FEDERAL RESEARCH PROGRAMME ON DRUGS

BENZOCARE

Persons with a BENZOdiazepine/Z-drugs use disorder in mental health CARE

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Contract - DR/91/BENZOCARE

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LIST OF ABBREVIATIONS

APB: Algemene Pharmaceutische Bond

BCFI/CBIP: Belgian Center of Pharmacotherapeutical Information

BELPEP: Belgian Psychotropics Expert Platform

BZRA: Benzodiazepine Receptor Agonists

COCOF: Commission Communautaire Française

DMS-V: Diagnostic and Statistical Manual of Mental Disorders (fifth edition)

FAGG: Federaal Agentschap voor Geneesmiddelen en Gezondheidsproducten (Federal Agency for Medicines and Health Products)

AFMPS: L'Agence Fédérale des Médicaments et des Produits de Santé (Federal Agency for Medicines and Health Products)

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

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)

GOC: Goal oriented care

GP: General Practitioner

HCP: Health care professional

LOK: Lokale Kwaliteitsgroep (accredited by RIZIV-INAMI)

MFO: Medisch Farmaceutisch Overleg (medical pharmaceutical councils)

CMP: Concertation Medico-Pharmaceutique (medical pharmaceutical councils)

RIZIV: Rijksinstituut voor de Ziekte- en Invaliditeitsverzekering (=INAMI)

INAMI: Institut National d'assurance Maladie-Invalidité (=RIZIV)

REM: rapid eye movement

SES: socio-economic status

SUD: substance use disorder

1. INTRODUCTION

The report you are reading is the end result of the BENZOCARE study, an interdisciplinary collaboration (2021-2024) between Hedera (Health and Demographic Research), Faculty of Sociology of Ghent University and the Department of General Medicine, Faculty of Medicine of the University of Liège, realised with the financial support of BELSPO.

1.1 Mothers' little helpers?

"Mother needs something today to calm her down
And though she's not really ill, there's a little yellow pill.

She goes running for the shelter of her mother's little helper.
And it helps her on her way, gets her through her busy day"

Already in 1966, the Rolling Stones criticised the widespread and rising societal use of sedatives and anxiolytics in their famous song 'Mother's little helper'. Ever since, the song title has become a cynical metaphor for benzodiazepines and Z-drugs, a class of psychoactive medications with a sedative and anxiolytic effect that act on the benzodiazepine receptors in the body. These medicines are also called benzodiazepine receptor agonists -abbreviated as BZRA. We have chosen to use this term throughout this report, as this is a more neutral description. Medication in this class has a similar pharmacodynamic action and a sedative, hypnotic, anxiolytic, muscle relaxant and anticonvulsant effect. At the time of the release of the Stones' song, benzodiazepines were marketed as the more sophisticated and safer alternative to the highly addictive barbiturates which often led to overdoses. Nonetheless, it soon became evident that even this newer generation of medication came with a price. By 1980 it was widely known that these medications also caused dependence, even in low doses and after short periods of time. Once treatment exceeds the recommended duration of two to four weeks, the risk/benefit ratio of prescribing BZRA is highly debatable (Del'Osso and Lader, 2013). Long-term, habitual use - i.e. more than four times a week for more than six months continuously (Kurko et al., 2015) - is not recommended due to adverse effects such as tolerance, physiological and psychological dependence and withdrawal and rebound symptoms following attempts to withdraw, even when used in low and constant doses (Soyka, 2017). Eventually, effects of habitual use might be subtle and difficult to differentiate from original symptoms. Overall, BZRA thus have a high potential for misuse and abuse (Casati et al., 2012). While many people on a habitual prescription develop a low dose dependence without dose escalation or drug seeking behaviour, others might develop high dose dependence. In general many users theoretically meet the DSM-V criteria of a substance use disorder (SUD) (Schmitz, 2016).

Why then are these medications called little *helpers*? BZRA have a 'powerfully calming effect on the brain' (Fluyau et al., 2018: 148), by acting on a neurotransmitter called GABA. GABA reduces the transmission of signals in the brain, helping to suppress awareness of external stimuli and thus naturally acts as a calming agent. BZRA thus amplify this effect, but they do not produce natural sleep. Research on the effects of benzodiazepines on sleep architecture indicates an increase in stage 2 of non-REM (NREM) sleep, accompanied by a reduction in the duration of stages 3 and 4 of NREM sleep, as well as a decrease in REM sleep during the night (De Mendoça et al., 2023). Alterations in the balance between NREM and REM sleep can contribute to impairments in concentration and working memory. Although the increased time spent in stage 2 NREM sleep may result in a perceived improvement in sleep quality, characterized by fewer awakenings, the restorative phases of sleep are reduced. Stages 3 and 4 of non-REM (NREM) sleep, collectively referred to as slow-wave sleep (SWS) or deep sleep, are crucial for the restorative quality of sleep.

Furthermore, the maternal part of the 'Mother's little helper' metaphor, neatly conveys a demographic dynamic behind the use of BZRA: more than half a century later, women are worldwide still being prescribed significantly more sedatives and tranquillisers than men in almost all age groups (Lader, 2011). Moreover, inequalities in BRZA use also stretch along a social gradient. People with a lower socio-economic status are systematically being prescribed more psychotropic medication in general, including BZRA (Colman et al., 2023a). It has been argued that this stratified pharmaceuticalisation might be linked to perceptions of prescribers, who might expect a patient with a lower SES to lack the social, personal and financial capital that are believed necessary for more 'active' and more expensive treatments like psychotherapy (Colman et al., 2023b). Finally, there also exists a geographical gradient in psychotropic medication use. Van der Heyden et al. (2020: 36) report that the percentage of benzodiazepine users in the Walloon Region is significantly higher than in both the Flemish and Brussels Regions, and significantly higher in the Brussels Region than in the Flemish Region (when accounting for differences in age distribution between the regions). As for the percentage of users of Z-drugs, no significant differences between the regions are observed.

1.2 State-of-the art in Belgium

The use of BZRA continues to be high in Belgium, with 12% of the adult population using BZRA at the start of our study (Drieskens, 2020). In July 2024, De Standaard announced the launch of new IQVIA data on the general use of BZRA in Belgium. These figures -based on a representative sample of Belgian retail pharmacies- show that 2.1 million prescriptions were delivered in 2023. This means that one in five Belgians had received a prescription. On the other hand, figures over a five year time span also show a slight decline in the number of prescriptions, a trend that had been described earlier (Coteur et al., 2022). Nonetheless, especially long-term use seems to remain fairly stable. Especially the number of multiple prescriptions -indicating use far exceeding recommended doses- is still alarmingly high. Equally alarming are the recent findings published by VAD, which indicate that the proportion of adolescents aged 12-18 who have ever used a BZRA has steadily increased, rising from 13% in 2010-2011 to 17% in 2022-2023 (Rosiers, 2024). 1 in 5 Flemish school girls between 12 and 18 has already taken a BZRA at some point in their lives (20.4% vs. 12.7% in boys). Within the past year, 10.9% of the girls and 6.1% of the boys had used a BZRA.

Since the start of our project, several initiatives saw the light of day at federal level to address this trend. Most notably RIZIV-INAMI allocated a budget for a tapering program since February 1, 2023. This multidisciplinary initiative involves collaboration among patients, prescribers, and pharmacists and allows for a gradual reduction over a period ranging from 50 to 360 days, through a reimbursement of compounded preparation by the pharmacist.

1.3 BENZOCARE: addressing persistent knowledge gaps

At the start of our study, there were several gaps in the literature, we aimed to address with this project. First, the project builds on the previous BENZONET study (DR/02/81), which focused on the perspectives of long-term BZRA users and several forms of online support (Ceuterick et al., 2021). The study ran between 2019 and 2021 and given that it was a small scale study, and interdisciplinary collaboration between Hedera (Health and Demographic Research) and the Heymans Institute for Pharmacology at UGent, the perspective of patients living in Wallonia remained still uncharted. Secondly, while the BENZONET project focused on experiences of habitual BZRA users and possible reasons for developing chronic use, the study did not explore the perspectives of health care providers in great detail. Hence, very little was known about Belgian health care providers' perspectives on the contemporary role of BZRA in clinical practice, as well as on how BZRA dependence is viewed upon by professionals in current mental health and addiction care. Thirdly, equally little was known about the potentially unmet treatment needs of the substantial proportion of people with a dependence on BZRA in Belgium and the accessibility of mental health and addiction care services for patients with a BZRA related substance use disorder in Belgium. Therefore, the aims of the BENZOCARE project were to address these **knowledge gaps**. More specifically the study was built around the following aims:

- to study the accessibility of (mental) health care for persons with a BZRA SUD
- to analyse professionals' experiences and perceptions of BZRA SUD (needs, gaps, barriers, facilitators)
- to investigate (recovered) users' experiences and perceptions of these services (needs, gaps, barriers, facilitators) as tailored treatment should take subjective experiences into account
- to explore and unravel the ambiguous role of BZRA in the (mental) health care sector
- to develop sound, tailored and feasible policy recommendations

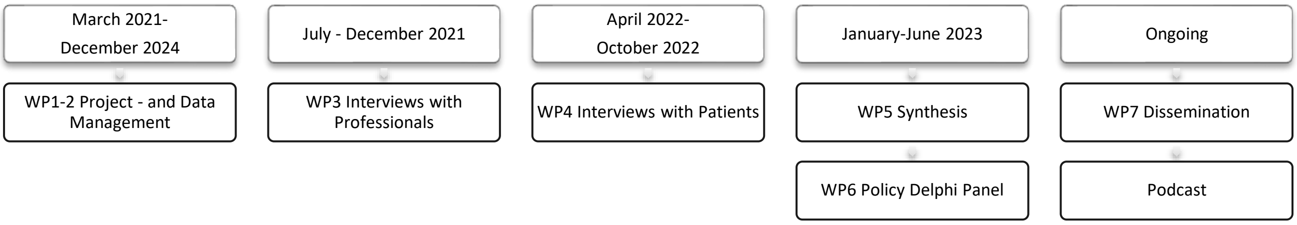
Slightly diverging from our original proposal (in which we initially envisioned a unique focus on mental and addiction care) throughout the study we soon took on a more integrated care approach, as preliminary results showed that in fact many patients seek and find care for a dependence on BZRA in primary care with only occasional referrals to secondary and tertiary care. This reflects a general move towards strengthening primary care as the first point of care for patients.

A qualitative and mixed methods design was developed with several qualitative WPs and a quantitative WP (in the form of a Policy Delphi Panel).

