed and often this was experienced as so annoying that they finally decide to quit.

> *“Because I also notice that I am a bit more dazed during the day. But then I refer to medication such as Lexotan® and Valium® and Rivo, wait, eh, yes, Rivotril® and Temesta®.”* (Man, 29, former use of zolpidem, clonazepam, bromazepam, alprazolam and lorazepam)

> *“Certainly the first few times you take that, you really seem to be in another world for a while, at least that was my experience. You are either very, very calm and then you may not see things realistically, or you are just very euphoric and then it is that realistic anymore. So that was especially in my case that I noticed that diminished, but it remained that I always felt that I functioned less sharply than usual.”* (Woman, 20, former use of prazepam, alprazolam and zolpidem)

Someone else mentioned an effect on his speech:

> *“The only thing I notice for myself is that I for example, when I have to get up really early on Sunday morning, and I had not been sleeping enough, I noticed in my speech that my language was not pure. My voice was different, in the sense that I spoke differently. It wasn’t my normal fluent speech.”* (Man, 66, relapse after withdrawing from zolpidem)

Some participants also mentioned unpleasant changes in their personality, such as in these quotes:

> *“Gigantic anxieties. These anxieties were hardly imaginable. In the past I have been abroad and I’ve been in situations in which I absolutely had no fear at all to in fact. So I had become a totally different person. My personality had changed so much. Those fears, I just can't describe it. I can't even think about it anymore.”* (Woman, 64, former use of clonazepam)

> *“Which was also a very clear side effect, (…) I became somewhat "brake-less". How do I say that? My natural inhibition was off a bit (…) And later when I just used it longer and a lot more, it also made me quite aggressive. I could just detonate out of the blue (…) I was also just a different person in the end. (….) It was [the people in] my environment that pointed out to me (…) [the people in] my environment also felt that I was becoming increasingly strange, behaving more and more strangely.”* (Man, 52, former use of diazepam)

Sometimes the negative effects are noticed and pointed out by people in the user’s close network, which inhibits the use or reinforces a desire to withdraw.

> *“Yes, two nights I am willing to hold on, and the third night I am like, hey, I would really like to sleep through the night. And then I relapse. It bothers me enormously that I am dependent on it. At one point, I took 1 uh, 1.5 for a very short period of time. But I don't do that anymore. My children spoke to me about this. Like, mama, we see you at night.. we went to the toilet and think you are acting strange and give strange answers, and the next day I would have forgotten about it. And, they had told me that it makes them feel anxious and… scared. And I was like, ah yeah, okay. So anyway I made up my mind to stick with that one [pill] even though I don't sleep well. And not passing that limit. And yes, perhaps my intention might be to try to stop again eventually.”* (Woman, 48, long-term use of zolpidem)

Conversely, an uncritical, submissive network that does not challenge BZD/Z use implicitly approves of the use and thus perhaps unwillingly helps to maintain the habit.

> *"My partner knew it, my family as well, but besides them... But no one fussed about it."* (Woman, 35, former use of bromazepam and zolpidem)

For others the impact of BZD/Z use on their quality of sleep was decisive to taper off:

> *"I had to have a sleep study done. And there they saw that I did not have REM sleep, and therefore I was never well rested in the morning (...) that was when I had been taking that medication for a while, and it did not work that well anymore. And then they looked deeply into the reason that I actually .. slept so badly and was not fresh in the morning ... and that was due to the lack of REM sleep (...) I had to taper off Zolpidem because it is actually not advisable to take it for that long."* (Man, 62, former use of zolpidem and bromazepam)
>
> *"And you can clearly see on that graph of that sleep study, yes, with what I now know as well that this infamous benzo sleep, that phase 3 and 4 completely can't get through anymore. That you don't actually sleep through the night."* (Man, 50, tapering off from clonazepam)

It is perhaps unsurprising that habitual users hardy ever mentioned experiencing side-effects, apart from being dependent on BZD/Z. Instead they rather seemed to defend their medication use, especially in the group of contented users. Nonetheless they did discuss symptoms that would probably be diagnosed as side-effect although these were generally not framed as such or were not considered serious enough to lead to a wish to quit or urge to withdraw.

> *"It has happened that I did not take one… but I started to feel weird again, drunk, and I get hyper nervous as well when I don't take one. I once fell while working in the field, because of drunkenness, with a knife in my hands.. o boy. I sometimes shook when I had to cut cabbages."* (Woman, 77, current use of lorazepam)

Furthermore, the interaction of BZD/Z with alcohol and the negative consequences thereof were also discussed several times, although in itself this was not reported as an actual reason for cessation.

> *"And I am also aware that there are certain risks, yes. That was actually in um, yes, a banal incident (…)I had visitors at home. And I had two or three glasses of sangria. And strangely enough, those people left and I took my sleeping aid. And I went to move the car after fifteen minutes, half an hour later. And I hit the front door (…)I had a complete blackout. That was something I had never, never experienced before. I realise very well that that was something that was totally, totally irresponsible, but it did happen. It happened sometimes that I went to see some friends and had to drive home and that from the moment I left those friends' house, I already took my sleeping aid. I am well aware that it was totally irresponsible for me to take such an irresponsible risk. At that time I had never thought about it because that drug, usually only worked after 45 minutes, an hour."* (Man, 66, relapse after tapering off from zolpidem)
>
> *"I also have to be careful with alcohol. A glass is okay, but I already feel the second one. And especially in the evening it is even worse (...) For example in the company of friends or just once at the weekend or when my daughter comes to eat when I have a good time, I cook. It happened during summer last year. So I had made mussels, put some white wine and sparkling water on the table. And then I also drank some of that wine and I've been through hell that night. That alcohol and that little pill really was hellish. Alcohol and that pill was hell. So I have to drink as little alcohol as possible… I felt very restless. You think that it has a dampening effect. But I feel like I have even more adrenaline in my body. And I feel like I drink alcohol in the evening - I can drink one, two or even three, that's a lot- but then I know that I am*

> *not going to sleep that night. I better take the day of the following day, because I know I will be chattered. I'd like to enjoy it sometimes, but the price is so high for me, that I don't want to do it anymore. I have already said that to my doctor, I am not resistant to alcohol. Luckily enough that is not really a priority in my life."* (Woman, 58, current use of lormetazepam)

It is quite striking that only one interviewee decided to stop based on explicit medical advice. One respondent made the final decision to stop following a series of incidents and a stop letter from his GP practice (based in the Netherlands). There may be more profit to be made if GPs themselves send a stop letter to their patients (Mehuys et al 2012).

In most former users, a combination of factors played in the decision to quit. The fear of health consequences in combination with the experience of negative physical and/or psychosocial consequences were crucial. Some of them did seek advice and guidance from a GP during withdrawal.

6.2.7.2. FROM GRADUAL TAPER TO COLD TURKEY

When asked which method they sued to quit, most former used explained how they gradually reduced their medication or tapered off. This was especially the case when they were under medical treatment or when they were guided by a GP or psychiatrist.

> *"It took a while… about two months before you are allowed to stop entirely… let's say that when I started tapering, I was on one entire pill, and then the first week it was three quarters and the second week one day three quarters and one day a half and it was tapered off gradually like that. But it took two months in total before it was completely tapered off."* (Man, 62, former user of zolpidem and bromazepam)

However, when medical guidance did not meet expectations, other ways were sought:

> *"From what one sees here and there in the Ashton manual, there is no fixed guideline for tapering off. It really just comes down to not going too fast. Also, don't wait too long between the steps, you have to get a feel for it and the guideline is about.. between twelve to eighteen, twenty days per step. "* (Man, 50, tapering off from clonazepam)

A gradual reduction is no guarantee for experiencing no side-effects, as described by this man:

> *"Rivotril® [standard recommended dose] that was something that I tapered off by myself in six or eight weeks, and yeah I was feeling irritated when I was halving a dose, I really felt that I was annoyed by everything, I felt uncomfortable and… just like, panicky and all that stuff."* (Man, 29, former use of zolpidem, clonazepam, bromazepam, alprazolam and lorazepam)[5]

These withdrawal symptoms are also mentioned in the 'Guideline on prescription drug abuse'[6] for general practitioners edited by Domus Medica (2017).

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[5] In this example, clonazepam was prescribed to treat a chronic motor tic disorder during his adolescence (between the age of 13 and 17).

[6] 'Richtlijn Geneesmiddelenverslaving'

Although not the most appropriate method, we recorded some stories of people who chose to quit "cold turkey", often on their own without the intervention of a doctor. In one case this seemed to have gone quite smoothly.

> *R:"Stopped very radically [with standard dose zolpidem]. From one day to the next. Yeah, I did not know that you had to taper off, I was never told…"*
>
> *I: "How did that go?"*
>
> *R: "Gosh, (pause) I still remember, I think, yeah, it's hard to say I was, uh, still scared. But um, those other complaints of fainting have all disappeared. I've never had it again (…) I never had to lie on the floor again since I stopped. And now I am done yes, I think I quit for over a year already."* (Woman, 35, former use of bromazepam and zolpidem)
>
> *"I first tried to quit zolpidem [double dose] cold turkey, but that's a no go! (…) I am lying awake at two o'clock and at three I am still there and perfectly wide awake at four o'clock. "* (Man, 29, former use of zolpidem, clonazepam, bromazepam, alprazolam and lorazepam)

In another case, the patient was incapacitated for work for over a year during tapering due to strong rebound and side-effects. However, this person had broken all contact with the general practitioner (out of disappointment).

> *"The first cold-turkey attempt was successful, but you shouldn't ask how. That was really too bad. Hallucinations. Shaking. Shivering. I've been trembling for half a year. And for half a year I had hallucinations. (…) Anxiety, anxiety, enormous anxiety, I didn't dare to do anything anymore, completely nothing anymore. I couldn't write anymore, I couldn't read anymore. I saw things that weren't there. I just really saw people walking who were not really there (…) I [said to myself] have to get through and it will pass. So I just locked myself up for half a year (…) Yes, that was really, really, really, really really very bad, very though. And what I thought was the worst, the absolute worst, were the hallucinations, I found that really, really scary. That was just scary. It was just scary that someone was always with me, so there was someone with me all day who wasn't there. Because I can draw it like that, I know exactly what it looks like. Very strange (…) I stopped on July 8th and he left around Saint Nicolas, then things got better (….) It is a very special fear, it is a very strange fear. It's chemical anxiety, I call it. It's not a natural fear. (…) That stuff does something to your brain which changes your brain structure and therefore also your behaviour and everything you observe."* (Man, 52, quit cold turkey from high dose diazepam 45mg/day)

6.2.7.3. WHAT HELPED DURING WITHDRAWAL?

Regardless of whether one tapered off alone or medically supervised, all former and withdrawing users searcher for a ways to deal with the consequences of tapering off and the sometimes recurring sleep and/or anxiety problems. These alternatives varied from sleep therapy (in a sleep clinic or through a physiotherapist), psychotherapy, meditation (self-taught through online videos), sports to natural remedies (herbs, melatonin). Inspirational examples also seem to help and motivate quite a lot:

> *"I went to that physiotherapist [who offers sleep therapy] through the mom of a friend. So that's also someone who was in her late sixties and then quit. Also eh, and it's actually because of her, because of her story that I thought, come one, it really must be doable! [laughs]. If she can do it, then I can too [laughs]."* (Woman, 46, former use of zolpidem)

In addition, the support of family and one's close network is of utter importance during withdrawal and cessation. Some people also mentioned the support of a peer who already quit and knows the process and its pitfalls.

A change in context and daily schedule (for example due to retirement, change of career,…) were also mentioned as important leverages. This is in line with current ideas in addiction care that dependence is first and foremost a matter of habit formation.

> *"Certainly when I was working, I took that because I thought, if I do not take anything now, I will not be able to sleep and I have to get up and I will not be rested and I will not be able to work and so it was a merry-go-round that didn't stop, but now that I no longer work... tapering off was actually quite easy... smoothly in the sense that if I could not sleep then yes... then I stayed awake and eventually you fall asleep surely. Because the fact that after all, I didn't have to get up in the morning, it didn't play that much of a role when I actually fell asleep."* (Man, 62, former user of zolpidem and bromazepam)

> *"If I actually had a meeting or whatever the next day, well then I could not sleep. And that's how it kind of started and then I took it for about twenty years. And then, when I retired, I did stop it."* (Man, 69, relapse after withdrawing from brotizolam)

Moral support of the attending physician, and recognition of the patient's experiences during withdrawal are also mentioned as extremely important. Several interviewees indicated they missed this.

> *"I just can't get my head around it… That there are other doctors and other specializations that may not be as familiar with benzos, you may have some understanding for that, everyone has their own aisle, as they say in Antwerp, but that a psychiatrist still denies it... Is it because she doesn't know any better or because she doesn't want to know? I'm actually starting to get quite angry about it (...) if you talk about it with a doctor and you want to stop, you will be told ok, we will do that in three or four weeks, every week a quarter less and then that is all right and the problem is solved. It isn't that simple, is it? And I am experiencing it myself now. And so she still sticks to that [idea], regardless of the concentration or the amount or dose that you have, in about three or four weeks you can taper off that, because she has already had several patients to whom it is not a problem. She doesn't understand what I'm complaining about. I was just literally told: I don't know where you get it from, because I have never heard of that problem before."* (Man, 50, tapering off from clonazepam)

> *"I had the feeling that, um, that he [psychiatrist] was minimizing a little bit what I said, what I said. Um, I say minimize because I also heard him say about the Rivotril® [taper] two weeks and then half again and I thought okay, he seems to think that this goes very quickly!"* (Man, 29, former use of zolpidem, also clonazepam, bromazepam, alprazolam and lorazepam)

Finally, accessibility to correct taper dosages is also important. Some people who had difficulties with withdrawal (of clonazepam in particular) therefore turned to specific methods. Community pharmacists can play an important role in this:

> *"Well, it was prepared by the pharmacist as a compounded preparation, huh. Because you actually have to go up to, an equivalent of 0.5 milligrams of Valium®. But in the latter case, if you see for example… Rivotril® is twenty times stronger than Valium, so before you get to an equivalent of 0.5 milligrams of Valium®, that's a super low dose, you can't break that anymore. For those last doses… that is a homeopathic pharmacy. They make it, so they have all the tools to go that far. And to make sure that was done very well, because we are so sensitive and it is very important that those doses are actually correct. The slightest fluctuation… the central nervous system is so triggered by that medication, you*

> *can actually become so much sicker and yes, they did that well.”* (Woman, 64, former use of clonazepam)

> *“In the Netherlands there are apparently a few hospitalization insurance policies or private insurance policies that do reimburse, because it is fairly expensive (…) As far as I know, that does not exist in Belgium. Could be, I don't know (…) The rainbow pharmacy*[7] *or something, if I'm not mistaken they are concerned with really tailor-made medication for tapering off. And that certainly doesn't seem like a bad idea to me. I have fun making it myself, in doses, with a cutter and as far as that all goes of course. But if that existed here, you can simply ask the pharmacist. Yes, it would be a bit easier (...) even with a stupid Rivotril®, I cut it in eight parts now, but that is not evident either. No, the last one I have now, from half a gram, from 0.5 to further reduce, they are - in two, that is still more or less, but in four you have to be careful with a cutter and I then observe them, so I also have to divide that quarter. And a pill, that is never evenly distributed in anyway, so I don't have the same dose every day either, no matter how well I cut them (...) I can only see it as a positive point, if you’d just could go to the pharmacist and he’d be able to make the doses exactly. ”* (Man, 50, tapering off from clonazepam)

6.2.7.4. A STORY OF RECOVERY

Former users mainly tell a story of recovery, which they frame as a finished chapter. The narrative is orderly organized over time, with a clear beginning and end. Both the starting point and the turning point constitute a biographical disruption. Although BZD/Z are initially taken to deal with a disruption, at a certain point that medication use is no longer consistent with how they see themselves, because the disruption has now been resolved, but more often because the medication use is no longer permitting them to be who they want to be at a certain point. These two aspects of an identity collide, as it were. Some people who have tapered off, and have experienced that process as problematic, will also medicalise the withdrawal, as illustrated in the following excerpts.