1.4 Project timeline

The BENZOCARE project was a collaborative effort where each team conducted similar fieldwork, respectively in French and Dutch in all regions of the country. The data project consisted of the following work packages:

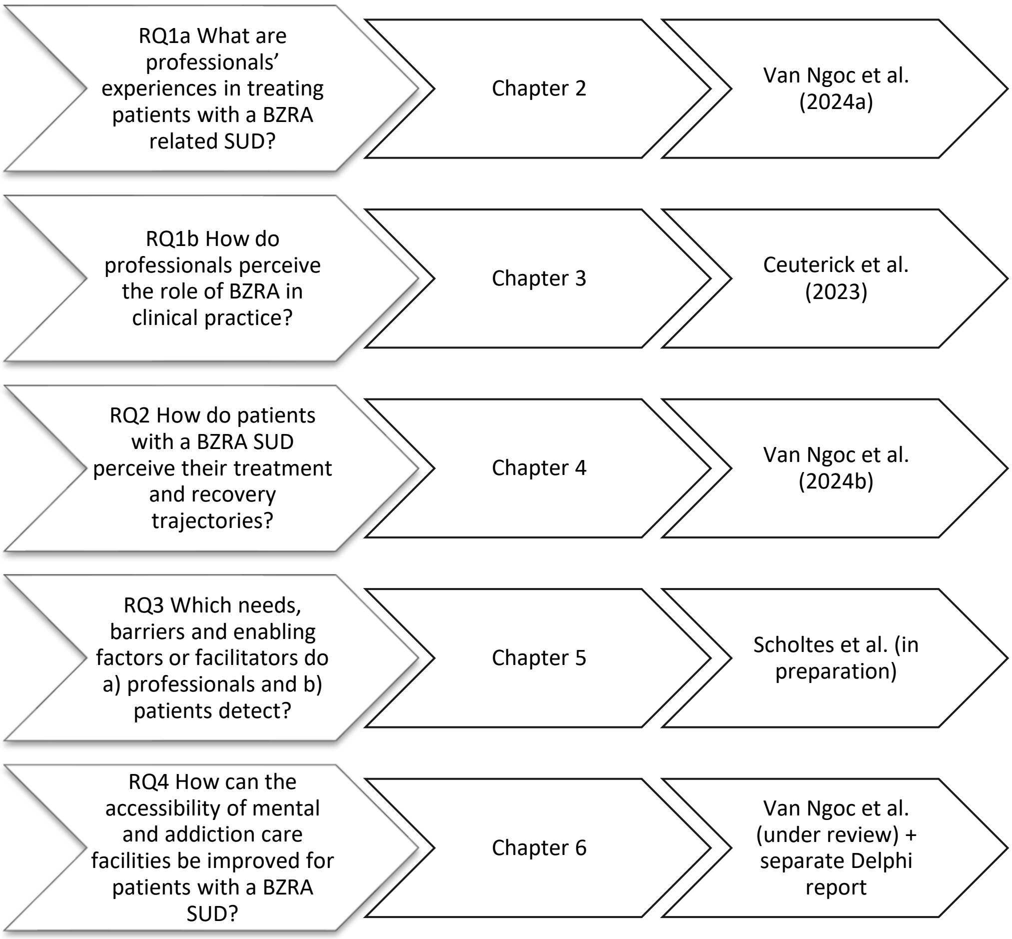
Figure 1 Project timeline



1.5 RQ's and outline

As shown in figure 2 below, the project aims were further distilled into separate research questions (RQs), each of which is addressed in a separate chapter (that has either been published or is currently under review).

Figure 2 Overview of research questions and chapters in which they are addressed



Chapter 2 of this report explores health care professionals’ experiences in treating patients with a BZRA related SUD. Chapter 3 further zooms in on the role of BZRA in clinical practice, from the perspective of prescribers. Chapter 4 unravels the lived experiences of long-term users with their treatment and recovery trajectories. Chapter 5 explores the accessibility of health care services for people with a dependence on BZRA in Belgium, from the shared perspective of both service users and health care providers (based on the model of accessibility of care developed by Levesque et al. (2013). In chapter 6 the most important policy recommendations that resulted from a policy Delphi panel are summarised. Finally, chapter 7 describes the process of the creation of a dissemination podcast based on the results of the study.

1.6 Ethics and team positionality statement

The overall study was granted ethic approval from the Comité d’Éthique Hospitalo-Facultaire Universitaire de Liège (reference number: 2021/121) and received a positive advice from the Ethics Committee of the Faculty of Political and Social Sciences of Ghent University (reference number EC-2021-22). At the start of the project a DMP+ data Management Plan was created through DMP Online. Ethical precautions taken during the study are outlined in each chapter separately under the respective methodology section.

Our team consists of three main researchers involved in the day-to-day implementation of the project: two postdoctoral researchers with respective experience in medical anthropology/health sociology and public health/systems thinking and a predoctoral researcher with a background in occupational psychology. The PI’s had a background in sociology and primary care respectively. Our disciplinary and departmental outlooks undeniably influenced specific choices that have been made during the project. This interdisciplinarity, however, allowed us to shed a nuanced and complex light on the topic of BZRA use, either by combining different theoretical perspectives or methodologies. Chapter 2 departs from a primary care perspective yet relied on qualitative data analysis experiences more common within social sciences. Chapter 3 on the other hand, took a more sociological perspective, and benefitted from having a primary care professional proving feedback on the data analysis stages. Chapter 4 employed an interpretative phenomenological analysis (IPA) that is most commonly used within psychology. Chapter 5 sheds a light on the accessibility of care, from a public health and systems approach. Finally, in the Policy Delphi study in chapter 6 all these insights are united into policy recommendations, as a mutual effort of the entire team. In general, the data collection and analyses were conducted by different team members in parallel, after which collective bimonthly team meetings were organised to discuss and extensively reflect on each step of the process. For more details about the specificities of this collaboration we refer to the methodology sections of the respective chapters.

2. PROFESSIONALS' TREATMENT GOALS FOR LONG-TERM BENZODIAZEPINE AND Z-DRUGS MANAGEMENT

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ABSTRACT

Benzodiazepines and Z-drugs (BZRA) are prescribed for longer than recommended. Through their interactions with patients taking BZRA, primary care and mental health professionals play a key role in the management of this medication. The aim of the study was to explore how primary care and mental health care professionals set treatment goals with long-term BZRA users. Semi-structured interviews were conducted, online and in person, with 24 professionals working in mental health and primary care in Belgium. Inductive thematic content analysis was performed. Seven themes were identified from the analysis. Professionals tend not to use the DSM-V standard to diagnose a substance use disorder to BZRA. They describe criteria based on their experience. They identified diverse types of patients that influence their choice of treatment goals. Professionals appear to position themselves according to their own treatment goals for their patients, either by promoting the goal of abstinence or harm reduction. Some of them report feeling trapped into continuing to prescribe and consider BZRA withdrawal to be difficult. Some are afraid to engage in a conversation that might break the bond of trust with the patient. Few professionals mentioned patient participation in the treatment goal setting. They asked for targeted withdrawal recommendations which they perceive to be too broad currently. Whether primary care or mental health care professionals are more in favour of a total abstinence or a harm reduction approach to BZRA, professionals should be guided towards greater patient participation in setting and evaluating goals with patients taking BZRA.

2.1 INTRODUCTION

Benzodiazepines and Z-drugs (BZRA) are broadly prescribed, and inappropriate consumption constitutes a major public health concern (Airagnes et al., 2016; Lader, 2011). Indeed, guidelines recommend BZRA for short-term use (between 2–4 weeks) (Lader, 1999, 2011). In this paper we define overconsumption considered as exceeding these guidelines. In Belgium, long-term use of BZD is high with 11.9 percent of people aged 65 and over had taken a BZRA in the 24 hours preceding the survey in 2018 (Van Der Heyden et al., 2020) and BZRA prescriptions have increased these last years (Coteur, Kristien et al., 2022). This trend persisted during the COVID-19 pandemic (Milani et al., 2021). Prolonged usage can lead to adverse side effects such as psychological, cognitive, and physical effects including vertigo, ataxia leading to falls and dysarthria (Lader, 1999). Besides, long-term use can induce a physiological and psychological dependence (Lader, 1999, 2011) and can lead to misuse, abuse or to a substance use disorder (SUD) as described in the DSM-V (American Psychiatric Association, n.d.). The length of long-term use is considered differently in studies but is most often defined as a use over six months (Kurko et al., 2015). Furthermore, a study from the USA reported that benzodiazepines (BZD) were frequently prescribed to patients with known risk factors which could have adverse effects due to BZD (Kroll et al., 2016). Unrestricted and unsupervised long-term use of BZD should always be a warning sign for abuse or malpractice (Dell'Osso et al., 2015). Indeed, BZRA use beyond short periods has been defined as low-value care (Verkerk et al., 2018), a treatment that does not clearly benefit the patient and which does not take into account cost, alternative options and patient preferences (Colla et al., 2017). Reducing overuse of low-value care such as long-term BZD use is therefore paramount in the interests of patient safety, quality of life and health care budgets (Verkerk et al., 2018). Gaps between evidence and practice are present and illustrate the difficulties that professionals face regarding long-term BZD prescriptions. A 2021 study analysed the barriers to BZRA deprescribing as perceived by providers in the USA, pointing to the complexity of deprescribing, a requirement for more time and support, reticence from patients to discontinue, and the challenge of coordination when several professionals are involved (Hawkins et al., 2021). Both primary and mental health care professionals play a key role in the management of BZRA. It is important that they are kept up to date on the clinical use including prescribing for specific groups such as the elderly, polysubstance users and persons at risk of suicide,… (Dell'Osso et al., 2015). Given the continuous and comprehensive therapeutic relationships with their patients, primary and mental health care providers are well placed to discuss the long-term BZD use *with* their patients in a patient-centred approach (Oldenhof et al., 2021). While biomedicine is founded on the disease-outcome-based paradigm where each disease is treated separately following guidelines and population goals, the goal-oriented care approach (GOC) focuses on goal setting according to the patient's needs and preferences (Reuben and Tinetti, 2012). Concerning patients with multiple chronic conditions, they are followed through different care processes for each of their conditions, which greatly increases the risk of having fragmented care (Berntsen et al., 2018; Boeykens et al., 2022; Ploeg et al., 2017). Indeed, a disease-specific approach may be appropriate for relatively healthy patients with an acute disease but may be inappropriate for patients with multiple conditions (Tinetti et al., 2004). Studies show that these long-term BZD users more often suffer from substantial needs in terms of mental health care (Harris and Edlund, 2005; Mistiaen et al., 2016). It seems appropriate therefore to adopt a GOC approach to these patients by setting goals guided by their needs and preferences. Consequently, we pose the following research question: how do primary care and mental health care professionals in Belgium currently set treatment goals with long-term BZRA users?

2.2 METHODS

Recruitment was carried out via Belgian mental health care and primary care networks and an announcement in a Belgian medical professional newspaper. Efforts were made to achieve a balanced and diverse sample in terms of experience by varying regions and professions (see table 1). Semi-structured individual interviews were mainly conducted by PV a psychologist by training (n=11), and MC (n=8) a medical anthropologist. The team was assisted by a female volunteer (experienced in clinical interviewing who conducted five additional interviews in Dutch). They were held face-to-face at the participant's workplace or by video conference without the presence of anyone else, in French or Dutch. The interviews took place between July and December 2021. The interview guide based on the model of accessibility by Andersen et al. (1995) was developed by the three researchers (MC, BS, PV) with the aim to cover a wide range of sections: diagnosis of long-term BZRA use, the types of patients, the treatment, their vision on the treatment, their institutional policy and their perceived barriers and facilitators on the access of care and the impact of recent Belgian mental health reforms in the treatment of BZRA. The researchers were in regular contact to ensure that the interviews were conducted in a uniform way. All the interviews were audio-recorded and transcribed. All identifying information was removed from the transcriptions. Field notes were not considered in the data analysis. Participants signed a consent form before the interview.

Table 1 Overview of interviewed professionals (WP3)

Code RESP	Sex	Profession	Type of practice	Region	Location	Interviewer	Mode of interview
1	Female	GP	Addiction care	Flanders	Urban	MC	Online
2	Male	GP	Addiction care	Flanders	Urban	MC	In person
3	Male	Social worker	Addiction care	Flanders	Urban	AV	In person
4	Male	GP	Addiction care	Flanders	Urban	MC	In person
5	Male	Psychiatrist	Addiction care	Flanders	Urban	MC	In person
6	Female	GP	Addiction care	Flanders	Urban	AV	In person
7	Female	GP	Addiction care	Flanders	Urban	MC	In person
8	Female	GP	Primary care	Flanders	Urban	MC	Online
9	Female	Psychiatrist	Addiction care	Flanders	Urban	MC	Online
10	Female	GP	Primary care	Flanders	Both	MC	Online
11	Female	Nurse	Mental health care	Flanders	Urban	AV	In person
12	Male	Psychologist	Mental health care	Flanders	Urban	AV	In person
13	Male	Psychiatrist	Mental health care	Flanders	Urban	AV	In person
14	Female	GP	Primary care	Wallonia	Rural	PV	In person
15	Male	GP	Primary care	Wallonia	Urban	PV	In person
16	Female	Psychologist	Addiction care	Brussels	Urban	PV	In person
17	Female	GP	Addiction care	Brussels	Urban	PV	In person
18	Female	Social worker	Addiction care	Wallonia	Rural	PV	In person
19	Female	Nurse	Addiction care	Brussels	Urban	PV	In person
20	Male	Psychiatrist	Mental health care	Wallonia	Rural	PV	In person
21	Male	GP	Primary care	Brussels	Urban	PV	In person
22	Male	Psychologist	Addiction care	Wallonia	Rural	PV	In person
23	Male	Psychiatrist	Addiction care	Brussels	Urban	PV	In person
24	Female	Social worker	Addiction care	Wallonia	Rural	PV	Online

Data analysis was performed using QSR NVivo (version 12). A first code matrix with recurring themes was produced utilising an inductive approach. This was discussed by the core research team (PV, MC, BS). The Dutch-speaking researcher (MC) coded the interviews in Dutch and the French-speaking researcher (PV) coded the interviews in French. To ensure that the coding was similar in both languages, two interviews in each language were coded by both coders by using the same coding tree. Several discussions were organised between the coders to review the themes in an iterative process. Data saturation was attained when all the data had been analysed (Braun and Clarke, 2006).