> *“I used to smoke and I had no problem quitting actually. I reduced gradually and in a disciplined way and I got rid of that. So yes, an addiction, I'm get rid of it if I have to. But this is not an addiction, this is a completely different level. Your receptors are paralyzed in such a way that they can no longer, uh, react, ... no longer function. And if you take away that product that replaces those receptors, you're going to have a serious problem. That's what happened to me actually. That realisation, when I read all that [Ashton] manual, read about the mechanism of benzos, that it also mimics system disorders and actually gives so many symptoms, it all made sense, because those receptors, they are not only in your brain, most are even in your gut (…) An addiction is just, that is actually a mental urge to take something for your well-being. But dependence is really a result of something physical that has gone wrong in your body. Now with those benzos, those GABA-A receptors that can no longer respond as a result of that benzo (...) are the same as if they have to (...) they have been flattened, they are no longer able to function, because that benzo has took over their task. And that is physical dependence. And those receptors that are all over your body, with the greatest concentration in your intestines (...) So if you do not take medication or if you reduce it too quickly, your body does not get the time to recover or those receptors don't get to recover and take over the function, then you get those symptoms.”* (Woman, 64, former use of clonazepam).

> *“I have in the period that I have been ill- eh, because I really call it sick. It's a disease, really, it's just- It really was a disease. And yes, then at a certain point - because I did not understand what was happening*

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[7] https://www.taperingstrip.nl/voorschrijven-en-bestellen/?q=

> *to me - then at a certain point I just made a study of (...) what is happening with my brain now, that I understand what happens. That I have a better understanding of what is happening to me (…) I was so far gone with… my drug addiction. I had been gone for months and months and it didn't get any better. It just got worse eh (...) I was desperate at the end, I mean when I was off that stuff for three months, four months (...) I think: this will never go away (...) so I did write him [psychiatrist specialized in addiction] and made a study of it, yes. Will this ever be okay again (...) I then received an email from him a few times about where to I should have a look, brain receptors there, brain receptors here and so. He says there is a huge imbalance (…) But he says, it takes a long time for that brain to recover, it is really three years on. He was also right, I am now three years further, it is now okay again."* (Man, 52, former use of diazepam)

Approaching the tapering off process (and the accompanying symptoms) as a disease is a hopeful approach, since it implicitly also means that a cure and thus recovery is possible. It also makes it possible to ask for additional care, because one assumes the role of "sick person" and (temporarily) unsubscribes from social expectations. In case study 2, this taking up a role as an "expert patient" has been further explained. Furthermore this also takes away a degree of (self) stigma as will be explained further.

6.2.7.5. OCCASIONAL USE AFTER TAPER

A specific type of user were those who had tapered off after long-term use but still used a BZD/Z occasionally, often for practical reasons, also referred to as instrumental use. Such as this man who works in a shift system and takes a BZD/Z once every fortnight when the shift system changes:

> *"And yes, so I really could not sleep well and because all the time I… you know how it goes, you worry all the time, you really do not feel well. And then I went to the doctor and that doctor prescribed me, zolpidem. And that did help at the time. But then I also noticed that, actually, if I just use it in a disciplined manner, it also benefits my job. So I've actually kept asking the doctor ever since, yes I'm actually okay with it. "* (Man, 36, instrumental use of zolpidem)

This occasional users seem to take their BZD/Z in a quite a rational, instrumental and responsible way. Yet this group is potentially vulnerable for relapse given their awareness and knowledge of the effectiveness of the medication.

6.2.7.6. RELAPSE: WHEN TAPERING OFF IS NOT SUCCESSFUL

In addition, there was a group of people who had relapsed into their former medication use after tapering off or stopping. These people generally felt a lot of shame about this.

> *"To my great regret and with some trepidation, I have to let you know that cessation was not an immediate success. (…) Although it doesn't feel right. The longer the more I become convinced that without extra motivation from a coach or other fellow sufferers withdrawing will become a very difficult process."* (Man, 66, relapsed after tapering off from zolpidem)

This shows that even people who were strongly motivated to taper off can also relapse if they have insufficient alternative strategies to deal with insomnia, as in the case above.

6.2.7.7. CONCLUSION: CESSATION AS A CONTINUUM

Withdrawal stories are highly individual, linked to contextual, personal and biological factors. There is not one type of withdrawing patient. Hence, cessation should rather be interpreted as a continuum, tailored to the individual patient, along the following different axes:

- Type of support: alone- with formal professional support – with informal support
- Mode of cessation: cold turkey - standard 6 weeks - many months or even longer
- Organisation: fully functioning (while at work) - on (sick) leave - in permanent disability
- Dosage: reducing therapeutic dose - prescribed yet increased dose - recreational (high) use

6.2.8.DEALING WITH THE IMAGE OF ADDICTION

6.2.8.1. TABOO OR NOT?

A common thread throughout all conversations was the theme of the (negative) societal perception of BZD/Z. There seems to be a taboo on discussing the long-term use of this medication. Not so much during the interview itself, because those who agreed or contacted the team themselves wanted to discuss their use, but rather during recruitment. Several persons who were invited for an interview via referral did not want to participate out of shame. Others who did participate indicated that they barely discussed their use of this medication unless with people close to them or with people they knew were taking similar medication (/ t) and, such as this woman:

> *"There may be people who have been taking those things for years as well, but nothing is said about it and I don't quite ask about it of course. I think that is also a problem, very little is said about it, very little is asked about it and I have the impression when it comes to that medication, it is still in the realm of antidepressant-like states and things like that. A lot of people apparently prefer not to say anything about it or dare not say anything about it."* (Man, 50, tapering off from clonazepam)

Most participants highly valued and stressed their confidential participation. For some interviewees it was the first time they discussed their experiences with someone other than their GP or psychiatrist. For some the interview also proved to have a liberating effect in the sense that it was the first time that they openly discussed their experiences. For others, their negative experiences instigated them to participate, and make a contribution that could prevent others from ending up in a similar situation. These motivations to a certain extend also formed what was said and how (openly) things could be discussed.

6.2.8.2. DEPENDENCE AND THE STIGMA OF ADDICTION

The ambiguity between the widespread use of BZD/Z and the apparent taboo that rests on openly discussing its use, appears to stem in part from the contrast between BZD/Z's status as "prescription drug" and the stigma that stems from a its addictive potential. In all interviews, the topic of dependence came up spontaneously. Usually the 'satisfied' or contented long-term users were also well aware of this, yet rationalized and minimalised the risk like in this quote:

> *"I realise that I am dependent on medication, but I don't think that's a problem. In my case, with the medication I'm taking, I don't mind. (…) Because I know if I drop that, those three… then yes, it will be a disaster again and I just don't want that anymore, voilà. There you go."* (Woman, 49, current use of alprazolam)

Or they rather magnified and underlined their self-perceived ‘addiction’ to BZD/Z, to demonstrate in the context of their medication story that they really need it. Remarkably, these users all employed the Dutch word for addiction (‘verslaving’) rather than dependence (‘afhankelijkheid’).

> *“Because I am addicted to them, I can no longer miss them. Well. (…) That's the same thing with drugs, or smoking. Habit, every day a half [pill], every day. Without fail.”* (Man, 70, current use of lorazepam)

> *“Addicted… I am addicted to that sleeping pill. I can't ... I can't quit, once you start you can't quit, I have to take it on eh yes, otherwise I wouldn't sleep either (...) You're addicted to it, it’s like.. yes.. someone who can't quit smoking . Exactly like someone who cannot quit smoking.”* (Woman, 84, current use of bromazepam)

> *“It is very strange. If I would no longer have them, I wouldn't be able to, really. I wouldn't survive anymore. Yes, you can say that you are somewhat addicted to it. I almost never forget [to take them].”* (Woman, 77, current use of lorazepam)

In the stories of the former users, it is especially striking that they do not want to be seen as someone who abuses medication, nor as someone who had an addiction. That semantic nuance between dependence and addiction is hugely important to most former users.

> *“Yes, I won’t say that I was really addicted, addicted, I don't see it that way. But maybe more than you realise yourself (…) That you take it by default, even if you don't have an important meeting or so the next day. Or even if it is weekend, for example. It was just easy. Actually, that's what it comes down to for me.”* (Woman, 35, former use of bromazepam and zolpidem)

Furthermore, some habitual users explicitly morally distance themselves from the stereotypical image of someone with an addiction/ “an addict” and the associated stigma, for example through emphasising the status of BZD/Z as prescription medicine, as opposed to (recreational) drugs.

> *“Why would you have to lie about it? It's not drugs that I take, is it?”* (Man, 77, long-term use lormetazepam)

In addition, persons suffering from addiction are often portrayed being responsible for that addiction. Most (although not all interviewees) clearly distanced themselves from such a position. Many former users put the responsibility for their long-term use partly with the prescribing doctor (sometimes to justify their long-term use, sometimes to avert responsibility and blame someone else- usually people who had stopped or had a desire to do so).

> *“We only did what the doctor prescribed us, didn’t we, and you are considered an addict once you are on those pills, because they [the doctors] realize that, too. And then you can't really get off. See, I got rid of it and my son got rid of it too. And the people that I've seen a lot on the [online] groups, many have got rid of it. People are victims, they have only done what the doctor prescribed them. And that is a very big difference with drug users who use that recreationally or use that as addicts, we are not the same person, this is a completely different input. We are not addicts, we are victims. We've become dependent on a drug because we've done what the doctor said. The blame is not on us, not at all.”* (Woman, 64, former use of clonazepam)

This blame-aversion discourse is typically used on online forums for withdrawing and former users.

Furthermore, former long-term users generally indicated that they did not use high doses and that they did not, or barely, exceeded the prescribed dose, which is cited by some as an argument for not being able to speak of an addiction. Taking a substance in higher amounts than intended is one criterium of a substance use disorder (SUD) [8] in the latest DMS-5.

In addition, the medication is often used or asked exactly to continue to meet a certain societal expectation and prevailing trend of productivity in order to be able to keep going (despite broken nights, mourning, etc.) Put differently: the need to sleep as efficiently as possible (to perform as efficiently as possible during the day) prevails. This of course stand in strong contrast with another criterium of an SUD, namely 'giving up important activities because of use'. And hence, here too, interviewees framed dependence on BZD/Z as substantially different from other addictive substances, which they saw as generally used recreationally (and rather preventing people from participating in society).[9]

The stigma associated with this medication rather seems to stem from the realisation that one needs the medication because of a lack elsewhere (rest, resilience or even willpower not to use medication) rather than specifically on the mere act of taking medication in itself (which is usually also positively named by the users themselves after they have stopped) as is the case with (other) addictive substances. This also explains why it was often easier to talk about the fact that someone takes a certain type of BZD/Z, but much less to talk about the underlying reason for that use (and the accompanying shame). This is certainly the case with older users, among whom the use of a sleeping pill is more normalized.

> *"I wouldn't tell, yeah, no, I am not the kind of person that will make a lot of noise about it (laughs). Well you don't like it and so you won't talk about it. Well, with people who also take it, you will discuss it more quickly. But to someone who doesn't take them, you can't really talk about it. It's immediately like: I don't want that! It's quite a discussion straight away."* (Woman, 77, long-term use of lorazepam)

The fact that BZD/Z use increases with age and is especially prevalent in older age groups in the entire population, proved to be a source of shame for some younger interviewees. Hence, ageist stereotypes attached to BZD/Z urged them to keep quiet about their medication use, as they do not want to be seen as someone who needs a 'pill for old people':

> *"In a thirty-year-old [I] think, come one, that's not right!"* (Woman, 46, former use of zolpidem)

> *"I remember that I once told a friend. And she said, come one, she says, you!... I told a few good friends. I wasn't embarrassed about it, because it's was in a context that I used it. It was because of my studies, so in that sense, I wasn't ashamed of it. And I remember that friend said: come one, that's for old people, old people take that. You are so young, why are you taking that? You have to get rid of it, that's poison!"* (Woman, 35, former use of bromazepam and zolpidem)

This ageist stereotype can even be confirmed in medical practice:

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[8] In the latest DSM-5, the previous categories of 'substance abuse' and 'substance dependence' have been merged into a single disorder, named 'substance use disorder' (SUD). This disorder is measured on a continuum from mild to severe, depending on the number of criteria one meets (Mc Lellan 2017). Criteria include: using in larger amounts or longer than intended, wanting to cut down or stop without managing to, spending a lot of time to get/use/recover from use, craving, inability to manage commitments due to use, continuing to use even when it causes problems in relationships, giving up important activities because of use, continuing to use even when it puts one in danger, continuing to use even when physical or psychological problems may be made worse by use, increasing tolerance and withdrawal symptoms. Meeting two to three criteria is considered a mild, four-five a moderate and six or more a severe SUD. Most long-term users meet more than two of the above criteria as they use the medication longer than intended, develop tolerance and show withdrawal symptoms.

[9] This is the emic point of view, as expressed by the interviewees in this study. Other studies show that for example cocaine users may equally use to function more efficiently and to meet the expectations of society (Harrison 1994), while the self-medication hypothesis suggests that some people may use both illicit and prescribed substances in an attempt to self-treat (undiagnosed) psychiatric symptoms (Khantzian 1997) .

> *"The doctor said: you are much too young for something like sedatives or anxiolytics, I don't want to start with that."* (Man, 50, long-term use of zolpidem and prazepam)

In addition to the stigma associated with a negative stereotype of the elderly, part of the stigma also stems from the idea that one will be labelled as weak, or even considers oneself to be so. This 'weakness' label partly stems from the idea that one is not strong or resilient enough to cope without medication or to even resist the medication in itself. In addition, it is also inherently attached to the underlying condition that is especially stigmatised when the cause is considered psychological.

> *"People I have known all my life, are no longer surprised, because they know that I sleep badly. And they also understand that I use or have used those things. If I tell it to people who have no sleeping problems, and who do not know me or do not know the situation up close, they look at me and say come on, do you really have to take pills for that? Get over it or just sleep, haha. You see, you get those very superficial, um, apathetic reactions."* (Man, 29, former use of zolpidem, clonazepam, bromazepam, alprazolam and lorazepam)

> *"But I do think that it should be like when I say I'm going to get a loaf of bread, you should be able to say, in a manner of speaking, now I have to go to the pharmacist to get my Valium®. We are still seen too much as unstable. We are, we are not strong enough, we have no character. If you have character, you don't need it."* (Woman, 64, long-term use diazepam, zolpidem, lormetazepam)

Furthermore, one person also mentioned experiencing a stigma in the medical world, where it was more experienced as being seen as a 'lost case'.

> *"Also, when I went to another specialist and said that you took that, n'importe qui, actually, if they heard that you took that (….)my GP as well now, we have moved places in the meantime, he was just thinking that people who are already there [have been using several years], they never get rid of it. That's the idea they have. Now, that's an older GP. The younger generations already have a little more [knowledge] about it, but the knowledge is still really insufficient."* (Woman, 64, former use of clonazepam)

Finally, the media are also seen as contributing to the stigmatisation of persons who use medication, sometimes by attributing BZD/Z users the label of being 'dangerous' or 'unpredictable'.