2.3 RESULTS

A purposive sample of 24 participants from the three regions of Belgium (Brussels, Flanders, and Wallonia) was recruited from different professional backgrounds in contact with patients taking BZRA. Among the participants, eleven general practitioners (GPs) working in primary care and/or addiction care, five psychiatrists, three psychologists, two nurses, and three social workers responded positively to participate in the study. In total, 24 semi-structured interviews were carried out, 11 in French in Wallonia and Brussels and 13 in Dutch in Flanders (see table 1): GPs (n=11), Psychologists (n=3), Psychiatrists (n=5), Nurses (n=2), Social workers (n=3). Seven themes emerged from the data about the treatment goals.

Theme 1 Diagnostic and recognition of a SUD to BZRA

Participants do not always use criteria such as those described in the DSM-V (American Psychiatric Association, n.d.) to diagnose a SUD to BZRA. The participants speak rather of a 'feeling' and identify a change in the patient's behaviour to obtain more prescriptions, a non-respect of the prescribed dose and where the BZRA becomes necessary for their proper functioning.

> *'There are behaviours that are adopted by the patient to get the prescription and I have to say also that I don't know if this will be true for all physicians, but I also feel when there is something wrong.'* GP, primary care, rural

> *'We really speak of extreme use when people often go medical shopping, when they do not actually follow the prescribed doses at all or they take them at the wrong times, things like that.'* Psychologist, mental health care, urban

The participants also explain how to differentiate between the different types of patients between, i.e. an elderly person who takes a BZRA every evening or a person who takes BZRA in addition to other drugs to become 'high'. This classification influences the choice of professionals in the patient's treatment goals. Indeed, the elderly person who takes his or her BZRA every night will be less likely to be associated with dependence or addiction than a person who takes it for recreational purposes.

> *'I'd say, if someone of eighty says, "I take half of a Stilnoct [Zolpidem] every day." And I feel good about that.'* GP, addiction care, urban

> *'For people who are completely slowed down. There, we see that the dosage is not adequate or that there is an abuse. Because they tell us that too… "I took some pills last night, I did that, and I don't remember anything."'* Nurse, addiction care, urban

Theme 2: Position concerning their treatment goals

Most of the participants position themselves, and their professional practices, within their own global treatment goals. Some professionals working in primary care or outpatient services focused on harm reduction by continuing to prescribe a low or high dose of BZRA to maintain the relationship with patients who need specialised support in terms of mental health, addiction, or social inclusion. On the other hand, others were in favour of abstinence, such as professionals working in residential care where the patient is not allowed to take any substance before or during their stay in the facility.

> *'And between the two centres, there was sometimes a bit of a cold war… Today, there is a situation of coexistence between those different visions.'* GP, addiction care, urban

These two groups seemed somewhat distinct. One participant mentioned a dogmatic vision for those who believe in abstinence and a 'cold war' between these approaches. There seems to be a coexistence between these distinct beliefs, or for some even 'professional identities' concerning what was possible for patients who take BZRA for a long-term use.

> *'I don't know if we can really believe in that "harm reduction".'* GP, primary care, urban/rural

Theme 3: Goal of abstinence

Some of the participants who described a belief in abstinence as an outcome work in institutions that have the same approach and patients know that if they are admitted, they will have to be abstinent at admission or become abstinent.

> *'So that is also a very clear, very clear message that people know: if you are admitted, it is for total abstinence.'* Psychiatrist, addiction care, urban

They consider a patient to be recovered when they are happy to be without any substance and have established other connections.

> *'Someone's recovery, for us who have a goal of abstinence and reintegration, is someone who is happy to live soberly and has managed to make other connections elsewhere and becomes satisfying for themselves and others.'* Social worker, addiction care, rural

Within this context a participant mentioned the value they perceive for the patient of experiencing life without any substances.

> *'The reason for this [centre's policy of demanding abstinence before admission] is that, in carrying out daily tasks sober, i.e. without products, people will rediscover themselves. (…) So, we're going to work with that, give ourselves room for error, where does that come from? How can you do differently? It's a sentence that comes up every day. How can you do otherwise?'* Social worker, addiction care, rural

Theme 4: Harm reduction

For participants in favour of harm reduction, they mentioned the intention that their patients achieve a degree of stability in their BZRA consumption. Some explained their experience of patients taking high doses of benzodiazepines with high tolerance. Some of them do not consider taking BZRA for a prolonged period to be a problem.

They described that the aim was for their patients to establish stability in their use and gain a quality of life to maintain '*a good addiction or the least bad'* (GP, primary care, urban).

> *'This [a person who has established a stable use of BZD] is someone who is not going to put themselves at risk financially, legally, judicially, professionally, familiarly with their use.'* GP, primary care, urban

Some participants described the importance for them of maintaining the therapeutic relationship with the patient and that they welcome patients unconditionally, whatever their consumption or their condition. They consider this to be more valuable than following the recommendations on BZRA prescriptions.

> *'Keeping the link long enough to possibly stabilise the patients and above all to allow them to get back on track for those who are socially disengaged.'* GP, addiction care, urban

Furthermore, if they are reducing BZD doses, they describe wanting to accommodate the patient's pace which can be slower than the withdrawal guidelines.

> *'I agreed to become less true to my principles as a prescriber, realising the advantage of keeping a link.'* GP, addiction care, urban

> *'That you have been able to achieve some kind of damage limitation in their use, and that is often a mix of uppers and downers.'* GP, addiction care, urban

Theme 5: Feeling trapped

Some participants reported feeling stuck with BZRA deprescription. They observe that sometimes even small dose reductions can be very complex and that it is difficult to apply the guidelines in a universal way. Moreover, they report that withdrawal is, in itself, very difficult for the patient.

> *'Benzodiazepine withdrawal is a dreadful mess. We're stuck.'* GP, primary care, urban

> *'A small decrease often takes an implausible turn.'* Psychiatrist, addiction care, urban

Some participants described difficulties talking with their patients about their long-term BZRA use due to fear of breaking the trusting relationship with their patients, or of upsetting the status quo established with the drug (particularly for elderly patients) as well as the fear of not being able to offer an alternative solution.

> *'Because, as I said earlier, there are patients with whom we get on very well and with whom the relationship is very good. And they are sometimes the worst ones to tell because there is a real risk of a breach of trust… And also, alongside the fear of a breach of trust, there's also the fear of not being able to offer anything else. And the fear of breaking a balance that is present. The elderly person who has been sleeping with his zolpidem for 10 years and then there you go…'* GP, primary care, rural

Theme 6: Patient participation

Participants explained how they take time with their patients to accompany them in their journey. They aim to find out where they are starting from and where they want to go to. But it is not clear whether the patient is involved in this decision-making process. For some, they expect a request, an active demand from the patient to decrease the doses.

> *'We accompany them wherever they want to go.'* Psychologist, addiction care, urban

> *'You need to know where they start from and where they want to go.'* GP, primary care, urban

One psychiatrist stated that he asks patients what they think about their treatment goals.

> *'Which ones do I set? I always ask them what they think.'* Psychiatrist, mental health care, urban

Theme 7: Targeted recommendations

Concerning the withdrawal, some participants described their difficulties applying guidelines that they considered were not appropriate for their patient group. Some change the molecules to the equivalent of diazepam and decreased more slowly than the recommendations depending on the patient's profile. In addition, some prescribers mention the need to keep the BZRA for a long time, without being able to remove it.

> *'It's a dependence, no more than a maximum of six diazepam equivalent per day. And then, we will really decrease, but depending on the duration of the addiction, depending on the patient's profile, his real motivation, etc. Sometimes it will be very slow.'* GP, addiction care, urban

A participant suggested making targeted recommendations for patients who do not fit into the current guidelines.

> *'Good practices are realistically made to measure for a group of, benzo-dependent people who do not fit into the current frameworks.'* GP, addiction care, urban

2.4 DISCUSSION

Our results show that patients are diagnosed according to professional criteria, not necessarily recognised guidelines. Professionals seem to have opposing views on treatment goals, some on abstinence, others on harm reduction. The patient appears to be hardly involved in the choice of the treatment goal and the process seems to be more professional-centred. Indeed, it is the professional who feels trapped between what the patient is able to do and what the guidelines recommend. This qualitative study explored how primary care and mental health professionals set their treatment goals with long-term BZRA users.

There seems to be two broad points of view: being in favour of total abstinence with zero tolerance or an approach prioritising harm reduction. This dichotomy has also been observed in mental health care literature in opioid treatment where there are either abstinence programmes *or* harm reduction programmes (Gallagher et al., 2019). Whereas the total abstinence approach to addiction treatment prevailed, harm reduction has made it possible to offer a choice of treatment goals (Brown and Stewart, 2020). Despite the existence of these different approaches, a study conducted in the context of treatment for alcoholism showed that some patients internalise total abstinence as the only goal and therefore see alternative options as a second choice or a failure (Heather, 2006). Faced with this diversity of approaches, Gallagher and colleagues propose a paradigm shift for professionals to view treatment and recovery differently (Gallagher et al., 2019). Indeed, the authors conceptualise recovery on a spectrum that is determined by patients and not a projection of professional or institutional values. In our results, patients' expectations are generally not the starting point for setting treatment goals. Some professionals appear to find it difficult to start a conversation about BZRA. They set goals according to what they project as being good for the patient, without necessarily involving the patient in this decision making. Then they describe feeling trapped between the guidelines recommending short BZRA use and what they prescribe. Only a few participants reported that they set treatment goals with patients. This can be analysed with a the ‘three-talk model’ that proposes three stages in the consultation: first, ‘team talk’ where the provider and the patient work together to describe the possible choices, offer support and describe the objectives; secondly, ‘option talk’ where alternatives are discussed and third ‘decision talk’ where decisions are made based on patient preferences (Elwyn et al., 2017). In our results, though some participants mentioned respecting the patient’s own pace during withdrawal, it is not clear whether the patient is involved in this decision-making and whether they applied the ‘decision talk’. To our knowledge, few studies have studied the management of patients taking benzodiazepines with a patient-centred approach or shared decision-making. Indeed, in a systematic review published in 2018, the authors did not find any studies that included a tapering intervention using specifically the concept of patient-centred care, nor did they find studies that measured the effect of such an intervention (Mokhar et al., 2018). Today, primary care literature is increasingly focussing on the GOC approach. It appears essential to set goals *with* patients to put the patient who needs care and support first. The GOC approach was hardly mentioned by our participants, despite the gradual paradigm shift in primary health care towards this approach. GOC requires working in partnership with users, families, health care professionals, citizens and other service providers (Boeckxstaens et al., 2020). The approach can have a positive impact on the patient experience, the well-being of professionals, lead to a reduction in health care costs and improve population health (Boeykens et al., 2022). It appears important to promote the GOC approach in the context of both initial prescriptions of BZRA and deprescription.

Our results indicate that professionals struggle to follow the guidelines concerning BZD prescribing. This disparity between application of the guidelines that recommend short BZD use and clinical practice is clear given the high percentage of patients taking BZRA over long periods. (Jacob et al., 2017; Kurko et al., 2015; Maust et al., 2019; Olfson et al., 2015). Prescriber behaviour is influenced by assumptions concerning patients' expectations, motivation and adaptability, such as anticipating patient resistance to initiating a deprescribing process (Cook et al., 2007; Sirdifield et al., 2013). This has also been described for hypnotic prescribing and insomnia management where they recommend that practitioners elucidate patients' beliefs and expectations (Dyas et al., 2010). For this purpose, a dialogue between the prescriber and the patient is necessary (Oldenhof et al., 2019). This tendency to avoid engaging in dialogue could be explained by provider's feeling of being trapped between clinical practice and applying guidelines for BZRA short term use. Due to the difficulty of deprescription and feeling unable to propose alternative solutions they feel obliged to prescribe or continue to prescribe BZRA following an insistent request from the patient. Furthermore, they are afraid of breaking the therapeutic relationship they have with their patient. This feeling is also experienced on the other side of the desk with some patients who feel stuck or imprisoned during their withdrawal from BZRA (Fixsen and Ridge, 2017; Mokhar et al., 2019). Patients are unaware of the potential problems that BZRA could bring them and do not realise that they are addicted to these drugs, until the day they try to quit (Mokhar et al., 2019).

Furthermore, In our study, some prescribing participants, usually in primary care, mentioned their fear of breaking the trusting relationship if they initiate the conversation about BZRA. This is consistent with other studies about BZRA users where physicians were reported to having experienced the same discomforts (Cook et al., 2007; Hawkins et al., 2021). While communication between doctor and patient is positively correlated with patient adherence to treatment (Zolnierek and DiMatteo, 2009), prescribers in primary care seem to be struggling to know how to engage the talk about BZRA (Oldenhof et al., 2019). As some participants mentioned, tapering off can be very difficult. However, one of the benefits of withdrawal mentioned by providers is the opportunity for the patient to know himself without substances and to make new connections. This can be contrasted with a study on the psychotropic self that described how both psychiatrists and patients want to make the patient feel 'normal' and achieve a 'normal' patient self, except that the definition of 'feeling normal' differs considerably between doctor and patient (Schlosser and Hoffer, 2012). Indeed, the participants in this study have built their 'self' in the context of addictions and want to continue to be that 'self'. However, with the treatment they receive, they are led to a different 'self'. The authors question what a successful treatment is, knowing that the treatment goals differ between patients and providers (Schlosser and Hoffer, 2012). This underlines the need for the professional and the patient to move together in the same direction. This would involve open dialogue with the patient and a GOC approach concerning whether to keep the same dose, stabilise it or reduce it.

This study was conducted in Belgium and data was collected in French and in Dutch. To ensure comparability and a deep understanding of the data, we made the decision to translate the Dutch-speaking transcripts into French. The team met several times during data collection and analysis to develop a coding tree and to achieve a shared deep understanding of the interview transcripts. Nevertheless, some misinterpretations may remain. We aimed to achieve a heterogeneous sample in terms of gender, type of practice, location, and professional backgrounds. This gave us a richness and diversity in terms of experience in this field but somewhat limits the representativeness of each professional profile included. This study included a possible selection bias in the willingness of professionals to answer questions about BZRA and a social desirability bias in the answers they gave.

Total abstinence, as promoted in the guidelines, appear to be complex to implement universally given the diversity of patients taking BZRA, especially regarding complete withdrawal within a few weeks. Some professionals ask for recommendations for target populations. It seems valuable to review these guidelines while taking into consideration the challenges faced by clinicians and integrating the views and preferences of patients. Professionals report feeling trapped by the issue of BZRA, which is detrimental to both them and their patients. A GOC approach could help align treatment and support with the patient's needs and desires and simultaneously support professionals navigating this complex issue. To our knowledge, while the literature on GOC in primary care is growing, this paper is one of the first to study the experiences of professionals concerning BZRA use through the prism of the GOC approach. In conclusion, wea call for renewed emphasis in professional training to promote patient empowerment in the context of BZRA prescription and deprescription. Future studies could focus more on the patient experience of BZRA dependence and withdrawal and the relationship to professionals.

3. FROM PRESCRIBING DILEMMA TO KNOWLEDGE IN PRACTICE: THE ONTOLOGICAL POLITICS OF BENZODIAZEPINES AND Z-DRUGS

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ABSTRACT

The discrepancy between official guidelines and clinical practice is hardly more pronounced than in the case of benzodiazepines and Z-drugs, also known as benzodiazepine receptor agonists (BZRA). Using social constructionist positioning theory, we unravel how health care professionals deal with the dilemma of prescribing this medication. Our results reveal a prescribing spectrum that is discursively organised around four different storylines used by professionals. The storylines are organised along three axes that are related to a) prescribers' opinions on prescribing and the negotiation of the related risks, b) the power dynamics between provider and patient in the prescribing process and c) the rhetorical use of arguments. The discerned storylines allow us to explore the emotional and moral side of prescribing and demarcate clinical mindlines -internalised tacit guidelines-that professionals adhere to when they prescribe. By relying on Annemarie Mol's conceptualization of ontological politics, we explain how these storylines enact multiple versions of this class of medication and justify seemingly contradictory prescribing practices.

3.1 Introduction

The double-bind of benzodiazepines

'We find ourselves at times trying to withdraw an individual from a drug we recently prescribed.' This quote could be interpreted as a reflection on the challenges faced by contemporary prescribers of psychotropics. However, it was Freedman (1972: 411) who was among the first to highlight the dilemma of potential iatrogenic effects caused by prescribing psychotropic medications. Interestingly, this observation came not long after the introduction of benzodiazepines, which were initially considered less harmful than the preceding barbiturates. Benzodiazepine receptor agonists -hereafter referred to as BZRA- are a class of psychoactive medications with anxiolytic, sedative, hypnotic, anticonvulsant and muscle-relaxing effects, most often prescribed as sleeping aids and tranquillisers. Already in 1961 Hollister and colleagues reported on withdrawal reactions from chlordiazepoxide or Librium® for people who suddenly withdrew from high dosages. Yet few subsequent cases of dependence were reported until the 1980s. And it was not until 1991 that the American Psychiatric Association formally acknowledged the risk of dependence associated with BZRA. Currently, official guidelines generally only recommend short-term prescribing for acute insomnia and severe anxiety as an alternative for non-pharmacological treatment and SSRI's (see table 2). Although the immediate effect generally produces desirable outcomes for the patient, use that exceeds two to four weeks is not recommended due to adverse effects such as tolerance, physiological and psychological dependence and rebound symptoms following attempts to withdraw, even when used in low and constant doses (Liebrenz, 2015; Soyka, 2017; Heberlein, 2008). Eventually, long-term effects of habitual BZRA use are subtle and sometimes difficult to differentiate from original symptoms. Overall, BZRA have a high potential for both abuse -or nonmedical use without prescription, usually for the pleasant effect it can provoke- and misuse or use that does not follow medical instructions or in a way other than prescribed (Al-Worafi, 2020), especially among younger adults (Maust et al., 2019). Thus, once treatment exceeds the recommended duration of two to four weeks, the risk-benefit ratio of

prescribing BZRA is contested (Dell'Osso and Lader, 2013; but see also: Baldwin et al., 2013; 2014 for a different standpoint). Nonetheless, long-term habitual use is common worldwide and seems to have increased since the COVID-19 pandemic (Sarangi et al., 2021). In general, prescribing practices thus do not reflect common guidelines (Sim et al., 2007). Belgium is no exception to this trend. Internationally, the country stands out as one of the prominent examples of overconsumption and -prescription of BZRA (Gisle et al., 2020). Data from the latest Health Survey indicate that 12% of Belgians currently use at least one BZRA, with an estimated one in three of those users becoming chronic consumers (Christiaens et al., 2018; Van der Heyden et al., 2020). Despite consecutive prevention campaigns, and an amalgam of guidelines (see table 2) prescription rates have not dropped over the past decade (Coteur et al., 2022). Clearly, BZRA usage is both substantial and persistent in Belgium. A rare study focussing on Belgium, by Anthierens et al. (2007) revealed that Flemish general practitioners (GPs) do not necessarily perceive the addictive nature of BZRA as a major concern with first-time users. However, to the best of our knowledge, in the Belgian setting, no studies have focussed on GPs working in Wallonia nor on other health care providers' perceptions of prescribing.

Table 2 Overview of Belgian prescribing guidelines

Organisation	Recommendation ***insomnia***	Recommendation ***anxiety***
BCFI-CBIP	- 3rd option after non-pharmacological treatments - Medium-acting BZRA - Maximum one week	- 2nd option (after CBT), or in acute situation combined with CBT - Long-acting BZRA - Maximum a few weeks
VAD	- Maximum one week	- Acute anxiety: two to four weeks
Domus Medica	- Last resort - Medium acting BZRA - Lowest possible dose - Maximum one week	
FOD	- Maximum one week - After one week: reduced efficacy, tolerance and possibility of physical and psychological dependence already after two weeks	- Only for exceptional acute crises - After one week: reduced efficacy, tolerance and possibility of physical and psychological dependence already after two weeks.
EBP Practice net	- Not recommended as first option Maximum one week - Medium-acting BZRA - Lowest possible dose	- Can be used in the initial stages - Attempt to discontinue after 4-6 weeks

The sociology of prescribing

Within health sociology and anthropology, prescribing is seen as a symbolic and social act that is formed by both the meaning attributed to the performance of prescribing and the substance that is being prescribed; not only by the patients but also by the prescriber (Van der Geest et al., 1996). As such prescribing is value-laden as it is embedded in a complex matrix of social and institutional values. According to Whyte et al. (2012: 117) prescribing is 'speaking without words, through medicines' or a way of communicating meaning. This interpretation of prescribing practices stipulates that prescribing is a way to deal with the unavoidable clinical uncertainty around anamnesis, diagnosis and treatment, impeded by the subjectivity of an illness experience that has to be communicated in a strictly limited timeframe. In all its concreteness, a prescription bypasses the abstractness of the unanswered questions of the patient (Van der Geest et al., 1996), which applies particularly to the underlying suffering related to insomnia and anxiety (Pilgrim et al., 2011). Hence, a prescription is also a token of concern for and a legitimation of the patient's suffering (Gabe and Lipshitz-Phillips, 1984). Moreover, a prescription is often expected and even explicitly demanded by patients and acts as a closing ritual of a medical consultation (Schwartz et al., 1989). A prescription therefore objectifies both the patient's request for help and the professional's medical diagnosis. The issuing of a prescription -written or electronic- is thus also seen as one of the most visual symbols of a prescriber's knowledge and experience and an essential act of asserting medical authority (Parish, 1974; Whyte et al. 2002; Stevenson et al., 2002; Britten et al., 2004; Rogers et al., 2007; Weiss, 2021).

BZRA in particular, are situated in an 'emotive and controversial area of prescribing, (…) in which the actions and professional norms (…) have been implicated in creating and maintaining a form of clinical iatrogenesis' (Rogers et al. 2007: 182) in the form of 'iatrogenic addiction' (Musto, 1985) and 'iatrogenic sedative dependence' (Lader, 1998). A cross-national meta-synthesis of eight qualitative studies on BZRA prescribing, showed how prescribing decisions are typically seen as uncomfortable, complex and demanding (Sirdifield et al., 2013), rhetorically illustrated in the use of terms like 'the lesser - or necessary evil' (Anthierens et al., 2007; Haw et al., 2007). This tension between the risk of iatrogenesis and the short-term advantages, creates the so-called 'prescribing dilemma' of BZRA (Sim et al., 2007).

Following Gabe (1990) we argue that the role of BZRA in clinical practice and the question and decision to prescribe or not, can only be fully understood, if one starts with the range of beliefs, experiences and expectations of prescribers in different settings. We thereby aim to contribute to the sociology of prescribing -the field of study that looks into the different social factors that shape prescribing practices- by a) exploring how prescribers in different settings make sense of their prescribing of BZRA and b) how they negotiate the existing guidelines and the ambivalence surrounding potential iatrogenic effects thereof. In this article, we thus aim to find out how prescribers manage the idealised position of the 'non-prescribing' or 'limited term prescriber', apparent from official guidelines, while navigating the pressures and demands of everyday practice. To understand this, we take on a social-constructionist perspective, as this allows us to understand the underlying mechanisms, meanings and value-laden aspects of prescribing that drive prescribers' practices. More specifically, we use positioning theory as both a theoretical premise and a methodological tool to explore how Belgian prescribers deal with the paradoxes of prescribing potentially harmful medications like BZRA.