> *"Because you notice it in the media. For example, after the murder of Ilse Uyttersprot, it was said that her murderer also took all kinds of medication and a lot was said and done about it, that it would be because of that [medication use]. Or about the group that takes such medication both antidepressants and tranquilizers and things like that, that they are people who are capable of such things, that that would define that group, when it absolutely isn't, and when there's a whole group that just functions normally on a daily basis thanks to that medication. There is a bit of stigma around that yes, that is also completely wrong. [I feel like people] just don't really realize that [BZD/Z use] is part of everyday life. That the people around them might equally take that as well and that they are just normal people and that they are not all people who are capable of such acts."* (Woman, 20, former use of prazepam, alprazolam and zolpidem)

6.2.8.3. THE ROLE OF PREVENTION CAMPAIGNS

Contradictory enough, the two most recent federal prevention campaigns were experienced by most interviewees as stigmatizing, or at least as too pedantic. Regarding the campaign from 2009-10 (see annex 1) the following quotes stand out:

> *"I find the older woman again quite stigmatising. That it is only the older population. While I think that there are quite a few younger people as well who take sleep medication and I also think that it is important to ensure that those people, that young people really can withdraw and then again manage again without sleeping medication."* (Woman, 46, former use of zolpidem)

> *"I find the image quite strong. I mean, you're really trapped in your capsule and yes, well, you don't just take it. And yes, talk about it with your doctor or your pharmacist, but of course a lot depends on your doctor and your pharmacist. I notice that quite clearly, when I take my prescription for Temesta® to a pharmacist who does not know me (…) At most usually the assistants, often still young girls, ask something like: are you familiar with the product? And then I say yes, yes. So you know how to take it? Yes, yes, I've known it, I've known it longer. And then it's okay. But you already have to be confident to say no, can you explain it to me. Yes and then in a pharmacy, openly, publicly, like that, right? I don't think a lot of people will do that."* (Woman, 41, long-term use of lorazepam)

In addition, the majority of habitual users experienced the advice of the latest campaign (see annex 1) as naive, and little in tune with their reality. The four solutions presented are considered too simple. Many felt that the campaign did not recognize the seriousness of their problems, which was also perceived as stigmatizing in itself. Of course, these posters do not state that they have been designed from a preventive point of view, for a specific target group of first-time users (or people who consider taking BZD/Z). Long-term users also see this material hanging in pharmacies and GP waiting rooms, and generally do not know or consider that initial aim.

> *"The last option… sounds very much… erm.. and then commit euthanasia, that is what it sounds like to me… Yes, very pedantic, but most of all, I would become very anxious.. because if that is the last option, then there is not more hope… That is the message that I get. I get the feeling that I am not doing well. It is all very stigmatising. Pff (sighs).."* (Man, 41, long-term use of alprazolam)

> *"But again I also find this quite a double message, because you can choose: this or that. And whoever takes that is just lazy, isn't it? Because they are saying that it works. I mean, look, you have options. And you choose this… Perhaps that is right, I don't know..."* (Woman, 41, long-term use of lorazepam)

> *"Actually, they don't see how serious this is. And people who have been using benzo's for a long time… you can offer that advice, but that is actually the very last thing. You really have to realise very well that these people have a serious problem when they are dependent on that pill, when that receptor is regulated actually."* (Woman, 64, former use of clonazepam)

So what could potential future campaigns address when targeting long-term users? Interviewees (both current and former users) mainly suggested about raising awareness about the side-effects of long-term use and the negative impact on health, but also, for example, on driving. In addition, former users also found it important to raise awareness about the possible symptoms during the cessation and tapering off process. All agreed that the tone of the message must above all be hopeful and positive. This can be done by using inspiring examples in which long-term users of all ages recognize themselves, but in particular by emphasizing a good prognosis when tapering off:

> *"You really have to inform them of the symptoms they can have during tapering. If they go through that that it will stop eventually, and that there is a good prognosis, that is very important."* (Woman, 64, former use of clonazepam)

"Actually, they should emphasize more that it is dangerous when you drive a car and take sleep medication or tranquillisers." (Man, 62, former user of zolpidem and bromazepam)

7. RECOMMENDATIONS

A series of expert focus groups (WP5) (with both professionals and experts by experience) was organised to present and discuss the results of the online case studies and semi-structured individual interviews in order to develop sound recommendations for policy and practice.

7.1. METHODOLOGY

In preparation for the focus groups each participant was sent an intermediate report (57p.) in Dutch with descriptive results of the online case-studies and the findings of the individual interviews as separate chapters. The intermediate report (WP4) was written for a broad audience and focussed mainly on the major results and to a lesser extent on the methodology. The report is available upon request.

In total 16 experts participated in the focus groups. This group included both professional experts as well as peer or patient experts. Most participants were recruited through an online announcement in various professional newsletters (e.g. Domus Medica), webpages frequently visited by users of BZD/Z (different social media and forums) and a special article published through the webpage of the VAD. In addition, the announcement was spread through the members of the follow-up committee. Of all experts who initially confirmed their attendance, three dropped-out last-minute (and are not calculated in the final number presented here). Hence the attendance rate was high. One peer expert was explicitly asked to join the focus group for his ample experience as a mentor by experience who sensitizing the broader public on chronic BZD/Z use.

Focus	Date	#
Peer experts	22/2/’21	3
Primary care- pharmacy practice - sickness funds	23/2/’21	8
Mental health and addiction care	24/2/’21	5

Table 10 Overview focus groups

In the peer expert focus group, patient experts with different withdrawal experiences participated. Two were currently coaching others during withdrawal as peer mentors. The number of participants in this group was kept low on purpose, to ensure full confidentiality and allow each participant to reflect extensively based on their previous personal experience. The second focus group was attended by two general practitioners, three pharmacists (community and hospital), two representatives of major sickness funds and an academic expert in deprescribing in family practice. The third focus group hosted a GP, two psychologists, a health care prevention worker and a nurse. All but one worked in residential care facilities. In line with the ethical consent form, their full names and affiliations are not mentioned here, to ensure confidentiality.

Prior to the focus groups a thematic analysis (Braun and Clarke 2012) was conducted on the results of the case-studies and interviews. This led to four main overarching themes: 1) the onset and road towards habitual use, 2) side-effects of long-term use, 3) withdrawal and 4) stigma and taboo. These themes served as the basis for the focus group discussions. For each of the overarching themes from the interviews a few illustrative and thought-provoking quotes were selected to start a discussion among participants. After the discussion a slide was added with a summary of the most important and overarching findings per theme, in which these results were linked to one of the case-studies or interview results.

All focus groups were digitally audio recorded after informed consent. In the second and third focus group two staff members of Hedera took notes, while the main researcher moderated the sessions. At the end of the focus group, on additional question inquired whether all relevant topics had been covered, and a final round of all participants was added to ensure that everyone had sufficient time to voice their opinion and recommendations.

There was a broad overlap in recommendations between the different focus groups, and as such both the patient or user perspective and the perspective of health care providers and policy makers is represented here. These recommendations were presented and discussed extensively with the follow-up committee during the final meeting. All recommendations around which there was broad consensus are included here. Two recommendations were highly debated and were not included (i.e. a contract between a patient, GP and pharmacist when prescribed or tapering off BZD/Z and using Farmanet for personalised sensitization of patients to withdraw). In the next part we further develop the recommendations clustered around the following topics: 1) prevention of habitual use, 2) cessation and 3) destigmatisation. We wrap up with one final and overarching recommendation to strive for patient engagement at all levels. All recommendations are mainly directed at providers and regional/federal policy makers.

It is important to notice that the results presented in this report are mainly based on experiences from the Dutch-speaking part of Belgium. Practices might differ from one region to another, and therefore results could have been slightly different if French speaking patients and health care professionals would have been included as well. Due to the limited scope and duration of the project, the main focus was on Flanders. However recommendations here are formulated with the federal level in mind. Furthermore, in the composition of the follow-up committee we have also aimed at a fair representation of experts from both parts of the country. Finally, it has to be kept in mind that these recommendations concern BZD/Z users in specific and are therefore not necessarily applicable onto poly substance users nor patients with a dual diagnosis.

7.2. RECOMMENDATION CLUSTER 1: PREVENTION OF HABITUAL USE

This first set of recommendations resulted from the discussion of the first thematic focus on ‘the onset and road towards habitual use’. Recommendations here focus on how it can be prevented that future new patients who get a first prescription become habitual users.

7.2.1. AN AWARENESS-RAISING LEAFLET FOR PATIENTS AT FIRST PRESCRIPTION

Obviously prescribers have an important responsibility when they deliver a prescription, yet our results also show that the prolonged use of BZD/Z is a shared responsibility, as patients show a high degree of agency and are hardly mere passive recipients. In order to fully inform patients from the start, a leaflet for patients could help to further sensitize and create awareness among new patients[10].

This leaflet should contain the following information:

- necessity of a clear agreement on the period of intake and set up of a follow-up appointment
- neutral, non-stigmatising information on long-term effects of BZD/Z use
- possible side-effects during use (including the effect on driving)
- importance of short-term use
- clear indication of the length of use

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[10] Although such a brochure cannot be a substitute for a comprehensive conversation and follow-up between the prescriber/pharmacist and patient.

- evidence-based information on tapering off (including warnings about stopping cold turkey, a general warning about possible side-effects during cessation)
- limited effect of the medication
- alternatives, sustainable solutions adjusted to the type of underlying problems (sleeping problems[11], stress, anxiety), in line with the FOD campaign materials
- advice or warning not to share medication with other people

Such a brochure could be an addition to the already broad activities and support materials developed by FOD-VAD-FAMPH. More precisely, this recommendation could be implemented as an update of the existing leaflet: http://www.somniferesetcalmants-manuelaide.be/wp-content/uploads/2018/03/NL-Afbouw-folder-Ik-wil-stoppen-met-slaapmiddelen-02.pdf

This leaflet could be distributed by prescribers and community pharmacists. Due to their role specific role and often personal relationship with patients (Abu-Omar et al. 2000; Mehuys et al. 2012) community pharmacists are well placed to educate patients and can explain what the medication does and does not do, what the side effects are in the long-term, which influence they might have on other medications and advise about tapering off. They can especially sensitise patients about the risks of sharing prescriptions and advise not to share medication with other people. Previous studies have shown that sensitisation brochures are more effective when they are discussed with patients, rather than just offered without any further advice. Hence when distributing the brochure, community pharmacists are advised to discuss some of the most important points of the brochure when they provide BZD/Z upon prescription.

7.2.2. CONTINUED GP TRAINING ON BZD/Z CONSULTS

Over the years a lot of initiatives have been developed to involve GPs and pharmacists to reverse the trend of BZD/Z use. Most professionals observed a mentality switch in the younger generations of GPs due to an increasing awareness of the harmful long-term effects (partly due to the focus that is given to this topic in the GP trainings) and agreed that GPs with fewer years of experience tend are less inclined to prescribe BZD/Z. Nonetheless, even for experienced GPs it is difficult to dismiss patients' demands and sometimes even threats. More than a decade ago Anthierens and colleagues (2007a,b) concluded that GPs should develop appropriate communication strategies to persuade their patients that their problem is being taken serious even when a consultation does not lead to a desired prescription. In fact, the latent functions of the act of prescribing can hardly be underestimated. Prescribing is in essence a social act, in which the prescriber shows empathy, and also provides a legitimation of the patient's struggle (van der Geest et al. 1996). These mutual needs should be fully acknowledged. Our results support that Anthierens' conclusions are still valid today. Hence, at prescriber/provider level further training is needed. In fact, validated educational tools on how to organise such a consultation are already available, in particular the recently updated Benzoconsult e-learning module[12] that includes a broad array of materials to strengthen GPs competences (skills, knowledge, attitude) to support patients with sleeping problems. As Creupelandt and colleagues (2019) have shown, this tailored e-learning

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[11] With regard to sleep: a normalisation of expectations regarding sleep quality was put forward. A good example here is the following brochure developed as a part of the project "Supporting primary care for sleep disorders, including insomnia, in an adult population" financed by EBPracticenet https://kristiencoteur5.wixsite.com/slapeloosheid

[12] This electronic learning program (developed by FOD and RIZIV) aims at training GPs and to provide adequate and rational assistance to patients with sleeping problems for which BZD/Z are prescribed. The different modules encourage GPs to take an adequate and rational way of providing assistance without prescribing BZD/Z systematically or long-term to consulting patients. The learning modules focus on providing appropriate, non-drug alternatives and interventions in order to achieve a rational prescription of BZD/Z. Accreditation is provided to GPs who take the training. Tapering off from chronic BZD/Z use, the specific approach to depression and anxiety disorders, and a drug approach to insomnia are all beyond the scope of this e-learning.

module has a sustainable long-term impact on the prescription behaviour of participating GPs. Hence, a further widespread dissemination of these materials among prescribers is an essential step in a more encompassing preventive strategy to reduce the use of BZD/Z. Federal financial support to ensure such a continued offer of trainings is recommended. This continuation would not only include further training but also a systematic update of the materials. Moreover we also advise to further invest in trainings in local meetings of GPs (LOK-GLEM) and train-the-trainer.

7.2.3.RENEWED ATTENTION FOR EXISTING GUIDELINES

Certain preventive elements that were lacking in the habitual user's medication trajectories are clearly included in the WOREL guidelines[13] on the management of sleeping problems in primary care. For example: the advice to make a follow-up appointment after one week with patients who present an acute form of insomnia when a BZD/Z is prescribed, and in other patients within two (maximum three) weeks, or the myriad alternative treatment modes of sleeplessness. Hence, these broad guidelines should be brought to practitioners' attention again, in particular through the umbrella organisations for general practitioners. For example, a reminder could be published in the newsletter or the bimonthly journal for GPs. The recent surge in BZD/Z use and prescription due to the pandemic could be used as a starting point, to underline the importance of this matter. This momentum could be used to bring the already established guidelines to prescribers' attention again. An inspirational example of such renewed attention can be found in the recent FAMPH communication towards prescribers based on their 2020 survey on BZD/Z use [14].

7.2.4.A COMMON POLICY ON PRESCRIPTION OF BZD/Z IN PRIMARY CARE

Furthermore, establishing a common policy on prescribing of BZD/Z especially in group practices is recommendable and has proven effective for example in British primacy care (Duerden et al. 2011). Such common agreement makes it easier for individual prescribers to refer to, in consultations with demanding patients. A common practice to prescribe as little BZD/Z as possible, is a measure that takes away a bit of the burden from the individual GP, since it is a common practice and shared agreement. This might also prevent doctor shopping within the same practice. Visual representations of this agreement, for example through messages in the common waiting room could further support such a measure. At the same time it may have a sensitizing effect on patients and their relatives. Again, a brief communication through the common platforms for GPs is advisable.

7.2.5.MULTIDISCIPLINARITY

It was generally agreed that an exchange of information between the different forms and levels of care and a patient who takes BZD/Z is currently often lacking.

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[13] Guideline developed on behalf of the Working group development guidelines in primary care (WOREL) of EBPracticeNet regarding the approach to sleep complaints and insomnia in adults in primary care. See also www.ebpnet.be

[14] https://www.fagg.be/nl/news/flash_vig_news_rationeel_voorschrijven_van_benzodiazepines_en_aanverwante_geneesmiddelen_bij
https://www.afmps.be/fr/news/flash_vig_news_prescription_rationnelle_des_benzodiazepines_et_apparentes_dans_le_cadre_des

For patients who receive a first BZD/Z prescription an opportunity for an improved fine-tuning was pointed out between secondary and primary care. Patients who get a BZD/Z prescription while hospitalised often continue that medication after hospitalisation. It is noticed that GPs often continue to prescribe based on the specialist's initial prescription. Although a tapering off during the last days of hospitalisation is recommended (and many hospitals set up projects to standardise this approach) a more critical evaluation of the necessity of such a continuation should be evaluated by the GP and openly discussed with the patient in cases where tapering during hospitalisation was not possible. This specific topic could also be added as another vignette to the Benzoconsult e-learning module on such a specific case could be one way to bring this point to the attention of GPs.

For patients who aim to stop their long-term us of BZD/Z, it was suggested that in line with existing care contracts[15] a similar contract could be devised. However, the majority of experts agreed that instead of setting up a contract between an individual GPs, community pharmacist and patient, it is more efficient to work on a larger scale through the regional medical pharmaceutical councils (MFO). These meetings between GPs and pharmacists enable regional agreements and therefore offer an opportunity to strengthen the communication and cooperation between GPs and pharmacists so that they can take care of the patient together and reduce medication-related problems. These meetings also allow to make agreements in a joint protocol. Hence, this level seems more appropriate to make set up further agreements on first prescription policies and tapering, to reach an economy of scale. There currently exists an MFO on 'Rational Use of Benzodiazepines Through Multidisciplinary Collaboration' (developed by KOVAG, the Royal East Flemish Pharmacists Guild). In the fall of 2020 a series of train-the -trainers has been organised for GPs and pharmacists. This initiative is a good practice that could be set up in other provinces.

7.2.6.LIMITATION OF THE AVAILABILITY: SMALLER PACKAGES

Since several years, APB and the Federal Agency for Medicines and Health Products (FAMPH) have been promoting smaller packages. FAMPH and RIZIV-INAMI (with support of the FOD) are currently in the process of advocating for smaller packages, trying to convince pharmaceutical companies and marketing authorisation holders to start producing smaller packages. However ironically enough the BZD/Z that comes in the smallest package (i.e. zolpidem) is also the most widely used. Smaller packages can give a clear signal to users that prolonged use is not standard. The psychological impact for smaller packages in denormalising usage for longer periods can thus not be underestimated. Needing a prescription renewal and purchase installs several additional figurative hurdles but also check-points where a patient can be sensitized again by both GP and community pharmacists. Promising political signals can be seen in a recent parliamentary question to the vice prime minister and the minster of public health (question 32 – 4 November 2020). Our findings support the ongoing advocacy of these parties for smaller packages. Another alternative mentioned by some, is to give pharmacists permission to deliver BZD/Z per piece as is already the case in the UK, and in the MASS/ Lama centres in Brussels[16].

7.2.7.CONTINUED MONITORING THROUGH REGISTRATION IN FARMANET

A final recommendation towards the federal level and more precisely towards RIZIV-INAMI is a plea for registration of BZD/Z in Farmanet. Current methods to analyse the prevalence of BZD/Z use in the populations

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[15] A care trajectory is a collaboration between a patient, general practitioner and a specialist in which they develop, evaluate and adapt an individual care plan in mutual agreement. This collaboration starts after the involved parties have signed the care program contract. https://www.riziv.fgov.be/nl/themas/zorgkwaliteit/Paginas/zorgtrajecten-modelcontracten.aspx

[16] In the latter, a specific amount of pills is delivered at a set date (either daily, every other day, weekly or biweekly maximum). It is important to discuss this dispense schedule with the patient and the pharmacist regularly.

are limited due to recruitment strategies (often depending on goodwill of participants) or due to limitations of the employed measures and scales (the national Health Survey for example does not allow to explore habitual use in-depth, e.g. length of use, types of BZD/Z, dosages etc.). Hence there is definite need for better data, which could be realised by adding BZD/Z as a separate category in the registration system of Farmanet. Farmanet is currently used for reimbursable medicines. However, most BZD/Z are not reimbursed. We recommend that benzodiazepines and Z-products be added to the category of non-reimbursable medicines that are already registered in Farmanet (such as laxatives and analgesics). As Farmanet data can be requested for scientific or educational purposes, this would considerably improve the epidemiological monitoring of BZD/Z consumption trends in Belgium (for example to assess the repercussion of the current pandemic on BZD/Z use), which would also allow a closer follow-up of the effect of policy initiatives as well.

7.3. RECOMMENDATIONS CLUSTER 2: CESSATION

The second set of recommendations bundles the outcomes of the next thematic foci on side-effects and withdrawal.

7.3.1.A CLOVER LEAF MODEL ON CESSATION

To organise the recommendations with regard to cessation, we present a data-drive, research based model with recommendations, which is extensively based on the experiences of former users. Each leaf of the model reflects a particular form of support during withdrawal. These domains are interconnected, equally valid and should ideally all be covered. All success stories of cessation that were registered during this study contained a combination of these broad elements. They are presented so that they can still be adjusted to the specific needs of an individual patient.

7.3.2.PLANTING A SEED

First, for the clover to grow a metaphorical seed has to be planted, i.e. patients have to be motivated to withdraw and be kept motivated during tapering off. (Although some experts added that it should be taken into account that cessation cannot be the sole and imperative objective for all. In some patients harm reduction is a more feasible.) Therefore we recommend further training for GPs, in the form of a separate module in the Benzoconsult e-learning. Not starting up a prescription and knowing which non-medicinal alternatives you can use as a GP are the central objectives of this training. Addressing tapering off is currently embedded as an extra exercise, but is not the scope of the e-learning. Hence, we recommend adding two specific modules to Benzoconsult, that are specifically targeted at 1) motivating patients to withdraw and 2) difficult taper and withdrawal. These modules could for example focus on dealing with side-effects during withdrawal, as these seem to be of particular importance to many former and withdrawing users. Scenarios could be based on selected patient narratives from this study (to be further compared to clinical practice). The module could focus on diagnosing and discussing such side-effects (amongst others using the BENDEP SRQ survey questions 31-40 as a screening tool to assess withdrawal symptoms). Symptoms that cannot be clearly linked to withdrawal can also be approached as medically unexplained symptoms, in Dutch abbreviated as SOLK[17] to increase recognisability towards the patient.

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[17] 'Somatisch onvoldoende verklaarde lichamelijke klachten', which can be best translated as somatisation. The concept borders on the Medically Unexplained Physical Symptoms (MUPS).

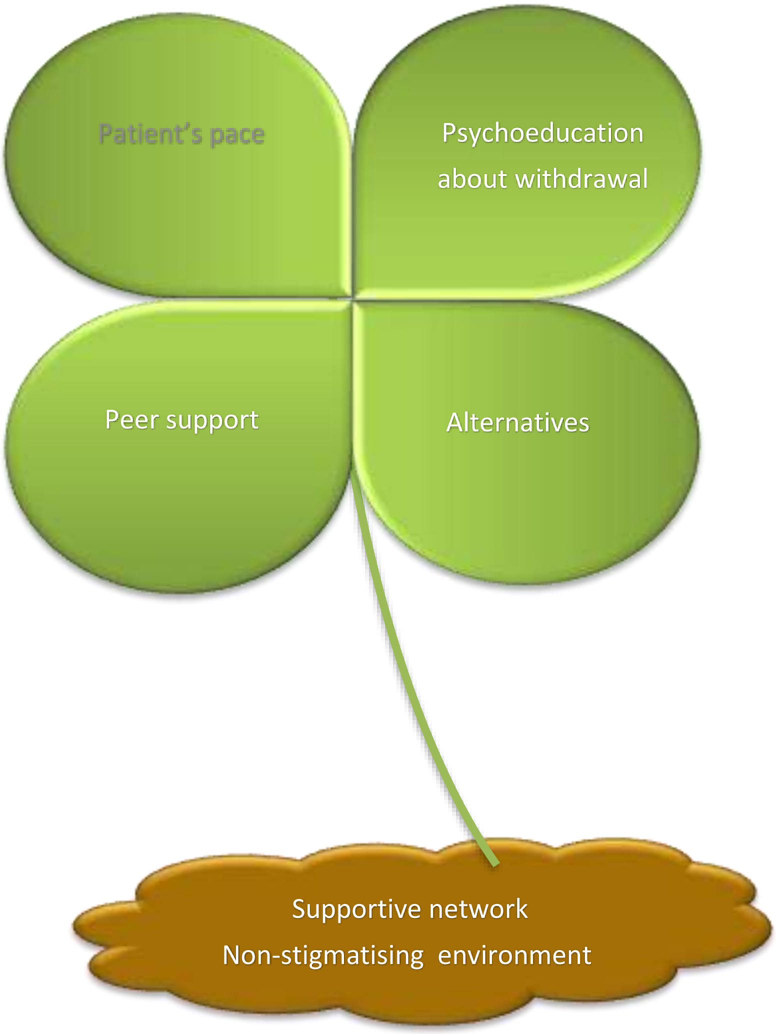

Figure 3 Clover leaf model on cessation

7.3.3.FIRST LEAF: THE PATIENT'S PACE

There is no gold standard for BZD/Z withdrawal. And hence ideally, the reduction scheme should always be assessed at individual patient level and realistic goals should be discussed with the patient. Otherwise said: the pace of the individual patient should be followed during tapering off. The central aim should be to aim for as little side-effects as possible. This first leaf comes with two necessary conditions. Firstly, the recognition of the treating practitioner of the patient's pace is crucial for a smooth process. Secondly, the availability of correct dosages to taper is another prerequisite. It is advisable to install a reimbursement of taper dosages prepared as compounded preparation by community pharmacists, in order to remove a financial hurdle for patients who are willing to start tapering off. Additionally, Belgian community pharmacies could prepare personalised tapering strips for their individual patients, comparable to what Dutch pharmacists at the Regenboog Apotheek (www.taperingstrip.nl) are doing for their patients. An often mentioned problem with a long taper is not only that dosages are often not correctly prepared (often on own initiative by cutting regular doses) or more expensive than the actual medication (for example when purchased as compounded preparations or even homeopathic preparations). The competent federal authorities can support tapering off as an important part of a rational use of psychoactive medication by reimbursing prescribed taper dosages. A control mechanism should possible also be installed to ensure that the maintenance dose is not prepared and delivered under the guise of a possible tapering process.

7.3.4.SECOND LEAF: PSYCHOEDUCATION ABOUT WITHDRAWAL

Our results show that when withdrawing or tapering off many users seek information beyond their health care practitioner. Sometimes out of shame (and then they might not address it) or sometimes because they don't get the satisfying answers when they do discuss it. Whatever the underlying reason, this shows a need for specific psychoeducation of patients about tapering off, the effect of medication withdrawal, realistic expectations regarding tapering and withdrawal. Overall tapering off can be a difficult and challenging process.

A patient information brochure with specific information on withdrawal would help to rule out erroneous information, attune expectations and provide support to patients. There currently exists a concise brochure for patients who want to stop[18]. Moreover the earlier mentioned WOREL guideline from 2018 is published on the reference platform for Evidence Based Practice (EPB)[19] for all Belgian healthcare providers with a link to information for patients on the Flemish platform 'Gezondheid en Wetenschap'[20]. An equivalent in French[21] is currently being developed. The different modules of the Big Bird trial also include information on tapering off, possible withdrawal effects and relapse (Coteur et al. 2020). However, not all patients find their way to this information or do not find the information they need in these materials. We therefore recommend to involve patients and former BZD/Z users when revising or updating the patient brochure.

Another option is to bring the Ashton Manual[22] to the attention of patients. An easy achievable first step could be to add the link to the manual to the FOD webpage with additional tools[23]. It has to be taken into account that the Ashton Manual is not an evidence-based guide, but rather practice based (through written by a psychiatrist) and hence a careful revision is highly recommendable, ideally by a multidisciplinary team. The Ashton Manual has some important advantages in that it is more detailed than the manual from the federal government and that it is considered to be a source of mental support by former and withdrawing users (as seen in case study 2) because of the recognition the manual offers.

7.3.5.THIRD LEAF: PEER SUPPORT

All former users who successfully stopped underlined the importance of peer support. The recognition of someone who has gone through a similar process seems to add additional emotional and mental support that a GP can only partially offer. Departing from the model (of behavioural change) of DiClemente and Prochaska (1998), peer support can be important during different phases of cessation. Due to the shared experience peers can offer inspiration and motivation to continue during taper, but can also help to normalise certain experiences (for example side-effects during withdrawal which decreases also some of the anxieties to can come along the taper process). Successful peers can be crucial to increase self-efficacy as they might provide prospects for a positive and hopeful outcome of the often long taper process. An online forum can help people to find each other more easily and relate. Peer support can minimally take on the form of realistic yet positive and hopeful

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[18] http://www.somniferesetcalmants-manuelaide.be/wp-content/uploads/2018/03/NL-Afbouw-folder-Ik-wil-stoppen-met-slaapmiddelen-02.pdf

[19] www.ebpnet.be

[20] https://www.gezondheidenwetenschap.be/richtlijnen/slaapmedicatie-benzodiazepines-afhankelijkheid-en-ontwenning

[21] https://www.infosante.be/

[22] A Dutch and French translation already exist: https://www.benzo.org.uk/amisc/dutchmanual.pdf and https://www.benzo.org.uk/freman/index.htm

[23] http://www.slaapenkalmeermiddelen-hulpmiddelenboek.be/medecins/#outils-et-liens-utiles

examples, especially in future campaigns that would address habitual users in specific. Maximally the possibilities for the creation of a Belgian peer support forum (with a Flemish and Walloon component) in line with existing international initiatives should be further explored. Ideally, such a forum should be moderated by a multidisciplinary professional team with expertise in cessation (psychiatrist, GP, psychologist, therapist) to guide the discussions and provide professional advice where necessary. Internationally such forums exists[24]. In the Netherlands for example it run by and is embedded in a private organisation for addiction treatment. In Belgium we see a role for both the regional level (public psychological and addiction care sector) and the federal level (general practice).

7.3.6.FOURTH LEAF: ALTERNATIVES

In all successful cessation stories, alternative[25] (non-drug) coping strategies, both during and after the tapering period offered crucial support to deal with the ordeals of withdrawal. These strategies were broad and ranged from sleep training, meditation, sport, psychotherapy, to changes in diet. It sometimes also entailed support to change a demanding lifestyle or other triggering situations. Both the general practitioner under whose supervision the cessation takes place, as well as the patient should be aware of possible options, so a suitable and patient tailored alternative can be found. Our results show that both providers and patients are not always aware of the range of existing possibilities. As described in recommendation 7.2.3, non-drug alternatives to cope with the initial problems for which BZD/Z were prescribed are addressed in the Benzoconsult e-learning module, in the WOREL guidelines and in LOK trainings. These guidelines should be brought to the attention of professionals' again. In addition, there already exists a digital overview of such alternatives for patients, with myriad tools[26]. This overview is provided through the professional's manual (resource book on sleeping pills and tranquillisers) developed by the FOD[27]. What is currently lacking on this page is an overview of sources to specifically cope with the difficulties of withdrawal (nor when dealing with high dose dependence or dual diagnosis[28]). Existing (international) patient platforms are for example not mentioned, nor the Ashton Manual. In a future updated version of this overview page, these sources could be added after assessing their value, along with the proposed peer support initiatives (here further discussed). Ideally this page should be brought to the attention of withdrawing patients again.