Positioning theory

First developed by social psychologists Davies and Harré (1990) to study microlevel identity work in interactional contexts, positioning theory provides a structure for discourse analysis. This social constructionist theory is based on the premises that firstly, people- including professionals- are socialised in different narrative models and discursive skills that form a cultural canon that is available to them to use as they speak (Slocum-Bradley, 2010), and secondly, that through talk and text, individuals position themselves and others -people or topics- both deliberately and unintentionally, or sometimes even compelled by others as is the case in interviews. In the act of positioning, social roles and their adjacent explicit and implicit rights and duties are assumed or rejected. Discursive positioning thus always occurs in reference to existing professional, ideological and cultural discourses. Furthermore, positioning theorists postulate that positioning is related to the obligation to perform in accordance with certain social expectations regarding a specific social or professional role. For example health care professionals are generally expected to follow official guidelines. When these social expectations are not met, speakers may provide an account to explain the inability to act according to those expectations. Unlike roles however, positions are not fixed, but rather fluid, overlapping and sometimes ephemeral (Baert et al., 2019).

The toolkit of positioning theory contains three core building blocks: i.e. storylines, subject positions and speech acts. The latter simply refer to different forms of speech like interviews, conversations, written text and so forth. Storylines are the available interpretative repertoires that people draw on, resist or renegotiate to make sense of themselves and their actions. Storylines are used to assume a specific subject position, i.e. how the speaker wants to be seen by others, and the perspective from which (s/)he sees the world [anonymised, 2017]. A subject position is thus created when people use language to negotiate positions for themselves (Harré et al., 2009; Davies and Harré, 1990). A position has also been called a cluster of rights and duties, typically recognised in a specific social setting (Green, 2020). Speakers can be either positioned by available conceptual repertoires or discourses, or newly created ones, throughout the interaction (Saini, 2022). The concepts of storylines and positions should thus not be seen as fixed templates or rules that should always be followed as if one is ordered to do so, but rather evolve through interaction. However, like books on a shelf in a library, discursive possibilities are not endless, and different storylines capture the range within which things can be said and accomplished in a given setting. Positioning theory is especially useful to gain a deeper understanding of how health care professionals make sense of the complex issues of BZRA prescribing. The aim of this paper is thus to unravel how prescribers manage the so-called prescribing dilemma. More specifically, drawing on positioning theory, we will answer the following research questions:

- How do prescribers perceive and position the role of BZRA in clinical practice?
- What storylines do they construct to motivate this?
- How do they position both themselves as prescribers and their patients in this process?

3.2 Methodology

We conducted 15 interviews with professional prescribers working in Belgium (see table 3). A purposive sample was designed to obtain a broad range of professional prescribers working in different settings (primary, mental health and addiction care). The sample contained a balance of professional experience (ranging from five to 30 years) and gender (eight female and seven male).

Table 3 Overview of interviewed prescribers (WP3)

Professional background	**Flanders**	**Wallonia - Brussels**
General practitioners (in addiction care)	5	2
General practitioners (in primary care)	2	2
Psychiatrists	2	2
Total	9	6
	15	

A topic guide was drafted, reviewed extensively by the project's multidisciplinary follow-up committee and piloted. Interviews were conducted between July and December 2021 by the first (MC) and second author (PVN), respectively in Dutch and French. In addition, one interview in Dutch was conducted by a volunteer at the research group. To ensure interviews were conducted in a uniform way, the team discussed the process iteratively and extensively during the interview phase. Interviews were conducted at the interviewees' workplace (n=10) or by video conference (n=5) (due to ongoing sanitary restrictions) and lasted between 32 and 126 minutes (Av. 74'). All interviews were audio recorded after obtaining full written consent from interviewees and transcribed verbatim in the original language. The analysis of the interviews started with a round of open coding of relevant fragments related to prescribing and the role of BZRA in clinical practice in general. Subsequently, the transcripts were coded using the different analytical devices of positioning theory (i.e. storylines and subject positions, as described above). To identify these storylines and positions, interviews were scrutinized in the original language for both content (argumentations) and recurrent linguistic devices and vocabulary such as contrasts, repetitions of words, metaphors, analogies and other remarkable schematic representations and coded accordingly. All researchers validated the intermediate coding results in an iterative process until analytical consensus was reached. In the final stage, the most illustrative excerpts were translated into English.

3.3 Results

Demarcation lines

In our dataset we identify four different storylines that are used by professionals to discursively deal with the described BZRA prescribing dilemma. These storylines have their own specific argumentation, rhetoric devices and vocabulary (see figure 3) organised along three different axes that are related to: a) the viewpoint on prescribing and the negotiation of the related risks (from none at all to restricted to liberal prescribing), b) the power dynamics between provider and patient in the prescribing process (i.e. provider-led or patient-led) and c) the overarching rhetorical use of logos (i.e. rational appeal) or pathos (emotional appeal).

Figure 3 Overview of different storylines and different demarcations

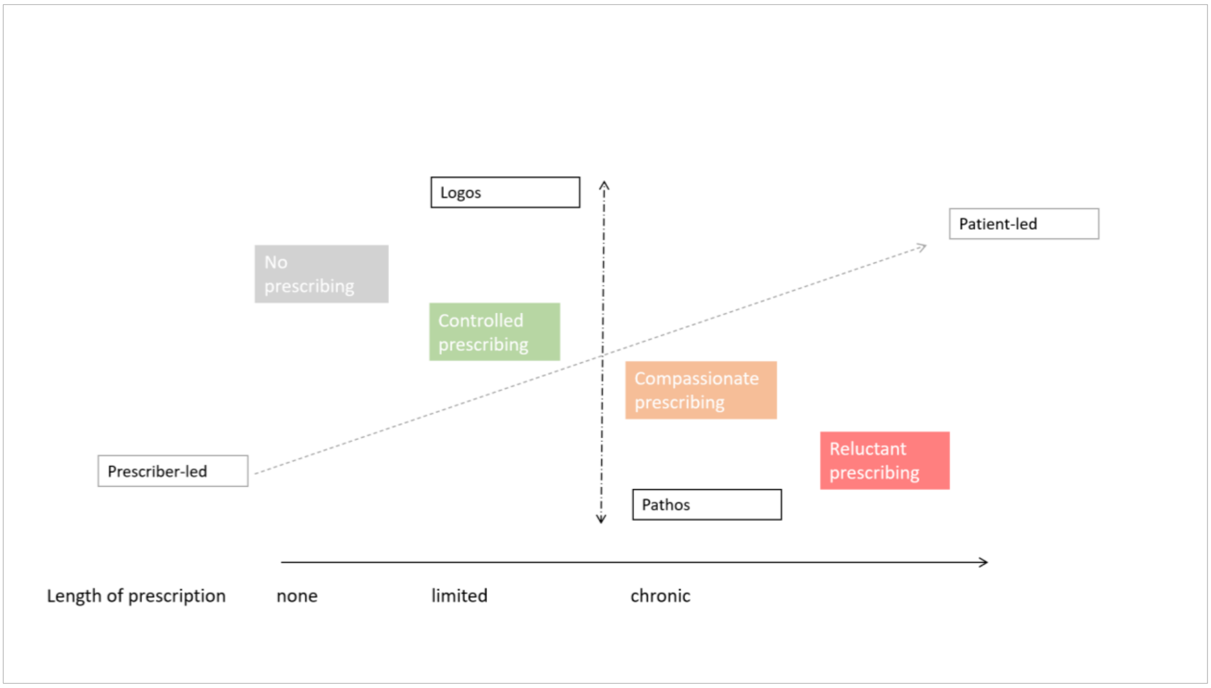

Table 4 Summary of storylines and resulting positions

Storylines	**Core elements**	**Linguistic features**	**Subject positions**
No prescribing	Emphasis on not prescribing at all Reason for not prescribing: BZRA use equals addiction	Vocabulary: 'drug', 'abstinence', 'zero tolerance', 'anti-addiction', 'to refuse' (active voice) <> 'to prescribe' (passive voice)	Firm non-prescriber Explicit juxtaposition to prescribers in general Passive, vulnerable patient
Controlled prescribing	Emphasis on minimising the risks of prescription (prevent dependence from becoming addiction) Reason for prescribing: (bio)medical, clinical indication	Vocabulary: 'under control', 'controlled', 'not derailing', 'on track', 'rational use', 'acceptable dose', 'exceptional', 'indication' Limitations (of dose, of length of prescription, of who can prescribe,…) 'a few', 'small dose',…	Conscious, responsible prescriber Explicit juxtaposition to 'frequent, liberal prescribers' Empowered, 'compliant' patient, 'responsible user'
Compassionate prescribing	Emphasis on, reducing suffering and maximalisation of patients' quality of life Reason for prescribing: biopsychosocial model	Vocabulary: 'comfort', 'helps', 'quality of life', 'supporting medication', 'maintenance treatment' BZRA are positioned as a 'mist', 'veil', 'shield', 'protection' 'To support the patients with medicines' (active voice) Trade-offs: 'the lesser evil', 'if no complaints', compared to risks of withdrawal, 'no tolerance on anxiety reducing effect', 'not toxic' Refuting rigidity of abstinence	Pragmatic, empathetic prescriber, with a duty to care (i.e. reduce suffering), explicit juxtaposition to prescribers who are 'too strict' 'Deserving patient', suffering patient Patient as equal partner, concordance is crucial
Reluctant prescribing	Emphasis is on reluctance to prescribe and internal struggle and disillusion Reason for prescribing: 'tricked into prescribing' (pathos) by patient who are 'unconsciously addicted'	Vocabulary: 'shopping', 'to supply', 'negotiation', 'trapped', 'tricked', 'having enough', 'to please patients', 'pressure', 'force', 'to have to' (obligation), metaphor 'dealers'	Duped prescriber Forcing patient

Storyline 1: 'No prescribing'

We name the first storyline 'no prescribing', since this storyline was used to strongly oppose any prescribing of BZRA, built on a rational argumentation around the risks of prescribing. The bottom-line here is that inducing an addiction, must be avoided at all times, as illustrated in the following quotes.

> *"It's not just the Hippocratic oath in short, but first of all do no harm. This is clearly a problem that can be induced by me. And so, I feel an additional responsibility not to bring it up and therefore to fight it, it's kind of the responsibility of each doctor. (…) What also motivates me is a personal propensity to be anti-addiction."* GP, community health centre

"Prevent them from becoming addicted, and if they are, then try to get them off." GP, ambulant addiction care

This storyline is characterised by metaphors that equate BZRA with hard drugs and underlines that BZRA are not medications, as we see in the following quotes:

"After all it is a drug that is prescribed." GP, private group practice

"There is a lot of comorbidity. But that does not mean they should have benzos, right? There is other medication. Some get antidepressants, mood stabilizers. But no benzos. Benzo's are not medicines." Psychiatrist, residential addiction care

Other recurring vocabulary in this storyline includes the verb 'to refuse', used in the active voice, first person. The verb 'to prescribe' on the other hand is usually used in the third person to distance oneself from the act.

"It is being prescribed too much." Psychiatrist, residential addiction care

Overall, this storyline does not contain any mitigating circumstances that justify the use or prescription of BZRA. Comorbidity, as illustrated above, is not considered an exception to that rule. Furthermore, in this storyline, no clear differentiation is made between dependence and addiction. An argument used to motivate this stance, includes the idea that BZRA act on the same receptors as other addictive substances such as alcohol. This equation, also leads to empathy for the difficulties to quit, as shown in the following quote. Here the interviewee makes use of both a comparison and category (expert patients) entitlement for discursive fact construction, which also indicates the tendency in this storyline to rely on rational argumentations.