Furthermore, it should be especially underlined that a reimbursement of additional professional help in the management of sleep, anxiety or stress complaints by a licensed therapist or practitioner can be an extra incentive for individual patients. Although many reimbursement measures have been implemented, for example for psychotherapy, these often only cover a limited number of consultations.

7.3.7.FERTILE GROUND

To continue in the clover leaf metaphor, in order for the clover to thrive, a fertile ground is needed. In this case such ideal setting to accomplish cessation includes firstly a supportive network (that offers support, recognition, but also a critical voice) and secondly, a non-stigmatising environment. How the latter can be supported will be

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[24] See for example (non-exhaustive) http://www.benzobuddies.org/ and https://forum.verslavingdebaas.nl/forum/29-benzodebaasnl/

[25] By this we do not mean 'alternative and complementary medicine' (CAM), but quite literally all that is alternative to BZD/Z, i.e. non-drug treatments. These options equally include sleep training by a physiotherapist, psychological therapies, as well as ambulant or residential detox programs, osteopathy and so forth.

[26] http://www.slaapenkalmeermiddelen-hulpmiddelenboek.be/medecins/#outils-pratiques-om-verder-te-gaan

[27] http://www.slaapenkalmeermiddelen-hulpmiddelenboek.be/

[28] This will be addressed in the upcoming BENZOCARE study.

discussed in the third cluster of recommendations. The former is something that can be openly inquired by the health practitioner. How supportive are close relatives of cessation? Are they involved and supportive? Are they using BZD/Z themselves? Is there an option to start up a shared taper trajectory? Can they be informed for example through the information leaflet (see recommendation cluster 1 as well). Finally, user's network (family or close relatives, friends, neighbours) should also be directly addressed in a possible broad sensitization campaign for habitual users to sensitize them.

7.4. RECOMMENDATIONS CLUSTER 3: DESTIGMATISATION

BZD/Z stigma has many faces. Habitual BZD/Z users seem to internalise negative stereotypes attached to BZD/Z use (weakness, ageism,..) or to the underlying condition for which they take those BZD/Z (= self-stigma). Yet many also feel stigmatised by some health care providers, by how medication use is portrayed in the media, and even by prevention campaigns (= public perceived stigma). This may limit their health seeking and access to care (some will seek for medication on the black market), it may hamper an open and transparent discussion with their prescriber and there might be an underreporting of the quantity actually taken or a denial of consumption all due to shame and guilt. The many attempts to withdraw on one's own without the help of any health care provider are a sign that that for many stigma also forms a barrier in seeking professional care. Stigma is also an important barrier in behaviour change. For habitual users it is often difficult to discuss cessation openly with their GP, but the opposite also applies, GPs find it often hard to start up a conversation about issues related to dependence. Destigmatisation starts with an ability to discuss chronic BZD/Z use openly, concretely and humanely. Hence, it is important to raise awareness among professionals on the considerable (self and perceived) stigma that BZD/Z user can experience and on developing an open, transparent and non-judgmental attitude.

7.4.1.TRAINING ON ADDICTION LITERACY IN PRIMARY CARE

It is recommended to work on the 'addiction literacy' of professionals in primary care and community pharmacy. Such training could include detailed information about the differences between dependence, addiction and substance use disorder, as well as methods and skills to motivate and openly discuss this with patients. A sound knowledge of addiction mechanisms has a destigmatizing effect (i.e. not inherent to your personality or biology but rather due to availability). A suitable setting for such training would be local meetings of GPs and community pharmacists (LOK's, groupes locales medicales or MFO's for example). Information leaflets could also provide a more accessible or easier alternative or starting point. Such trainings should be developed in a multidisciplinary collaboration between partners in public health and in mental and addiction care. Perhaps there are also opportunities to integrate attention to risks of medication dependence/addiction as part of the envisioned multidisciplinary LOK trainings developed by the FOD. Finally, there could again be opportunities to integrate this as an additional module to the existing e-learning Benzoconsult module as well, in addition to the other suggestions.

7.4.2.FUTURE CAMPAIGNS

Lay epidemiology or the processes by which laypeople understand and interpret their health care choices and the related risks, are often seen as a barrier to prevention initiatives (Davison et al. 1991). Health promotion initiatives should therefore include lay epidemiology in campaign development (Allmark and Tod 2006, Heikkinen et al. 2010) by tuning in with the broad discursive backdrop that prevails among targeted groups.

Each of the repertoires found in case study 1, the accounts of former and withdrawing users in case study 2 and the narratives developed in the interviews with current and former habitual users have potentially relevant elements that could be of use in developing future campaigns, through awareness raising on negative side-effects, tackling disengagement beliefs[29] and opening up roads to recovery.

Firstly, the warnings in the risk and addiction repertoire from case study 1 are limited to the potential addictive properties of BZD/Z and to a lesser extent to a few side effects such as drowsiness, hallucinations and confusion. Remarkably, other side-effects that might be of importance to this age group of people over 65 such as an increased risk of falling or cognitive decline were not discussed in any of the posts, despite a recent campaign addressing these topics (Milisen 2014). In-depth knowledge of the broad range of negative health impacts of BZD/Z is lacking in this sample. In the interviews, only former users indicated a series of side-effects that eventually urged them to stop. The clearest overview of side-effect was mentioned by posters on the specific forum for withdrawal presented in the second case study. Future campaigns could include raising awareness of potential risks and side-effects (such as paradoxical effects, signs of dependence, falls, higher risk of accidents). However, as van 't Riet and Ruiter (2013) show, simply raising awareness of negative side-effects through 'scare tactics' do not suffice and might just cause cognitive dissonance among habitual users. Hence, the rather negative feedback by habitual users on the campaign designed for first-time users.

In addition, campaigns should also tackle disengagement beliefs of habitual users widely presented in the rationalisation repertoire in case study 1 and in some of the interviews with contented habitual users. Is there such a thing as rational, moderate daily use of BZD/Z? Does medication truly help to sleep better or longer or is the impact on users' quality of sleep negligible? Is medication truly the best trade-off? Is not experiencing side-effects truly an indicator that long-term BZD/Z use does not negative affect one's health? Do doctors always know best? Although some of these rationalisations (such as 'old enough to choose') may be true in themselves, they do not comprise a valid reason for engaging in unhealthy behaviour. Furthermore, our results show that habitual users do not rely on the same repertoire to motivate their use. Hence, messages could be adjusted to these different types of habitual users, depending on the stage of dependence they can be situated in (Van Deun 2018)[30]. Different arguments could appeal to habitual users who rely on the emotionalisation repertoire and hardly contemplate negative aspects of their use as compared to habitual users who are well aware of those trade-offs and rationalise their usage. Hence, when designing campaigns to raise awareness around cessation among habitual users of BZD/Z these multiple repertoires and the diversity of users should be taken into account. Communication can also be further adjusted to the underlying beliefs regarding the cause of their sleeping distortion. For example the mere medicalisation of sleep can be debunked in terms that are used by peers in the same age group.

Thirdly, to reduce the negative effect of disengagement beliefs self-affirmation strategies are crucial to encourage people to accept self-threatening information to ensure that habitual users perceive other ways in which they can affirm and maintain a positive self-view (Ten Wolde et al. 2008). The success stories and hopeful micronarratives available in the cessation and alternative pathways repertoires could serve to inspire current habitual users and augment their self-efficacy, as well as the successful withdrawal stories from the interviews. Positive paths to follow are extremely important during cessation as identities transition from addiction to recovery (Malvini-Redden et al. 2013, Van Deun 2020). The hopeful tone of these repertoires and narratives can

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[29] Disengagement beliefs as justifications aimed at lowering perceived health threats and exempt someone from mitigating the undesirability of his/her unhealthy habit (Ten Wolde et al. 2008).

[30] In the first phase, users maximalise their problems that lead to their use. They stress their powerlessness in 'resisting' their use and emphasise their lack of personal agency. Users consider themselves incapable of successfully fighting the underlying cause and thereby justify the need for their substance use. In the second phase, users start to acknowledge the negative effects of their use, yet renegotiate them by claiming that they would be even worse off without the addictive substance. There are broad resemblances to the emotionalisation and rationalisation repertoires in our data.

be more appealing for contemplating users as they offer resources that can function as efficacy recommendations, or skills to reduce or quit the use of benzodiazepines (Ten Wolde et al. 2008).

Furthermore, the results from the interviews offer further insights that can inspire future campaigns. The fact that especially the most recent FOD campaign was met with a great deal of confusion or even reluctance in many of the habitual users involved in our study, indicates an important pain point of the campaign: namely that it is unclear to the broader public that this campaign is targeting a specific group of people who consider taking medication. Hence, in the development of new campaigns, it will be crucial to acknowledged the unintended stigmatising side-effects of previous campaigns and formulate the core messages in such ways that it becomes clear immediately to whom the message is directed. A pilot phase with a broad participatory consultation round could be a feasible way to attain this. Although it is not easy to find suitable patients due to the lack of a patient organisation of BZD/Z users. If by then a Belgian user forum would be established, peer experts could be approached via that platform, or through health care professionals. The envisioned 2022 FOD campaign towards health care professionals or other future communication initiatives could potentially target habitual users, by focusing explicitly on the feasibility of cessation (rather than on the negative aspects of dependence or on focusing on alternatives while one is already dependent). Finally, the language used in campaigns is of utter importance and is crucial as it might perpetuate stigmatisation (see for example the strong reaction to the wordings ‘last option’). The recommendations on language and stigma by the VAD are applicable here as well (see Evenepoel 2021).

7.5. CONCLUSION: PATIENT ENGAGEMENT AT ALL LEVELS

Overall, the benefits of patient involvement have been widely described and generally, countries with higher levels of patient engagement not only lead to improved health outcomes and overall quality of care, lower rates of medial error and an increased patient satisfaction in the experience of care (Snyder and Engstöm 2016, Krist et al. 2017). Especially public health campaigns have so far rarely been co-designed in partnership with the target audience (Thorn et al. 2020) although the importance of co-design is increasingly being recognised (Greenhalgh, 2009; see also Coteur et al. 2020).

Our results plea for a more active engagement of patients at all levels, covering all three types of patient engagement described by Dent and Pahor (2015), i.e. voice, choice and co-production. Patient should be involved when:

- designing a personal care/ withdrawal plan (recommendation 7.2.5)
- creating patient information brochures (recommendation 7.3.1)
- developing policies (recommendation 7.2.4)
- creating a peer support platform (recommendation 7.3.1)
- planning prevention or awareness raising campaigns (recommendation 7.4.2).

A particular difficulty in creating opportunities for patient engagement is that the ‘BZD/Z using patient’ does not exist. BZD/Z are prescribed and used for myriad reasons. In Belgium so far BZD/Z users or patients are not united in an organised group or patient organisation unlike patient groups who have a chronic condition or dependence [31] or international BZD/Z patient movements[32] that are striving to get prolonged withdrawal symptoms recognised as a disease. Creating a Belgian platform where former and withdrawing users -experts by

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[31] See for example http://www.vlaamspatientenplatform.be/ and https://www.luss.be/

[32] See for example https://www.benzo.org.uk/ https://w-bad.org/ https://www.benzofree.org/ https://www.benzoinfo.com/ https://benzoreform.org/ https://www.benzowarrior.com/

experiences- and patients can meet each other would be the first step towards a more organised community that would function as full partner in future initiatives.

8. FUTURE PROSPECTS

Parts of this research report will be submitted to academic journals (chapter 4, 5 and 6). The results of the current project will also serve as input for a project on the accessibility of mental and addiction care services for patients with a substance use disorder related to BZD/Z: BENZOCARE. This three-year (2021-2024) project is a collaboration between the University of Liège (Department of General Medicine) and the University of Ghent (Health and Demographic Research) and will cover the perspectives of professionals and patients in both Wallonia and Flanders, as such this new project will address an important hiatus of the present study.

REFERENCES

Abu-Omar SM, Weiss MC and Hassell K 2000. Pharmacists and their customers: a personal or anonymous service? *International Journal of Pharmacy Practice* 8(2): 135-143.

Allmark P, Tod A (2006) How should public health professionals engage with lay epidemiology? *Journal of Medical Ethics* 32(8): 460-463.

Anrys P, Strauven C, Foulon V, Degryse J, Henrard S and Spinewine A. (2018). Potentially inappropriate prescribing in Belgian nursing homes: prevalence and associated factors. *Journal of the American Medical Directors Association* 19 (10): 884-890.

Anthierens S, Grypdonck M, De Pauw L, Christiaens, T (2009) Perceptions of nurses in nursing homes on the usage of benzodiazepines. *Journal of Clinical Nursing* 18 (22): 3098-3106.

Anthierens S, Habraken H, Petrovic M, Christiaens T (2007a) "The Lesser Evil?: Initiating a Benzodiazepine Prescription in General Practice: a Qualitative Study on GPs' Perspectives." *Scandinavian Journal of Primary Health Care* 25 (4): 214–219.

Anthierens S, Habraken H, Petrovic M, Deveugele M, De Maeseneer J and Christiaens T (2007b) First benzodiazepine prescriptions: qualitative study of patients' perspectives. *Canadian Family Physician* 53(7): 1200-1201.

Anthierens S, Tansens A, Petrovic M and Christiaens T (2010). Qualitative insights into general practitioners views on polypharmacy. *BMC family practice* 11(1): 1-6.

Armon R (2016) Expert positions and scientific contexts: Storying research in the news media. *Discourse & Communication* 10(1): 3-21.

Ashton H (2002) *Benzodiazepines: How They Work and How to Withdraw*. http://www.benzo.org.uk/manual/.

Ashton H (2005) The diagnosis and management of benzodiazepine dependence. *Current opinion in Psychiatry* 18(3): 249-55.

Azermai M, Wauters M, De Meester D, Renson L, Pauwels D, Peeters L and Petrovic M (2017) A quality improvement initiative on the use of psychotropic drugs in nursing homes in Flanders. *Acta Clinica Belgica* 72(3): 163-171.

Baker P (2006) *Using corpora in discourse analysis*. London: Continuum.

Baker P (2010) *Sociolinguistics and Corpus Linguistics.* Edinburgh: Edinburgh University Press.

Baker P and Levon E (2015) Picking the right cherries? A comparison of corpus-based and qualitative analyses of news articles about masculinity. *Discourse & Communication* 9(2): 221-236.

Bardhi F, Sifaneck SJ, Johnson BD and Dunlap E (2007) Pills, thrills and bellyaches: Case studies of prescription pill use and misuse among marijuana/blunt smoking middle class young women. *Contemporary drug problems* 34(1): 53-101.

Bissell P, Ryan K and Morecroft C (2006) Narratives about illness and medication: a neglected theme/new methodology within pharmacy practice research. Part I: conceptual framework. *Pharmacy world and science*, 28(2): 54-60.

Bourgeois J, Elseviers MM, Azermai M, Van Bortel L, Petrovic M and Vander Stichele RR (2012) Benzodiazepine use in Belgian nursing homes: a closer look into indications and dosages. *European journal of clinical pharmacology* 68 (5): 833-844.

Braun V and Clarke V (2012) Thematic analysis. In: Cooper H (ed.) *APA Handbook of Research Methods in Psychology*: Vol. 2. Research Designs: p. 57-71. DOI: 10.1037/13620-004

Brown P, Zavestoski S, McCormick S, Mayer B, Morello-Frosch R and Gasior Altman R (2004) Embodied health movements: new approaches to social movements in health. *Sociology of health & illness* 26(1): 50-80.

Bülow H and Söderqvist T (2014) Successful ageing: A historical overview and critical analysis of a successful concept. *Journal of Aging Studies* 31: 139-149.

Carr E (2010). Enactments of Expertise. *Annual Review of Anthropology* 39: 17–32. https://doi.org/10.1146/annurev.anthro.012809.104948

Ceuterick M and Vandebroek I (2017) Identity in a medicine cabinet: discursive positions of Andean migrants towards their use of herbal remedies in the United Kingdom. *Social Science and Medicine*, 177: 43-51.

Cheung M, Saini B, Bartlett J, Laba L and Mason H (2017) Mapping the illness trajectories of insomnia: a biographical disruption? *Sociology of Health & Illness* 39(5): 659-679.

Christiaens T, Creupelandt H, Rogiers R and Thoen A (2018) *Slaap- en kalmeermiddelen, hoe kunt u uw patiënten bijstaan op zoek naar andere oplossingen?* FOD Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu. Projectgroep Benzodiazepines.

Cloetens H, Declercq T, Habraken H, Callens J and Van Gastel A (2018) *Aanpak van slaapklachten en insomnie bij volwassenen in de eerste lijn*. Herziening. Domus Medica.

Coteur K, Van Nuland M, Vanmeerbeek M, Henrard G, Anthierens S, Van den Broeck K, De Sutter A, Creupelandt H, Devroey D, Van Overmeire R, Offermans A, Kacenelenbogen N, Laenen A and Matheï C (2020) Effectiveness of a blended care programme for the discontinuation of benzodiazepine use for sleeping problems in primary care: study protocol of a cluster randomised trial. *BMJ open* 10(2).

Coveney C, Williams SJ and Gabe J (2019) Medicalisation, pharmaceuticalisation, or both? Exploring the medical management of sleeplessness as insomnia. *Sociology of Health & Illness* 41(2): 266-284.

Creupelandt H, Anthierens S, Habraken H, Sirdifield C, Siriwardena AN, and Christiaens T (2019). A tailored e-learning gives long-term changes in determinants of GPs’ benzodiazepines prescribing: a pretest-posttest study with self-report assessments. *Scandinavian journal of primary health care* 37(4): 418-425.

Davison C, Smith GD and Frankel S (1991) Lay epidemiology and the prevention paradox: the implications of coronary candidacy for health education. *Sociology of Health & Illness* 13(1): 1-19.

Davison P, Pennebaker W and Dickerson S (2000) Who talks? the social psychology of illness support groups. *American Psychologist* 55 (2): 205-217.

De Donder E (2017) Factsheet Psychoactieve Medicatie. Brussel: VAD.

De Simoni A, Shanks A, Mant J and Skelton JR (2014) Making sense of patients’ internet forums: a systematic method using discourse analysis. *British Journal of General Practice* 64(620): e178-e180.

Declercq J, Tulkens S and Van Leuven S (2018) The produsing expert consumer: Co-constructing, resisting and accepting health-related claims on social media in response to an infotainment show about food. *Health*: 1-19.

Dell’osso B and Lader M (2013) Do benzodiazepines still deserve a major role in the treatment of psychiatric disorders? A critical reappraisal. *European Psychiatry* 28(1): 7-20.

Dent M and Pahor M (2015) Patient involvement in Europe–a comparative framework. *Journal of Health Organization and Management* 29(5): 546-555.

Dew K, Chamberlain K, Hodgetts D, Norris P, Radley A and Gabe J (2014) Home as a hybrid centre of medication practice. *Sociology of Health & Illness* 36(1): 28-43. DOI:10.1080/17843286.2017.1287230

DiClemente CC and Prochaska JO (1998) Toward a comprehensive, transtheoretical model of change: Stages of change and addictive behaviors. In Miller WR and Heather N (Eds.) *Applied clinical psychology. Treating addictive behaviors*: 3–24. Plenum Press. https://doi.org/10.1007/978-1-4899-1934-2_1

Duerden M, Millson D, Avery A and Smart S (2011) *The quality of GP prescribing*. London: The King’s Fund.

Ekström M (2016). Medical authority and ordinary expertise. *Discourse, Context and Media* 13: 20-28. https://doi.org/10.1016/j.dcm.2016.05.002

Engman A (2019) Embodiment and the foundation of biographical disruption. *Social Science & Medicine* 225: 120-127.

Evenepoel T (2021) *Taal en stigma. Over ‘druggebruikers, drinkers, gokkers’ versus mensen die gokken, alcohol of andere drugs gebruiken. VAD.* vad.be/assets/inspiratietekst_taal_en_stigma_11dec_def

Fixsen A (2016) “I’m Not Waving, I’m Drowning”: An Autoethnographical Exploration of Biographical Disruption and Reconstruction During Recovery From Prescribed Benzodiazepine Use. *Qualitative Health Research* 26(4): 466-481.

Fixsen A and Ridge D (2017). Stories of hell and healing: Internet users’ construction of benzodiazepine distress and withdrawal. *Qualitative Health Research* 27(13): 2030-2041.

Fox N, Ward K and O'rourke A (2005a) Pro-anorexia, weight-loss drugs and the internet: an ‘anti-recovery’ explanatory model of anorexia. *Sociology of Health & Illness* 27(7): 944-971.

Fox N, Ward K and O'rourke A (2005b) The ‘expert patient’: empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Social Science and Medicine*, 60: 1299-309.

Gabe J, Coveney CM and Williams SJ (2016) Prescriptions and proscriptions: moralising sleep medicines. *Sociology of Health & Illness* 38(4): 627-644.

Gisle L, Drieskens S, Demarest S and Van der Heyden J (2020) *Geestelijke gezondheid: gezondheidsenquête 2018.* Brussel, België: Sciensano; Rapportnummer: D/2020/14.440/4. : www.gezondheidsenquete.be

Goodman S (2017) How to conduct a psychological discourse analysis. *Critical Approaches to Discourse Analysis Across Disciplines* 9(2): 142-153.

Greco M (2012) The classification and nomenclature of ‘medically unexplained symptoms’: Conflict, performativity and critique. *Social Science & Medicine* 75(12): 2362-2369.

Greenhalgh T (2009) Patient and public involvement in chronic illness: beyond the expert patient. *Bmj* 338:b49 doi: https://doi.org/10.1136/bmj.b49

Harrison LD (1994). Cocaine using careers in perspective. *Addiction Research* 2(1): 1-20.

Hartzler A and Pratt W (2011) Managing the personal side of health: how patient expertise differs from the expertise of clinicians. *Journal of medical Internet research* 13(3): e62.

Harvey K, Brown B, Crawford P, Macfarlane A and McPherson A (2007) 'Am I normal?' Teenagers, sexual health and the internet. *Social Science & Medicine* 65(4): 771-781.

Heikkinen H, Patja K and Jallinoja P (2010) Smokers' accounts on the health risks of smoking: Why is smoking not dangerous for me? *Social science & medicine* 71(5): 877-883.

Hislop J and Arber S (2004) Understanding women's sleep management: beyond medicalization-healthicization: A response to Simon Williams. *Sociology of Health & Illness* 26(4): 460-463.

Howlett M (2020) Looking at the 'field' through a Zoom lens: Methodological reflections on conducting online research during a global pandemic. *Qualitative Research*, 1468794120985691.

Huisman M, Biltereyst D and Joye S (2018) Gezondheidsinformatie in het digitale tijdperk: een kwalitatief onderzoek naar het gebruik van gezondheidsinformatie-en media onder oudere volwassen Vlamingen. *Gids op Maatschappelijk Gebied*: 25-34.

Huisman M, Biltereyst D and Joye S (2020b) Sharing is caring: the everyday informal exchange of health information among adults aged fifty and over. *Information Research* 25(1).

Huisman M, Joye S and Biltereyst D (2019) Searching for Health: Doctor Google and the Shifting Dynamics of the Middle-Aged and Older Adult Patient–Physician Relationship and Interaction. *Journal of Aging and Health*: 1-21.

Huisman M, Joye S and Biltereyst D (2020a) Health on Wikipedia: a qualitative study of the attitudes, perceptions, and use of Wikipedia as a source of health information by middle-aged and older adults. Information. *Communication & Society*: 1-17.

Hunt D and Harvey K (2015) Health Communication and Corpus Linguistics: Using Corpus Tools to Analyse Eating Disorder Discourse Online. In: McEnery A and Baker P (eds) *Corpora and Discourse Studies*. London: Palgrave, pp. 134–154.

Irvine A (2011) Duration, dominance and depth in telephone and face-to-face interviews: A comparative exploration. *International Journal of Qualitative Methods* 10(3): 202-220.

Irvine A, Drew P and Sainsbury R (2013). 'Am I not answering your questions properly?' Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. *Qualitative research* 13(1): 87-106.

Jenner BM and Myers KC (2019) Intimacy, rapport, and exceptional disclosure: a comparison of in-person and mediated interview contexts. *International Journal of Social Research Methodology* 22(2): 165-177.

Juhila K (2009) From care to fellowship and back: Interpretative repertoires used by the social welfare workers when describing their relationship with homeless women. *British Journal of Social Work* 39(1): 128-143.

Kaufman S and Whitehead K (2018) Producing, ratifying, and resisting support in an online support forum. *Health* 22(3): 223-239.

Khantzian EJ (1997) The self-medication hypothesis of substance use disorders: A reconsideration and recent applications. *Harvard review of psychiatry* 4(5): 231-244.

Kint H (2017) *Actieve afbouw van slaap- en kalmeermiddelen: opstart en implementatie van een praktijkverbeterend project in het UZ Gent.* Master thesis. Master of Science in Pharmaceutical Care. UGhent.

Kleinjan M, van den Eijnden RJ, Dijkstra A, Brug J and Engels RC (2006) Excuses to continue smoking: The role of disengagement beliefs in smoking cessation. *Addictive Behaviors* 31(12): 2223-2237.

Krist AH, Tong ST, Aycock RA and Longo DR (2017) Engaging patients in decision-making and behavior change to promote prevention. *Information Services & Use* 37(2): 105-122.

Kurko TAT, Saastamoinen LK, Tähkäpää S, Tuulio-Henriksson A, Taiminen T, Tiihonen J and Hietala J (2015) Long-term use of benzodiazepines: definitions, prevalence and usage patterns–a systematic review of register-based studies. *European Psychiatry* 30(8): 1037-1047.

Lewis A, Gee M, Ho L and Miller S (2018) Understanding why older adults with type 2 diabetes join diabetes online communities: semantic network analyses. *JMIR aging* 1(1): e10649.

Liang J and Luo B. (2012). Toward a discourse shift in social gerontology: From successful aging to harmonious aging. *Journal of aging studies* 26(3): 327-334.

Liebrenz M, Gehring M, Buadze A and Caflisch C (2015) High-dose benzodiazepine dependence: a qualitative study of patients' perception on cessation and withdrawal. *BMC psychiatry* 15(1): 116.

Lumme-Sandt K, Hervonen A and Jylhä M (2000) Interpretative repertoires of medication among the oldest-old. *Social Science and Medicine* 50(12): 1843-1850.

Macken L, De Clercq O and De Paulussen H (2011) Dutch Parallel Corpus: A Balanced Copyright-Cleared Parallel Corpus. *Meta* 56: 374–390.

MacLean D, Gupta S, Lembke A, Manning C and Heer J (2015) Forum77: An analysis of an online health forum dedicated to addiction recovery. *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing:* 1511-1526.

Malvini Redden S, Tracy SJ and Shafer MS (2013) A metaphor analysis of recovering substance abusers' sensemaking of medication-assisted treatment. *Qualitative Health Research* 23(7): 951-962.

Marshall L (2015) *Anti-ageing and identities.* Routledge Handbook of Cultural Gerontology. Routledge: 210-216.

McDonald D and Woodward-Kron R (2016) Member roles and identities in online support groups: Perspectives from corpus and systemic functional linguistics. *Discourse & Communication* 10(2): 157-175.

McLellan A. (2017) Substance misuse and substance use disorders: why do they matter in healthcare? *Transactions of the American Clinical and Climatological Association* 128: 112.

Mehuys E, Dupond L, Petrovic M, Christiaens T, Van Bortel L, Adriaens E (2012) Medication management among home-dwelling older patients with chronic diseases: possible roles for community pharmacists. The *Journal of Nutrition, Health & Aging* 16(8):721-6.

Milisen K (2014) *Brochure 'Van slaappillen kan je vallen'*. Expertisecentrum Val- en fractuurpreventie Vlaanderen (EVV). www.preventiemethodieken.be [last consulted 6/6/2020]

Morrow P (2006) Telling about problems and giving advice in an Internet discussion forum: Some discourse features. *Discourse studies* 8(4): 531-548.

Mortelmans D (2013) *Handboek kwalitatieve onderzoeksmethoden*. Leuven: Acco.

Mudry T and Strong T (2013) Doing recovery online. *Qualitative Health Research* 23(3): 313-325.

Nambisan P (2011) Information seeking and social support in online health communities: impact on patients' perceived empathy. *Journal of the American Medical Informatics Association* 18(3): 298-304.

Nimrod G (2010). Seniors' online communities: A quantitative content analysis. *The Gerontologist* 50(3): 382-392.

Novick G (2008) Is there a bias against telephone interviews in qualitative research?. Research in nursing & health, 31(4), 391-398.

Oborn E, Barrett M, Gibson S and Gillard S (2019). Knowledge and expertise in care practices: the role of the peer worker in mental health teams. *Sociology of health & illness* 41(7): 1305-1322.

Parr J, Kavanagh D, Young R and McCafferty K (2006) Views of general practitioners and benzodiazepine users on benzodiazepines: a qualitative analysis. *Social Science & Medicine* 62(5): 1237-1249.

Partington A, Duguid A and Taylor C (2013) *Patterns and Meanings in Discourse: Theory and practice in corpus-assisted discourse studies (CADS)*. Amsterdam/Philadelphia: John Benjamins.

Pickersgill M (2012) What is psychiatry? Co-producing complexity in mental health. *Social Theory & Health* 10(4): 328-347.

Pino NW, Tajalli H, Smith CL and DeSoto W (2017) Nonmedical prescription drug use by college students for recreational and instrumental purposes: Assessing the differences. *Journal of Drug Issues* 47(4): 606-621.

Potter A, Markowitz B, Smith E, Rajack-Talley A, D'Silva U, Della J and Carthan Q (2016) Healthicization and lay knowledge about eating practices in two African American communities. *Qualitative Health Research* 26(14): 1961-1974.

Potter J (1996) Discourse analysis and constructionist approaches: Theoretical background. *Handbook of qualitative research methods for psychology and the social sciences:* 125-140.

Potter J (2004) Discourse analysis. In: M. Hardy and Bryman, A. (Eds). *Handbook of Data Analysis* (pp. 607-24). London. Sage.

Quintero G (2009) A cultural analysis of collegiate polydrug use. *Journal of Psychoactive Drugs* 41 (1):39–47. doi:10.1080/02791072.2009.10400673.

Rayson P, Berridge D and Francis B (2004) Extending the Cochran rule for the comparison of word frequencies between corpora. In: *7th International Conference on Statistical analysis of textual data (Louvain-La-Neuve)*, pp. 926-936.

Recuber T (2015) Occupy empathy? Online politics and micro-narratives of suffering. *New Media & Society* 17(1): 62-77.

Rueger J, Dolfsma W and Aalbers R (2020) Perception of Peer Advice in Online Health Communities Access to Lay Expertise. *Social Science & Medicine*: 113117.

Ryan K, Bissell P and Morecroft C (2007) Narratives about illness and medication: a neglected theme/new methodology within pharmacy practice research. Part II: medication narratives in practice. *Pharmacy world & science* 29(4): 353-360.