"Patients (…) who were on both, say that it is indeed harder to get off pills than [to get off] alcohol." Psychiatrist, residential addiction care

As a result, patients who do use BZRA are positioned as being 'addicted' to medication and should be put on a complete tapering schedule (limited in time). Subsequently, when the patient signals that a tapering schedule goes too fast, this is interpreted as negotiation and a sign of addictive behaviour. As such, patients are not framed as equal partners in a process of shared-decision making, if they wish to get a prescription for a BZRA, but rather as passive recipients who must accept the conditions for care:

"They can't choose to take benzos again of course. They can't do that." GP, private practice and residential addiction care

This 'no prescribing' storyline leads to a self-positioning of the speaker as a firm but fair and responsible practitioner who does no harm and helps to withdraw or who protects patients from the perceived harm of BZRA and sometimes from themselves. Despite their firm refusal to prescribe (also illustrated in the literal use of the verb 'to refuse'), non-prescribers self-position as being empathic and protective of their patients, as illustrated below:

"I think I'm quite driven to get rid of them [BZRA], in that sense I may be a flag bearer after all, perhaps a little too much; meaning that sometimes I would be a bit too strict (…) [but] I am empathetic… I protect them [patients]." GP, ambulant addiction care

This storyline is mostly used by health professionals in addiction care, and to a lesser extent also in primary care. In many addiction care facilities total abstinence is part of the overall treatment goal and a necessary requirement for patients to access continued care. So when professionals use this storyline, they implicitly defend their institution's policy or their own professional position and credibility. This position also leads to distancing from peers who maintain different prescribing policies. By comparing themselves to others, they implicitly defend their own stance, as illustrated in the following quote:

> *"No one leaves here with benzos. (Interviewer: Is it another story in the other wards?) I don't decide that, do I? (…) There is one doctor per department. And, of course, he has his own therapeutic freedom…"* Psychiatrist, residential addiction care

Storyline 2: 'Controlled prescribing'

In the second storyline, prescribing is presented as legitimate, but only under strict conditions, hence the name 'controlled prescribing'. By limiting the instances in which they do tend to prescribe, adherents to this storyline, underline the exceptionality of prescribing. A common argument in this storyline, is that of 'medical indication' or 'selective prescription', that limits the options to prescribe. These exceptions include the following indications: drug substitution (e.g. alcohol), schizophrenia, acute panic attacks or psychosis, anxiety, muscle relaxant and sporadic instrumental use (e.g. for long flights, for switching night shifts). Overall, prescribing -either a first prescription or prolonging a prescription- is framed as a conscious and well-balanced choice. This does not mean that the risks are ignored, yet to the contrary, in this storyline, different discursive devices minimise those risks. An argument that is used to discursively balance the negative effects of BZRA is that of 'controlled and stable use', without dose increase, under (strict) medical supervision. This approach is preferred over an uncontrolled, increasing use, without medical supervision. Hence recurring vocabulary in this storyline relates to that control (see table 4).

> *"People who depend on benzos only get prescriptions from a regular doctor and at certain times, so it is clearly stated in the patient file, the next prescription can only be given then (…) If we are in a fixed trajectory, with the pharmacy, there are often agreements, for example, that the patient can go and get a few pills every week". GP, community health centre*

> *"Small doses, frequent controls, under supervision."* GP, private practice and residential psychiatric care

In this storyline patients with a long-term prescription, are positioned as 'dependent' on BZRA and showing 'symptoms of tolerance'. Yet this degree of dependence is tolerated and presented as a suitable option as long as patients remain 'on track' and do not indicate that their use has become 'derailed'. However, when signs of addiction appear, then deprescription is advisable. Unlike in the first (no prescription) storyline, a clear distinction is made between dependence and addiction. This differentiation also seems to be maintained to negotiate one's responsibility in causing harm as a prescriber. It is accepted that BZRA can cause dependence, while addiction in the form of misuse or abuse by the patient should be kept under control. Dependence is thus presented as some sort of acceptable collateral damage, to be taken into account when considering offering a prescription.

> *"People who only take one benzo, perhaps for years, do not actually have an addiction problem in itself. (…) Dependence means if you were to take the drug away, they would*

> *have withdrawal symptoms or that they are very anxious to let it go. And an addiction problem is actually that you need it just to be able to function, that you do everything to get it (…) And most importantly, that your behaviour changes and also, your way of feeling emotions and all that changes."* Psychiatrist, residential addiction care

> *"Dependence, yes, dependence where you keep it [consumption] within boundaries, is still different from dependence that keeps on increasing, where you move to abuse or addiction."* GP private practice and residential addiction care

> *"By going along with the benzo story, we have that really addictive behaviour better under control."* GP, ambulant addiction care

The resulting self-position of professionals who adhere to this storyline is that of a correct professional and self-aware, agentic prescriber, or a rational prescriber, who limits addiction and tries to stay close to the official guidelines. Empowered by this supervision and guidance, patients are positioned accordingly as 'compliant' or 'responsible users'. Patients are thus assigned a more active position than in the first, 'no prescribing storyline'. Furthermore, prescribers who adhere to this storyline also distance themselves sometimes explicitly from more liberal prescribers:

> *"Doctors who are socially incapable and who really need patients… that is what I have already heard from patients."* Psychiatrist, private practice and ambulant addiction care

> *"Performance medicine, eh, if someone is dependent, they keep coming, eh. So that's a win-win situation. That's very harshly said, isn't it? I don't believe all GPs want their patients to be dependent, absolutely not. There is already a huge change in providing quality healthcare or providing evidence-based healthcare. But I still think that it's in there unconsciously, because of the privatization."* GP, community health centre

In Belgium GPs can be financed on a fee for service basis, meaning that a patient pays a fee each time they see the GP, or by capitation fee, whereby the GP receives a lump sum per patient per month directly from the health insurance. The interviewee in the last quote is referring to and criticising unintended outcomes of the former system.

Storyline 3: 'Compassionate prescribing'

In this storyline, BZRA are framed as useful means of 'support' that increase the patient's comfort.

> *"Then they already have part of the day that they don't have to sit in fear and tension all the time, which also increases their comfort somewhat."* Psychiatrist, private practice and ambulant addiction care

> *"Removes a lot of the burdens from the people"* GP, ambulant addiction care

> *"Maintenance benzos is a full-fledged therapeutic option."* GP, ambulant addiction care

In this storyline the focus lies less on limiting a prescription in time. Consequently, this storyline includes statements such as 'I don't believe in abstinence' or 'abstinence is a waste of time'. Unlike in the controlled prescribing storyline, the harm potentially caused by long-term prescribing is minimised. Possible negative effects are renegotiated, as illustrated in the following quotes. In the first quote, the comparison of tolerance of the anxiety reducing effects of BZRA to tolerance of the hypnotic effect, implies that anxiety is an indication for a long-term prescription (compared to insomnia) and minimises the risks of prescribing. In the second quote, the dependence forming properties are more explicitly questioned, while also retreating briefly to the controlled prescription storyline.

> *"Yes, substance-related disorder (…) severe mild or moderate disorder in the use of BZRA in this case (…) but actually [with this definition], we are selling short a group of people who take BZRA chronically on indication (…) There are indeed indications for long-term BZRA use, and those are for example anxiety, because for anxiety it has been proven the least of all that there is a tolerance, to the anxiolytic effect, quite contrary to [tolerance to] the hypnotic effect."* GP, ambulant addiction care

> *"Dependent, I would hardly even dare to use that word. If people can maintain themselves and someone who is recovered in as far that that person can work, has a relationship, a stable household situation, and if he stays on a very light dose, under guidance, I find that already a very, very nice recovery."* GP, private practice and residential addiction and psychiatric care

When acknowledged, the potential harm of prescribing BZRA is presented as a trade-off:

> *"It can be discussed, but I believe that it is better to have a little dependence than to be completely weaned. For certain personalities."* Psychiatrist, ambulant and residential addiction care

> *"If your really can't get people out, then that harm reduction is better. So, that is sometimes so difficult, such a difficult choice, to choose for the lesser evil. That is what I mean by not always demonising".* Psychiatrist, private practices and ambulant addiction care

> *"Abrupt withdrawal is more dangerous [than prescribing longer than recommended]"* GP, private practice and residential addiction and psychiatric care

> *"It is a good thing that benzos are not very toxic. They destroy very little in the body. In that sense it's sometimes better for people to take benzos for life than to drink for life."* GP, ambulant addiction care

Furthermore, divergence from the guidelines is motivated mainly by the fact that patients should be helped. The implicit norm here is that the psychosocial situation of the patient has to be taken into full consideration when prescribing. Reducing the suffering of the patient is put forward as the decisive element when prescribing. The emerging subject position is that of an empathic prescriber who diverges from the guidelines in the best interest of the patient, to 'support' the patient, while the patient is positioned more as an equal partner in striving for concordance.

> *"How can we improve your comfort? (…) you provide an answer to the client's demand."* GP, private practice and residential addiction and psychiatric care

> *"Yes, sometimes someone has to bypass the guidelines, the information leaflets, to get closer to the patient, right? Eh, although still, you have to be able to justify it, of course (…) this is what we have to do, otherwise we will not get any further with those people."* GP, ambulant addiction care

> *"We're all thinking we should just prescribe less, and we should just sell less. But anyway, I think that is not the solution, I think that people feel the need for a certain anaesthesia, they're looking for that in the products they can find, right? And I think, uh, if we want to*

> *do prevention, we have to start much, much earlier with, what stress is everyone exposed to? Doctors prescribe too much, the pharmacy sells too much, and that this need does exist is, in my opinion, not recognised enough. We can all fight against the benzos and then something else will emerge."* GP, private practice and residential addiction and psychiatric care

In the latter quote an understanding of the need for a treatment for suffering (the 'need for anaesthesia') is displayed, yet the speaker's responsibility for prescribing is also diverted to underlying societal causes of stress and suffering, thereby implicitly diverting the responsibility for prescribing and in turn presenting it rather as an empathic act.

In this storyline there is also a clear renegotiation of the existing guidelines. In the following quote a prescriber is hinting to the discrepancy between the guidelines and the actual practise of prescribing. Reaching the patient and providing the right care is put forward as the primordial goal of prescribing. Furthermore the speaker also mentions the emotion that accompanies prescribing beyond the guidelines ('feeling bad'). Hence, instead of questioning prescribing practises the speaker is questioning the rigidity of the guidelines.

> *"How do we explain to psychiatry students the discrepancy between the guidelines that say you cannot prescribe benzos and psychiatric wards that are full of benzos? Because students, want to do well, but they hear a theory that is miles away from practice, how can we understand that and how can we reconcile this? (…) either our theory is incorrect or our policy has not been adapted sufficiently. And what I suspect is that there is a lot of effort done on the policy- but I don't think the theory is entirely correct that we should only prescribe benzos for a week and after that you must start to feel bad as a doctor that you are still doing it… And with that theory we are not going to reach the people and provide the right care, so we have to offer a broader framework… There is no black and white, there is only grey in the world of benzo's."* GP, ambulant addiction care

Finally, the legal risk that a prescriber runs by prescribing against the guidelines is also discussed. This storyline is used to juxtapose oneself with colleagues who maintain a more rigid view on prescribing and who might even report others (caricaturised as 'troublemakers who are holier-than-thou' by one interviewee), or as described in the following hypothetical sketch:

> *"If you are going to punish our colleague for [prescribing BZRA], then we have to stop doing our job".* GP, ambulant addiction care

Storyline 4: 'Reluctant prescribing'

We named the last storyline 'reluctant prescribing'. Prescribers who adhere to this storyline, do so to explain how they feel forced by circumstances to prescribe or continue a prescription, although they are in principle opposed. They feel pressured either by the explicit demand of patients themselves, or by circumstances. (Although not refunded by the sickness funds in Belgium, BZRA are a less costly and initially efficient solution compared to for example psychotherapy. Hence, prescribers often feel pressured by patients' socio-economic circumstances.) Rhetorically, this storyline uses more emotive reasoning (pathos) to evoke empathy in the listener or to express personal emotions. Words like 'negotiation', 'shopping', struggle' are used to describe the process of prescribing, as in the following quote:

> *"There is this underlying demand, this negotiation almost, where the patient tries to have more or a stronger molecule. These are consultations that are very complicated because we know what would please patients and it's difficult to get by and try to find a common ground and a way to avoid overconsumption of BZRAs in these consultations."* GP, private group practice

> *"There are many [patients] who conceptualize that they can't live without. And if we don't give them to them, there's a power struggle..."* Psychiatrist, ambulant addiction care

This storyline depicts how some prescribers struggle with conflicting values. On the one hand, they do not really want to prescribe, yet they feel heavily pressured to do so, often to keep a therapeutic relationship or working alliance with the patient. This internal struggle with the ambiguity and responsibility of prescribing is a recurring idea in this storyline.