Salzmann-Erikson M and Eriksson H (2012) LiLEDDA: a six step forum-based netnographic research method for nursing science. *Aporia: The Nursing Journal* 4(4): 7-18.

Sciensano. 2020. Vijfde COVID-19-gezondheidsenquête. Eerste resultaten. Brussel, België; Depot nummer/2020/14.440/95. Available: https://doi.org/10.25608/69j2-hf10

Scott M (2020) *WordSmith Tools version 8. Stroud*: Lexical Analysis Software

Sirdifield C, Anthierens S, Creupelandt H, Chipchase SY, Christiaens T and Siriwardena AN (2013) General practitioners' experiences and perceptions of benzodiazepine prescribing: systematic review and meta-synthesis. *BMC family practice* 14(1): 191.

Smedley RM and Coulson NS (2018) A practical guide to analysing online support forums. *Qualitative Research in Psychology*: 1-28.

Smith G and Farrimond H (2019) Active ageing, emotional care and the threat of stigma: Identity management in older adults using sleeping medication long-term. *Health* 23(3): 255-272.

Snyder H and Engström J (2016) The antecedents, forms and consequences of patient involvement: a narrative review of the literature. *International Journal of Nursing Studies* 53: 351-378.

Soyka M (2017) Treatment of benzodiazepine dependence. *New England Journal of Medicine* 376(12): 1147-1157.

Starks H and Brown Trinidad S (2007) Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research* 17(10): 1372-1380.

Sugiura, L, Wiles R and Pope C (2017) Ethical challenges in online research: Public/private perceptions. *Research Ethics* 13(3-4): 184-199.

Ten Wolde GB, Dijkstra A, Van Empelen P, Neven AK and Zitman FG (2008) Social-cognitive predictors of intended and actual benzodiazepine cessation among chronic benzodiazepine users. *Addictive behaviors* 33(9): 1091-1103.

Thorn P, Hill NT, Lamblin M, Teh Z, Battersby-Coulter R, Rice S, Bendall S, Gibson KL, Finlay SM, Blandon R, de Sousa L, West A, Cooksey A, Sciglitano J, Goodrich S and Robinson J (2020) Developing a suicide prevention social media campaign with young people (The# Chatsafe project): co-design approach. *JMIR mental health* 7(5): e17520.

Vampini C and Gallelli L (2014) Anxiety and benzodiazepines: A Delphi method-based survey of knowledge on their pharmacology and clinical use. *Journal of Psychopathology* 20: 322-340.

van 't Riet J and Ruiter RA (2013) Defensive reactions to health-promoting information: An overview and implications for future research. *Health Psychology Review* 7(sup1): S104-S136.

van de Straat V, Buffel V and Bracke P. (2018) Medicalization of sleep problems in an ageing population: a longitudinal cross-national study of medication use for sleep problems in older European adults. *Journal of ageing and health* 30(5): 816-838.

van de Straat V. and Bracke P (2015) How well does Europe sleep? A cross-national study of sleep problems in European older adults. *International journal of public health* 60(6): 643-650.

Van den Bogaert S, Ceuterick M and Bracke P (2018) The silver lining of greying: Ageing discourses and positioning of ageing persons in the field of social health insurance. *Health* 24(2): 169-186.

Van der Eecken C (2016) Waar bevinden de chronische gebruikers van benzodiazepines en Z-producten uit een praktijk in Lede zich in de cirkel van Prochaska en Di Clemente? Wat verhindert hen om deel te nemen aan een geplande afbouwstudie van benzodiazepines? Master thesis. Master of Medicine in Family Medicine. UGhent.

Van der Heyden J, Berete F and Drieskens S (2020) *Gezondheidsenquête 2018: Gebruik van geneesmiddelen*. Brussel, België: Sciensano; D/2020/14.440/17 . Beschikbaar op: www.gezondheidsenquete.be

Van Deun P (2017) Verslaving: van instrumenteel naar impulsief en automatisch gedrag. *Tijdschrift Klinische Psychologie* 47(4): 36-42.

Van Deun P (2018) *Het gekaapte brein. Verslavingsgedrag beter begrijpen*. Pelckmans Pro.

Van Deun P (2020) Mensen kunnen leren om de neurobiologische verslavingsmechanismen te slim af te zijn. Naar een andere behandeling van verslaving. *GZ-Psychologie* 12: 24-29.

van Hulten R, Isacson D, Bakker A and Leufkens H (2003) Comparing patterns of long-term benzodiazepine use between a Dutch and a Swedish community. *Pharmacoepidemiology and drug safety* 12(1): 49-53.

Votaw VR, Geyer R, Rieselbach MM and McHugh RK (2019) The epidemiology of benzodiazepine misuse: a systematic review. *Drug and alcohol dependence* 200: 95-114.

Wall M, Lambert S and Horan A (2018) An Evaluation of Practitioner's Experience of Service Users Seeking Community Detoxification from Benzodiazepines. *Journal of Psychoactive Drugs* 50(3): 224-230.

Wetherell M and Potter J (1988) Discourse analysis and the identification of interpretative repertoires. In Antaki, G. (ed.) *Analysing everyday explanation: A casebook of methods*: 168-183.

Whyte SR, van der Geest S and Hardon A. (2002) *Social lives of medicines*. Cambridge University Press.

Williams S, Gabe J and Davis P (2008) The sociology of pharmaceuticals: progress and prospects. *Sociology of Health & Illness* 30(6):813-24.

Wood LA and Kroger RO (2000) *Doing discourse analysis: Methods for studying action in talk and text*. Sage.

Yang XY, Kelly BC and Yang T (2014) The influence of self-exempting beliefs and social networks on daily smoking: A mediation relationship explored. *Psychology of Addictive Behaviors* 28(3): 921.

ANNEXES

ANNEX 1 OVERVIEW OF SENSITIZATION CAMPAIGNS BY THE FOD HEALTH

Figure 1 campaign 2002-2004

Figure 4 campaign 2005-2006

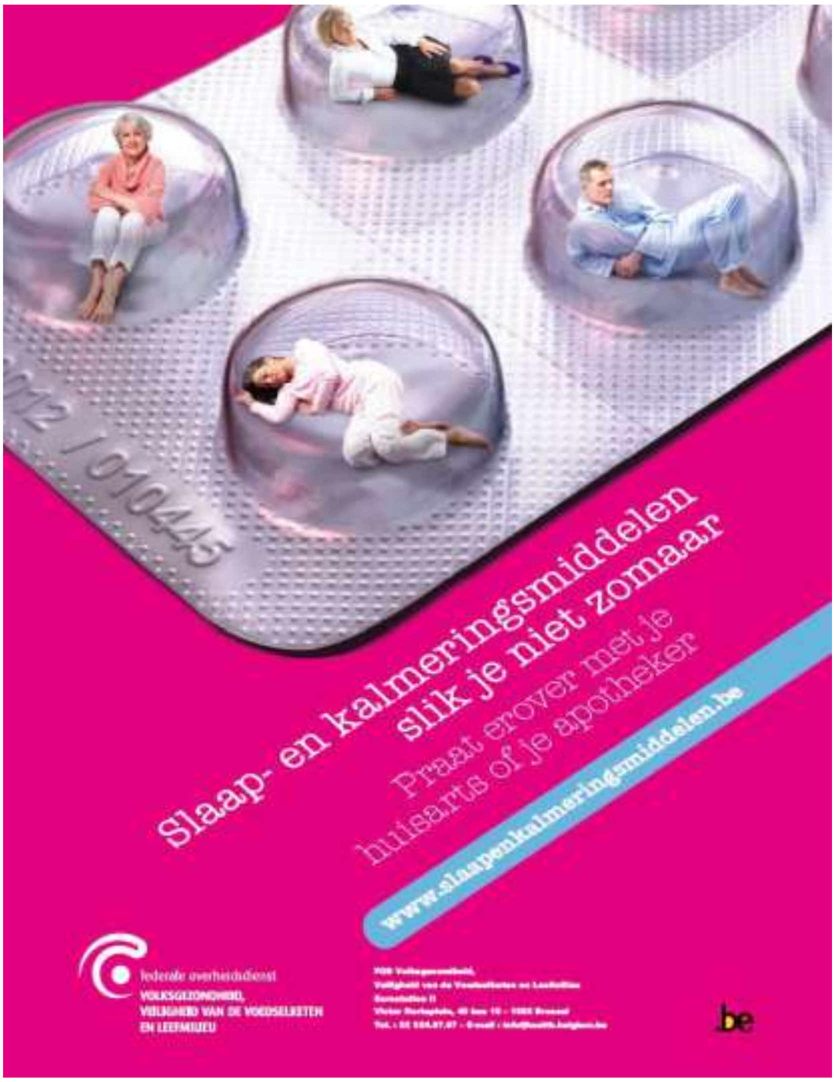

Figure 5 campaign 2009-2010

Figure 6 campaign 2009-2010 (brochure)

SLAAP- EN KALMEERMIDDELEN,
DENK EERST
AAN ANDERE OPLOSSINGEN.

BEWEGING, VOEDING, RELAXATIE, ...

SLAAP- EN KALMEERMIDDELEN
MOETEN DE **LAATSTE OPTIE** ZIJN.

Praat erover met je arts
of je apotheker

.be

Figure 7 campaign 2018

ANNEX 2 OTHER CAMPAIGNS

Het FAGG biedt u 12 tips voor een goed gebruik van geneesmiddelen op www.eengeneesmiddelisgeensnoepje.be

Federaal Agentschap voor Geneesmiddelen en Gezondheidsproducten

Uw geneesmiddelen en gezondheidsproducten, onze zorg.

Figure 8 FAMPH campaign 2011

ANNEX 3 RECRUITMENT MATERIAL (WP3)

UNIVERSITEIT GENT

belspo

ONDERZOEK NAAR ERVARINGEN VAN GEBRUIKERS VAN BENZODIAZEPINES EN Z-PRODUCTEN

ONDERZOEKSGROEP Hedera (Health and Demographic Research) –Universiteit Gent

ZOEKT PERSONEN VOOR EEN INTERVIEW OVER SLAAP- OF KALMERINGSMIDDELEN

Gebruikt u **langer dan 6 maanden slaapmedicatie en/of kalmeringsmiddelen** (minstens vier keer per week)?

Of heeft u **vroeger** gedurende meer dan 6 maanden slaapmedicatie en/of kalmeringsmiddelen gebruikt ?

En bent u **ouder dan 18**?

Dan kan u deelnemen aan een **eenmalig interview** (op afspraak) over uw persoonlijke ervaringen met deze medicatie.

Elke deelnemer ontvangt een **waardebon van 25 euro**.

Interesse?

Gelieve contact op te nemen met

Melissa Ceuterick (verantwoordelijke BENZO_NET)

☎ 09 264 68 01

✉ melissa.ceuterick@ugent.be

www.ugent.be/ps/sociologie/nl/onderzoek/benzo_net.htm

UNIVERSITEIT GENT

FACULTEIT POLITIEKE EN SOCIALE WETENSCHAPPEN

FACULTEIT GENEESKUNDE EN GEZONDHEIDSWETENSCHAPPEN

Hedera | Health and demographic research Ghent University

ANNEX 4 CONSENT FORM INTERVIEWS (WP3)

GEÏNFORMEERDE TOESTEMMING – INFORMED CONSENT

Deelname aan onderzoek "BENZO_NET": langdurig gebruik van benzodiazepines

Beste,

Universiteit Gent voert in opdracht van Belspo een onderzoek uit naar langdurig gebruik van slaap- en kalmeringsmiddelen (benzodiazepines).

Daarom zouden wij u graag een aantal vragen willen stellen over uw ervaringen met het gebruik van deze medicatie. Het interview wordt afgenomen door Melissa Ceuterick (onderzoekster Hedera).

Daarnaast bevragen we in het kader van dit onderzoek een aantal van uw persoonsgegevens (postcode, geboortejaar, gezinssamenstelling). Deze zullen enkel in functie van het onderzoek gebruikt worden en zullen op geen enkele wijze publiek gemaakt worden. Om uw privacy te vrijwaren zullen alle onderzoeksresultaten volledig geanonimiseerd bewaard en gerapporteerd worden. Het ondertekende formulier zal door de onderzoekster bewaard worden op een beveiligde plaats

Als u verder nog vragen heeft, kunt u steeds contact opnemen met Melissa Ceuterick, verantwoordelijke onderzoekster BENZO_NET of met de Data Protection Officer van UGent privacy@ugent.be Meer informatie kan u tevens vinden op de webpagina.

Hartelijk dank voor uw medewerking!

Melissa Ceuterick – verantwoordelijke onderzoekster BENZO_NET
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+32 (0) 473 71 69 89
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Ik, (ondergetekende),

………………………………………………………………………

ga ermee akkoord mijn medewerking te verlenen aan het onderzoek en ga akkoord met de volgende voorwaarden:

(1) ik heb voldoende informatie gekregen omtrent het doel van het onderzoek;

(2) ik neem op vrijwillige basis deel aan het onderzoek;

(3) ik stem in met een digitale opname van het interview en ben op de hoogte dat het audio bestand na transcriptie gewist wordt;

(4) ik geef de toestemming aan de onderzoeker mijn resultaten anoniem te bewaren, verwerken en rapporteren;

(5) ik begrijp dat de gegevens die ik in het kader van dit interview verstrek, geheel vertrouwelijk en anoniem zullen worden verwerkt en enkel in functie van dit onderzoek worden gedeeld binnen het onderzoeksteam;

(6) ik ben op de hoogte van de mogelijkheid om mijn deelname aan het onderzoek op ieder moment stop te zetten en dit zonder opgave van reden;

(7) ik ben ervan op de hoogte dat ik een samenvatting van de onderzoeksbevindingen kan krijgen op aanvraag;

Ik geef wel/ geen *(schrappen wat niet past)* toestemming om de gegevens anoniem en vertrouwelijk te hergebruiken in het kader van wetenschappelijk vervolgonderzoek door het onderzoeksteam.

Voor akkoord,

Plaats en datum Naam + handtekening van de deelnemer

……………………… ………………………………………………………………

Plaats en datum Naam + handtekening van de onderzoeker

……………………… ………………………………………………………………

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ANNEX 5 POST-INTERVIEW INFORMATION LEAFLET FOR PARTICIPANTS

INFORMATIEBROCHURE

Heb je na dit interview vragen over het gebruik van slaap-of kalmeringsmiddelen? Vraag raad aan je huisarts of apotheek.

Wil je jouw gebruik van slaap- en of kalmeringsmiddelen testen? Deze anonieme zelftest helpt je bepalen of jouw gebruik van deze medicatie risico’s inhoudt. Afhankelijk van je score krijg je advies. https://www.druglijn.be/test-jezelf/test/zelftest-slaap--en-kalmeringsmiddelen

Wil je meer te weten komen over de werking van slaap-en kalmeringsmiddelen? VAD ontwikkelde een brochure met de meest gestelde vragen over dit type medicatie.

https://www.vad.be/assets/de-meest-gestelde-vragen-slaap--en-kalmeringsmiddelen

Wens je jouw medicatie af te bouwen of ben je op zoek naar professioneel advies? Dan kan je terecht op www.Benzodebaas.nl Op deze website kan je je aanmelden voor een online afbouwprogramma begeleid door professionals. Ook vind je er een forum waar je (anoniem) ervaringen kan delen met lotgenoten.

Eén op vier mensen krijgt in zijn of haar leven te maken met een geestelijk gezondheidsprobleem. De website Geestelijk Gezond Vlaanderen maakt je wegwijs in het hulpverleningslandschap: https://www.geestelijkgezondvlaanderen.be/hulp-zoeken. Ook over slaapstoornissen kan je er heel wat informatie vinden: https://www.geestelijkgezondvlaanderen.be/ slaapstoornissen Je vindt er een overzicht van bestaande behandelingen.

Een centrum voor geestelijke gezondheidszorg in je buurt, vind je hier: https://www.zorg-en-gezondheid.be/centra-voor-geestelijke-gezondheidszorg

Nood aan een anoniem luisterend oor? Bij Teleonthaal kan je dag en nacht terecht. Telefonisch op 106. Als je liever chat kan je hier terecht: https://www.tele-onthaal.be/

De verschillende Vlaamse ziekenfondsen bieden heel wat informatie rond het aanpakken van slaapproblemen:

https://www.cm.be/slaapwel

https://www.bondmoyson.be/ovl/gezond-actief/gezond-leven/gezonde-geest/aandoeningen/Pages/Beter-slapen.aspx

https://www.partena-ziekenfonds.be/nl/ziekenfonds-en-voordelen/voordelen-en-terugbetalingen/slaaptherapie

https://www.lm.be/NL/Uw-mutualiteit/Publicaties/Brochures/Documents/Slapen.pdf

https://www.nzvl.be/jouw-gezondheid/gezond-ouder-worden-medicijnen

ANNEX 6 INTERVIEW TOPIC GUIDES IN DUTCH

Interviewleidraad (a): Versie huidige gebruiker

Introductie (voor start opname)

- Informed consent procedure (zie formulier)
- Neutraliteit en rol onderzoeker
- Doel van het onderzoek

Start opname

Drop-off persoonlijke gegevens (bevragen indien nog niet bekend uit voorafgaand contact)

- Gender
- Geboortejaar
- Gezinssituatie
- Woonplaats/ postcode
- Arbeidssituatie (wat doet u in het dagelijks leven?)

Deel 1 Huidig gebruik (algemeen)

- Welke (slaap/kalmeer)medicatie gebruikt u momenteel? (Soort/type, merknaam?)
- Hoe vaak gebruikt u dit?
- In welke hoeveelheid? Wat is de dosering op de verpakking? Hoeveel neemt u dagelijks in?
- Hoe verkrijgt u deze medicatie? (PROBE: op voorschrift van een arts of gekregen van familielid/vriend(/in),…?)
- Sinds wanneer neemt u deze medicatie? Hoe lang gebruikt u deze medicatie al?

Deel 2 Opstart medicatie

- Hoe bent u ertoe gekomen om met deze medicatie te starten? Wat was de reden?
- Op wiens initiatief? (PROBE: Op aanraden arts? Eigen aansturen? Vrienden/kennissen)
- Indien door arts: Wat vond u van die aanbeveling van de arts? Welke andere oplossingen stelde de arts eventueel nog voor?

- Welk advies gaf de huisarts bij het voorschrijven? (PROBE: dosering, gebruik, mogelijke bijwerkingen, voorgeschreven duur van gebruik)
- Hoe zou u uw band met uw (huis)arts omschrijven? Is het (nog) steeds dezelfde arts die deze medicatie voorschrijft?
- Welke zaken had u eventueel ervoor reeds geprobeerd? Waarom werkte dit onvoldoende?
- Combineert u dit momenteel met andere medicatie? Zo ja, welke?
- Gebruikt u momenteel nog andere behandelingen? (PROBE: therapie, natuurlijke geneesmiddelen, yoga, relaxatie,…)
- Wordt deze medicatie terugbetaald door uw ziekenfonds? Hoe belangrijk is dit voor u?

Deel 3 Gezondheidsidentiteit en betekenis van gebruik

- Hoe zou u uw gezondheid in het algemeen omschrijven?
- Hoe zou u uw slaap/angst/… omschrijven?
- Indien voor slaapproblemen:
    - Heeft u een bepaalde routine voor het slapengaan?
    - Wat is een goeie nacht voor u?
    - Welke hinder ondervindt u van een slechte nacht? Hoe voelt u zich de dag erna?
    - Wat doet u bij wakker liggen?
- Welk verschil maakt het gebruik van deze medicatie voor u?
- Wat ervaart u na inname van deze medicatie?
- Hoe zouden uw dagen/nachten eruit zien zonder deze medicatie?
- Hoe is uw slaap/angst met deze medicatie? Kan u dit eens omschrijven?
- Hoe belangrijk is het gebruik van deze medicatie voor u? (PROBE: zou u zichzelf als een tevreden gebruiker omschrijven?)

Deel 4 Sociale netwerken

- Wie weet dat u deze medicatie gebruikt? Met wie praat u hierover?
- Hoe denkt men in uw familie, vrienden- en kennissenkring over het gebruik van deze medicatie? (PROBE: Is dit taboe? Is dit algemeen verspreid?)
    - Hoe praten jullie over deze medicatie? Met andere woorden, hoe wordt ernaar verwezen? Geef eens een voorbeeld. (vraag om specifiek taalgebruik in kaart te brengen)
- Waar zoekt u informatie over deze medicatie (PROBE: arts, apotheker, bijsluiter, vrienden, online bronnen)?
- Praat u soms op online fora over deze medicatie? Zo ja: welke? Op welke manier helpen deze fora u? Wat kan er beter?

Deel 5 Kennis over langdurig gebruik, persoonlijke ervaring met neveneffecten

- Waar schiet deze medicatie (eventueel) tekort volgens u?
- Heeft u zelf ooit ongewenste effecten gehad van deze medicatie?
- Hoe heeft u dat ervaren?
- Wat weet u over mogelijke bijwerkingen van deze medicatie?

Deel 6 Perceptie van effectiviteit en (persoonlijke) afhankelijkheid

- Is uw inname van deze medicatie veranderd doorheen de tijd? Op welke manier?
- Bent u ooit gewisseld van soort/merknaam?
- Heeft u de dosering al moeten aanpassen?
- Ervaart u nog steeds hetzelfde effect? Kan u dit beschrijven?
- Heeft u ooit (al dan niet toevallig) een dosis overgeslagen? Wat ervaarde u toen?
- Bent u ooit gestopt met het nemen van deze medicatie?
- Hoe is dat dan gelopen?
- Wat was de aanleiding om te stoppen?
- Wat heeft u toen geholpen? Wat liep goed? Wat liet niet goed?
- Ervaarde u toen steun uit uw omgeving? Waarom wel/niet?
- Heeft u toen bepaalde klachten ervaren? Welke? Zijn dit ontwenningsverschijnselen volgens u?
- Wat betekent afhankelijkheid voor u?
- Denkt u dat u afhankelijk bent van deze medicatie? Waarom?

Deel 7 Visie op afbouw/stoppen en intentie

- Op welke manier zou u (eventueel) anders willen omgaan met deze medicatie?
- Wat zou u kunnen overhalen om te stoppen?
- Wat denkt u dat er nodig is om te stoppen met deze medicatie?
- Denkt u er zelf aan om (eventueel op termijn) te stoppen?
- Wat houdt u tegen om te stoppen? Wat maakt het moeilijk?
- Hoe kijkt men in uw familie, vrienden en/of kennissenkring naar afbouwen en stoppen van deze medicatie?

Deel 8 Campagnes en rol van de overheid

- Welke maatregelen van de overheid kent u met betrekking tot dit type medicatie?
- PROBES: materiaal campagnes 2018 en 2011 (materiaal wordt getoond)
- Heeft u deze affiche al ergens gezien (bv. wachtzaal arts, bij de apotheek,…)?
- Heeft u dit filmpje al gezien (bv. op tv, wachtzaal arts, internet, scherm apotheek…)?
- Wat spreekt u hierin aan? Wat spreekt u net niet aan?
- Wat kan volgens u anders/beter in deze campagnes?
- Hoe kunnen dergelijke campagnes eventueel beter worden afgestemd op langdurige gebruikers?
- Hoe staat u tegenover andere maatregelen van de overheid, zoals bijvoorbeeld het verbod op rijden na inname van slaap- of kalmeringsmiddelen?
- Welke rol kan de overheid volgens u nemen?

Afrondende vraag

- Zijn er nog andere zaken die u zou willen meegeven?

Einde opname

Afsluiter (na opname)

- Afspraken opvolging (vertrouwelijkheid-doornemen transcriptie-bezorgen resultaten)
- Dankwoord + overhandigen cadeaubon + informatiebrochure

Interviewleidraad (b): Versie voormalige gebruiker

Introductie (voor start opname)

- Informed consent procedure (zie formulier)
- Neutraliteit en rol onderzoeker
- Doel van het onderzoek

Start opname

Drop-off persoonlijke gegevens (bevragen indien nog niet bekend uit voorafgaand contact)

- Gender
- Geboortejaar
- Gezinssituatie
- Woonplaats/ postcode
- Arbeidssituatie (wat doet u in het dagelijks leven?)

Deel 1 Voormalig gebruik (algemeen)

- Welke slaap/kalmeermedicatie gebruikte u? (Soort/type, merknaam?)
- Hoe vaak gebruikte u deze medicatie?
- In welke hoeveelheid? Wat was de dosering op de verpakking? Hoeveel nam u dagelijks in?
- Hoe verkreeg u deze medicatie? (PROBE: op voorschrift van een arts of gekregen van familielid/vriend(/in),…?)
- Hoe lang heeft u deze medicatie gebruikt?

Deel 2 Opstart medicatie

- Hoe bent u ertoe gekomen om met deze medicatie te starten? Wat was de reden?
- Op wiens initiatief? (PROBE: Op aanraden arts? Eigen aansturen? Vrienden/kennissen)
- Indien door arts: Wat vond u van die aanbeveling van de arts? Welke andere oplossingen stelde de arts eventueel nog voor?
- Welk advies gaf de huisarts bij het voorschrijven? (PROBE: dosering, gebruik, mogelijke bijwerkingen, voorgeschreven duur van gebruik)
- Hoe zou u uw band met uw (huis)arts omschrijven? Gaat u nog steeds naar dezelfde arts?
- Welke zaken had u eventueel ervoor reeds geprobeerd? Waarom werkte dit onvoldoende?
- Combineerde u dit met andere medicatie? Zo ja, welke?

- Gebruikt(e) u nog andere behandelingen? (PROBE: therapie, natuurlijke geneesmiddelen, yoga, relaxatie,…)
- Werd deze medicatie terugbetaald door uw ziekenfonds? Hoe belangrijk is dit voor u?

Deel 3 Gezondheidsidentiteit en betekenis van gebruik

- Hoe zou u uw gezondheid in het algemeen omschrijven?
- Hoe zou u uw slaap/angst/… nu omschrijven?
- Indien voor slaapproblemen:
    - Heeft u een bepaalde routine voor het slapengaan? Is die veranderd sinds u gestopt bent met deze medicatie? In welke zin?
    - Wat is een goeie nacht voor u?
    - Welke hinder ondervindt u van een slechte nacht? Hoe voelt u zich de dag erna?
    - Wat doet u bij wakker liggen?
- Welk verschil maakte het gebruik van deze medicatie voor u?
- Wat ervaarde u na inname van deze medicatie?
- Hoe was uw slaap/angst met deze medicatie? Kan u dit eens omschrijven?
- Hoe zien uw dagen/nachten er nu uit zonder deze medicatie?
- Hoe belangrijk was het gebruik van deze medicatie voor u? (PROBE: zou u zichzelf als een tevreden gebruiker omschrijven?)

Deel 4 Sociale netwerken

- Wie weet/wist dat u deze medicatie gebruikt hebt? Met wie praat u hierover?
- Hoe denkt men in uw familie, vrienden- en kennissenkring over het gebruik van deze medicatie? (PROBE: Is dit taboe? Is dit algemeen verspreid?)
    - Hoe praten jullie over deze medicatie? Met andere woorden, hoe wordt ernaar verwezen? Geef eens een voorbeeld. (vraag om specifiek taalgebruik in kaart te brengen)
- Waar zocht u informatie over deze medicatie (PROBE: arts, apotheker, bijsluiter, vrienden, online bronnen)?
- Praatte u soms op online fora over deze medicatie? Zo ja: welke? Op welke manier helpen deze fora u? Wat kan er beter?

Deel 5 Kennis over langdurig gebruik, persoonlijke ervaring met neveneffecten

- Waar schoot deze medicatie (eventueel) tekort volgens u?
- Heeft u zelf ooit ongewenste effecten gehad van deze medicatie?
- Hoe heeft u dat ervaren?

- Wat weet u over mogelijke bijwerkingen van deze medicatie?

Deel 6 Perceptie van effectiviteit (persoonlijke) afhankelijkheid

- Voordat u gestopt bent, is uw inname van deze medicatie veranderd doorheen de tijd? Op welke manier?
- Bent u ooit gewisseld van soort/merknaam?
- Heeft u de dosering ooit moeten aanpassen?
- Ervaarde u nog steeds hetzelfde effect?
- Wat is afhankelijkheid voor u? Denkt u dat u afhankelijk was van deze medicatie? Waarom?

Deel 7 Afbouw en stoppen

- Wat voor u de aanleiding om te stoppen? Wat heeft u ertoe gebracht om te stoppen? (PROBE: bent u zelf gestopt of op aanraden van anderen (arts? omgeving? doorvragen op onderliggende redenen)
- Hoe bent u gestopt? Hoe is dat verlopen? (PROBE: Ging dat geleidelijk of heel abrupt?)
- Waar vond u hulp? Wat heeft u toen geholpen? Wat liep goed?
- Wat hielp er net niet? Wat liep niet goed?
- Wat hield u eventueel tegen om te stoppen? Wat maakte het moeilijk?
- Welke steun heeft u ervaren uit uw omgeving? Hoe kijkt men in uw familie, vrienden en/of kennissenkring naar afbouwen en stoppen van deze medicatie?
- Heeft u bepaalde klachten ervaren tijdens de afbouw? Welke?
- Heeft u bepaalde klachten ervaren na het stoppen? Welke?
- Doet u nu bepaalde (andere) zaken om uw slaap/angst (aanleiding) te behandelen?
- Wat zou u willen meegeven aan andere langdurige gebruikers hierover? Wat zou anderen kunnen overhalen om te stoppen? Wat denkt u dat er nodig is om te stoppen met deze medicatie?

Deel 8 Campagnes en rol van de overheid

- Welke maatregelen van de overheid kent u met betrekking tot dit type medicatie?
- PROBES: materiaal campagnes 2018 en 2011 (materiaal wordt getoond)
- Heeft u deze affiche al ergens gezien (bv. wachtzaal arts, bij de apotheek,…)?
- Heeft u dit filmpje al gezien (bv. op tv, wachtzaal arts, internet, scherm apotheek…)?
- Wat spreekt u hierin aan? Wat spreekt u net niet aan?
- Wat kan volgens u anders/beter in deze campagnes?
- Hoe kunnen dergelijke campagnes eventueel beter worden afgestemd op langdurige gebruikers?

- Hoe staat u tegenover andere maatregelen van de overheid, zoals bijvoorbeeld het verbod op rijden na inname van slaap- of kalmeringsmiddelen?
- Welke rol kan de overheid volgens u nemen?

Afrondende vraag

- Zijn er nog andere zaken die u zou willen meegeven?

Einde opname

Afsluiter (na opname)

- Afspraken opvolging (vertrouwelijkheid-doornemen transcriptie-bezorgen resultaten)
- Dankwoord + overhandigen cadeaubon + informatiebrochure