> *"One would say that benzos are a bit more vicious (…) We, doctors, are also responsible for prescribing BZRA. It's very complicated afterwards to go tell a patient that there is abuse and that there is something wrong because we also feel responsible. It is a kind of poker game where somewhere, it is more complicated to broach the subject during a consultation because it is not easy for the patient."* GP, private group practice

The ambiguity is even more highlighted in the use of the word 'poker game' to describe the (de)prescribing process and the taboo that lies on openly discussing tapering-off.

In this storyline, subtle discursive strategies to avert responsibility include not just diverting partial responsibility to the patient, but also to predecessors. Full responsibility for prescribing is also subtly diverted by the use of the verb 'to have to'.

> *"We recuperate the medicinal legacies of the doctors before us. Patients come here with prescriptions for benzos they have for a long time"* GP, private group practice

> *"This is what we have to do, otherwise we do not get any further with those people."* GP, ambulant addiction care

> *"We would rather they [BZRA] weren't there, but they are, so we have to do something with them, right?"* GP, ambulant addiction care

A lack of genuine agency on the prescriber's part and an accompanying disillusionment, colour this storyline. This disappointment is illustrated in the following quotes, respectively uttered in a sarcastic, a resigned and an irritated way.

> *"We are good legal dealers.."* GP, group practice

> *"I renew the prescription and that's it."* GP, ambulant addiction care

> *"I'm sick of it!"* GP, ambulant addiction care

All this leads to self-positioning as a pressured and internally struggling prescriber who sometimes even feels 'tricked' by patients who in turn are positioned as demanding and dominating the prescribing process, forcing the prescriber into a more passive, accepting position.

Drawing on different storylines

Within the interviews, prescribers sometimes draw on different storylines. They switch positions in three instances, first when they compare their prescribing practises between two different settings in which they concurrently work. Professionals who work in two or even three different settings, often differentiate between those contexts as to whether or not they strive for zero tolerance or they will prescribe under strict conditions, a stance that is then either motivated with the ‘no prescribing’ or ‘controlled prescribing’ storylines, for example when they both have a private practice as GP and work in an addiction care facility with more strict guidelines. Secondly prescribers also shift storylines during an interview when they juxtapose their prescribing practises to the idealised guidelines. For example the ‘no prescribing’ storyline was sometimes used by interviewees to juxtapose their idealised personal vision of prescribing and their actual, often contradicting prescription practices. Thirdly, interviewees also adhere to different storylines when they describe an evolution over time in their personal opinions and practices as illustrated in the following quote:

“Well, I'm also from the, I, I used to be stricter in the sense that, I used to be so right, I think I was from the first generation where, uh, the benzos were labelled as a great danger in our medicine courses. And you were never allowed to prescribe that and it was outrageous that people prescribed that and so on. So in the beginning I've always refused that so hard and, and, uh, trying to get people off it. But actually over the years I've learned both a bit with er, experience that you have ‘people and people’. People who have a potential addiction profile and others who don't.” Psychiatrist, residential addiction care

3.4 Discussion

Unfolding mindlines

Challenging the gold-standard evidence-based practice movement, Gabbay and le May developed the concept of ‘clinical mindlines’, to explain how practitioners actually develop and apply clinical knowledge (Wieringa and Greenhalgh, 2015). Mindlines are collectively reinforced, internalised tacit guidelines based on health care practitioners’ experience and are experiential knowledge in practice (Gabbay and le May, 2004) and thus socially constructed. While founded in training, mindlines are continuously reconstructed over time and collectively refined in clinical organisational settings, often through discourse and storytelling (Gabbay and LeMay, 2011; 2016). At the root of these mindlines are implicit norms and values which determine the degree of acceptable flexibility around textbook practice and clinical guidelines. Unlike guidelines, mindlines are more flexible and thus better adapted to coping with the sometimes conflicting demands of clinicians’ diverging roles. Precisely such tacit norms and values become visible through the identified storylines. Specifically, these storylines reveal varying underlying norms and values regarding prescribing, as well as to how interviewees see their role as a prescriber.

A first norm that informs the mindlines on prescribing BZRA is centred around the prescriber’s evaluation of the involved risks. In each storyline, the negotiation of potential negative outcomes of prescribing differs and hence the motivation to prescribe outside the guidelines also differs. In the ‘no prescribing’ storyline, dependence and addiction are not separated. Hence, any prescription is seen as causing harm, whereas in the ‘controlled prescribing’ storyline’, the potentially inflicted harm is discursively minimized by separating dependence from addiction. In the ‘compassionate prescription’ storyline, there is even a further subdivision of types of dependence. The ‘controlled prescribing’ storyline and its premise that if BZRA use is under control, it is not addiction (at the maximum a dependence) is linked to the limitation of additional damage in the harm reduction discourse in addiction care (Roe, 2005).

Secondly, we see a shift in power dynamics that influences the prescribing process across the storylines. While the ‘no prescribing’ storyline is fully prescriber-led, the ‘reluctant prescribing’ is presented as patient-led. The other storylines on the other hand are situated towards the middle of that continuum. According to Dowell and colleagues (2007), the prescription of BZRA is often more patient- than provider led on the prescribing spectrum. The described storylines can indeed be distinguished based on where they can be situated on this prescription continuum, yet also show that this nuance is needed, since who leads the decision is equally dependant on the health care setting and the ideas of the prescriber. A study by Anthierens et al. (2007) showed that GPs often feel overwhelmed by the psychosocial problems of their patients, and therefore offer a prescription as a form of empathy. Likewise, Cook et al. (2007) showed how prescribers construct a prescription as compassionate. Forced by a perceived limitation of other options and pressured by time constraints, they retreat to what has been called ‘the lesser evil’. GPs in the study by Anthierens et al. (2007) specifically mentioned patients’ demand as an element for starting a prescription. Gabe and Lipshitz-Phillips (1982) showed that the idea of the ‘lesser evil’ is also expressed by patients and later also debunked the idea of a deliberate creation of BZRA dependence by prescribers (Gabe and Lipshitz-Phillips, 1984). Similar arguments appear in the ‘reluctant -‘ as well as the ‘compassionate prescribing’ storylines. In the words of Leibovici and Lièvre (2002: 866) ‘there is a boundary beyond which medicine has only a small role. When doctors are forced to go beyond that role they do not gain power or control: they suffer’. This is exactly what is portrayed in the latter two storylines: doctors feel directly or indirectly forced by patients and their circumstances to accept to pharmaceuticalise their problem and thus to prescribe. Prescribers have equally been criticised for maintaining a purely medical biological explanatory model and thus for medicalising psychosocial problems with a medical prescription (Calmeyn and Petrovic, 2023). In the ‘compassionate prescribing’ storyline however, we do not see a lack of understanding of the biopsychosocial reasons for human suffering, it just shows the limitations of prescribers to constructively and sustainably deal with that human suffering within the limitations of their own institutional setting and practises. Depending on the setting in which they work (especially in residential addiction care settings with a strict abstinence policy) prescribers feel they have more freedom to resist this explicit and implicit demand by patients.

Furthermore, earlier work on interpretative repertoires of patients shows how the imaginary of BZRA is constructed around a tacit societal norm on the undesirability of pharmaceuticalising sleeping problems [anonymised, 2021], reflecting the moral positions (used to deal with conflicting values) of patients as either ‘noble non-users’, ‘deserving and/or compliant patients’ or ‘rational users’, also found in offline settings (Gabe et al., 2016). The positions of a ‘responsible user’ and ‘deserving patient’ also result from our storylines (as illustrated in the last column of table 4), which reveals that prescribers equally draw on similar moral positionings of patients when making sense of a decision to prescribe. These findings show that the decision to prescribe is more nuanced than merely opting for the ‘lesser evil’ (Anthierens et al., 2007) and the latter is just one of many arguments that inform decision-making processes of prescribers.

The ontological politics of BZRA

The shifts in storylines between different settings in which several of our interviewees concurrently work, or over time throughout their careers, do not only illustrate how practice-based guidelines emerge in the daily practice of prescribers. The described storylines also align with what Ferris et al. (1989) have called organisational myths which serve to maintain certain organisational politics. For example, in the 'no prescribing' storyline, BZRA are incorporated in the wider organisational policy of total abstinence, which is a prerequisite for certain types of residential addiction care. That this does not necessarily concur with prescribing practices in another division of the same institute, is not seen as something contradictory yet is explained away as 'therapeutic freedom'. Moreover, what is so puzzling about this specific example is that the exact same class of medication, with its similar chemical structure and effect, changes dramatically depending on the setting in which they are either prescribed or deprescribed. To unravel this apparent contradiction, we retreat to the theory of 'ontological politics'. This conceptualisation by Mol (1999) theorises how different versions of reality - also called 'alternative ontologies' (Dennis et al., 2020) - come into being not only through social practices, but also through material arrangements or technologies, like pharmaceuticals. The reality of the setting in which BZRA are prescribed or deprescribed, constitutes the multiple ontologies of this class of medication and their prescribing. The sometimes contradictory portrayals of BZRA across the respective storylines, as a drug, a medication to control, a support or even a leverage in the relationship between patient and prescriber, show how the different realities of BZRA 'are neither given, nor fixed' (Pienaar and Dilkes-Frayne, 2017: 145) but shaped within specific prescribing practices and thus diverge from the idealised strictly prescribed BZRA portrayed in the official guidelines. With Lancaster and Rhodes (2020: 1), we agree that thinking ontopolitically 'calls into question the realist presumptions' which in our case underpin the official prescribing guidelines namely that BZRA are one, set and fixed, and also provokes critical thinking about what counts as 'evidence' and the 'evidence-based' paradigm itself. This approach draws attention to the object of BZRA, which, because of their particular materiality and their similar chemical structure, seems finished, static and one. Yet our results show that there are multiple versions of BZRA, embedded within prescribing mindlines and enacted through storylines. With this, we situate our contribution to the sociology of prescribing, in the addition of an ontopolitical lens to the conceptualisation of the shifting meaning of a prescription in itself, which varies, almost metonymically along with the meaning of the prescribed medication.

3.5 Conclusion

With this article we have shown that outside the realm of prescription guidelines, there exists a world in which prescribing practices and decisions are never as black and white as on paper. Prescribers juggle with priorities that oscillate between the official guidelines, patients' demands and interests, and the duties related to their specific institutional position and policy. The discerned storylines capture these dilemma's in a way previously not shown as nuanced and illustrate different mindlines that prescribers in different sectors in Belgium draw on to base prescribing decisions on. Furthermore, our data show how multiple versions of the same class of medication are performed, or enacted, by and through these storylines.

Finally, the nuances that our data add to the existing literature ask for a more tailored approach when addressing the BZRA problem on the prescribers' side. Future policy initiatives that aim to tackle the high prescription rates by targeting prescribers, need to take into account how knowledge-in-practice unfolds, and should be sensitive to the underlying norms and values that inform these mindlines as well to the multiple ontologies of BZRA, thereby also taking into account possible differences in prescribing depending on the indication (insomnia or anxiety).

4 'I HAVEN'T DISCUSSED ANYTHING WITH ANYONE': LIVED EXPERIENCE OF LONG-TERM USERS OF BENZODIAZEPINE RECEPTOR AGONISTS REGARDING THEIR TREATMENT FOR SUBSTANCE USE DISORDER

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ABSTRACT

Treatment for substance use disorder (SUD) to benzodiazepine receptor agonists (BZRA) can be challenging and lengthy. BZRA are prescribed for anxiety and insomnia and, though guidelines recommend an initial prescription duration of one to four weeks this is frequently longer. Understanding the multiple challenges associated with withdrawing from BZRA and exploring the nuance and complexities from the patient's perspective is crucial. In this study, we explore the experiences of SUD to BZRA with nineteen users, who have subsequently either stabilized, reduced, or discontinued their usage. The data were analysed using Interpretative Phenomenological Analysis. Our study identified five key themes regarding the long-term use of BZRA which address inadequate patient information, strict adherence to prescribed medication, minimal involvement in cessation plans, respecting patient readiness for tapering and personalised tapering approaches. These findings indicate that patients' blind trust in their providers can prevent them from voicing concerns, highlighting the importance of an authentic and collaborative relationship between the patient and healthcare provider, while respecting patient autonomy. The goal-oriented care approach could improve BZRA management by aligning treatment with individual goals, enhancing satisfaction, and addressing the complexities of long-term use and withdrawal.

4.1 Introduction

Benzodiazepine receptor agonists (BZRA), which encompass both benzodiazepines and Z-drugs, are commonly prescribed for anxiety, sedation and sleep disorders. Nevertheless, both short and long-term use of this class of psychotropic medications can result in adverse effects, including physiological and psychological dependence, increased cognitive impairment, and elevated risks of injuries such as falls, hip fractures, road accidents, and even suicide attempts or completions (Dodds, 2017; Lader, 1999, 2011). Furthermore, individuals who have been taking BZRA may experience significant challenges with withdrawal symptoms when attempting to discontinue these medications (Lader, 2014). During attempts withdraw from BZRA, patients may experience diverse symptoms, including exacerbation of anxiety and insomnia (Ashton, 1991), and the reappearance of symptoms for which the medication was prescribed, which can be destabilising for patients. The duration of withdrawal symptoms can be prolonged, and varies depending on the duration of medication use, even when employing a gradual deprescription approach. The escalation of withdrawal symptoms is especially prevalent when discontinuing the medication abruptly (Ashton, 1991; Socias et al., 2021). Patients can obtain BZRA in a variety of ways, including legal and illegal strategies. Some of these molecules can be found on the black market or shared with friends or colleagues (Liebrenz et al., 2015). The definition of six months for long-term BZRA use is based on common clinical understanding of the risks, including tolerance, and is supported by a systematic review indicating that six months is the cutoff for studying BZRA use (Kurko et al., 2015).

Belgium has a high number of BZRA prescriptions with 1,260,034 defined daily doses delivered by pharmacies in 2016 according the Association of Belgian Pharmacists. Moreover, a study conducted in Flanders (Belgium) demonstrated that between 2000 and 2019, prescriptions for BZRA increased among long-term users aged 18 to 44 and those aged over 65 (Coteur et al., 2022). While they play a short-term role in specific conditions, their use should be limited or discontinued after a short time (maximum one week for insomnia and four weeks for anxiety (Centre Belge d'Informations Pharmacothérapeutique, n.d.)) in cases where they are unnecessary. In situations where alternatives are available, BZRA could be substituted or complemented in accordance with the patient's preferences and agreement.

In light of these considerations, official guidelines recommend the use of these medications as a last resort and at the lowest possible dose (Cloetens et al., 2018). However, a 2020 report revealed that, in Belgium, these guidelines are not consistently followed in terms of prescription duration (Kiridis et al., 2022). The discrepancy between official guidelines and actual BZRA prescription practices may stem from prescribers facing a dilemma. In the face of clinical guidelines, prescribers are confronted with emotional and ethical aspects that impact the decisions they make regarding the prescription of BZRA (Ceuterick et al., 2023). Other factors may play a part in prolonged benzodiazepine prescribing, including prescribers' knowledge, beliefs and attitudes about the advantages and disadvantages of these molecules (Anthierens et al., 2010). Conversely a meta-analysis of patient and professionals identified that this is a misperception of the problem and patients do not necessarily expect or wish to receive a pharmacological solution to their problem (Sirdifield et al., 2017).

Deprescribing from BZRA has received a lot of attention from researchers in terms of initiating deprescribing (Tannenbaum et al., 2014), supporting the process (Coteur et al., 2022) and examining facilitators and barriers at provider and system level (Linsky and Zimmerman, 2018) and among patients (Lynch et al., 2021). In terms of detailed studies that delve into the lived experience of the process of deprescribing from the patient's perspective an autoethnography was undertaken by Fixsen (2016). Examining the lived experiences of patients provides valuable insights into the complex process of deprescribing. By exploring these experiences, we can better understand the underlying factors influencing the success or failure of different approaches. This approach also draws attention to the role of the patient managing a shared process between patient and provider.

Lived experience

In the case of patients taking BZRA long-term, it is crucial to acknowledge that each experience is unique, influenced by factors such as personal context, medical and social interactions. Understanding the lived experience of patients deprescribing from BZRAs is important to help develop supportive interventions. Patient expertise and motivation is a vital resource in their own process of deprescribing and their experience provides valuable contribution to scientific knowledge on the subject. Indeed, motivation is a key element for the success of BZRA deprescription. It enables patients to understand the importance of discontinuing the use of these medications and encourages them to actively engage in the process in collaboration with their healthcare providers (Ribeiro and Schlindwein, 2021).

There is a growing body of literature reporting on patients' lived experiences with substance use disorder of illegal and legal drugs (Bacon et al., 2020; Carey and MacGregor, 2019; Kassai et al., 2017; Park et al., 2023; Wagstaff et al., 2023) and the experience of service users in the mental health care system (Chorlton et al., 2015; Dawood and Done, 2021; Wangensteen and Hystad, 2022). However, few qualitative studies focus on the experience of patients taking BZRA. These studies employ various methodologies, such as thematic content analysis of patient interview data (Anthierens et al., 2007; Cook et al., 2007; Kapadia et al., 2007), content analysis of free-text responses (Lynch et al., 2024), and a quantitative analysis of an online survey (Reid Finlayson et al., 2022). Using different methodologies, these articles examine patients‘ perspectives when first prescribed benzodiazepines (Anthierens et al., 2007), factors influencing older patients’ willingness to consider stopping benzodiazepines (Cook et al., 2007), patients’ perceptions of current health services (Kapadia et al., 2007) or evaluate the experiences of individuals who are using, tapering off, or have discontinued BZRA (Reid Finlayson et al., 2022) and the impact of BZRA use on patients’ lives, particularly symptoms, and barriers and facilitators to benzodiazepine withdrawal (Lynch et al., 2024).

The Interpretative Phenomenological Analysis (IPA) methodology facilitates the exploration of participants' lived experiences by allowing them to express their personal story (Smith and Nizza, 2021). This method delves deeply into how participants construct meaning from their experiences, perceptions and perspectives (Smith and Nizza, 2021). Such an approach aims to reposition the patient at the forefront of healthcare and promote a more inclusive and effective approach within the current healthcare system (Bergqvist et al., 2023). By focusing on the lived experiences with an IPA method, the nuances and complexities are revealed from the point of view of the patient within their own context and setting (Smith and Nizza, 2021). These results can often differ from other forms of research taking perhaps a more quantitative approach or qualitative analyses such as thematic content analysis which can fail to capture nuance.

In this study, we explore the experiences of BZRA users who have stabilised, reduced or discontinued their BZRA use as part of long-term treatment, using semi-structured interviews. Our objective was to understand how patients experienced this process, as well as how their interactions with healthcare services unfolded. We posed the following research question: What is the lived experience of long-term users of BZRA regarding their treatment for substance use disorder?

4.2 Methodology

Sampling and recruitment

A purposive sample of long-term BZRA users (≥ 6 months (Kurko et al., 2015)) was recruited through various Belgian mental health networks and primary healthcare channels, as well as by extending invitations through social media and to individuals involved in a documentary (on French-speaking Belgian television) focusing on the long-term use of BZRA. Participants were eligible if they had prior experience with BZRA and had stabilized, reduced, or discontinued their usage. A diverse sample was sought by considering variations in experiences, geographic locations, and the participants' progress in their cessation journey.

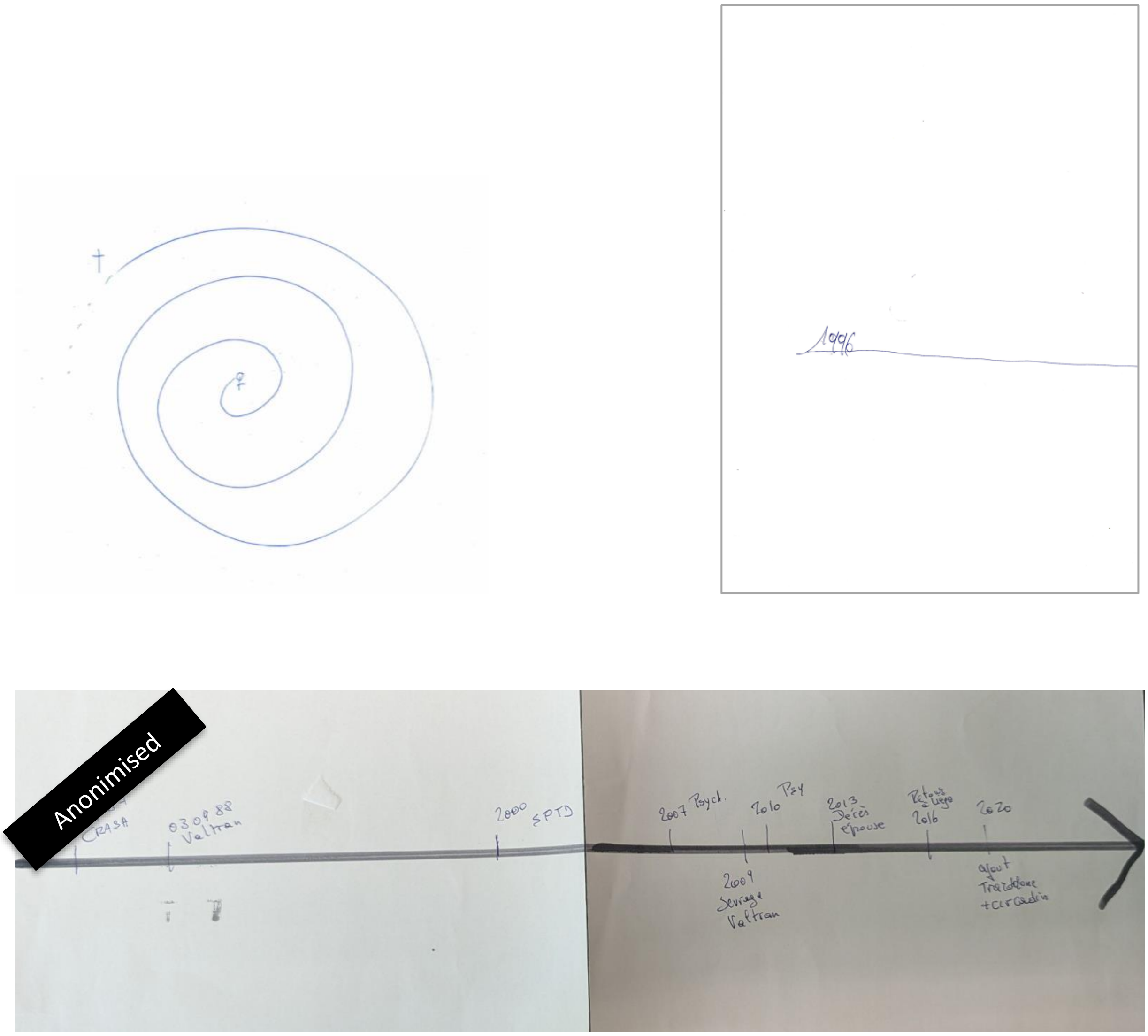
Development of interview topic guide

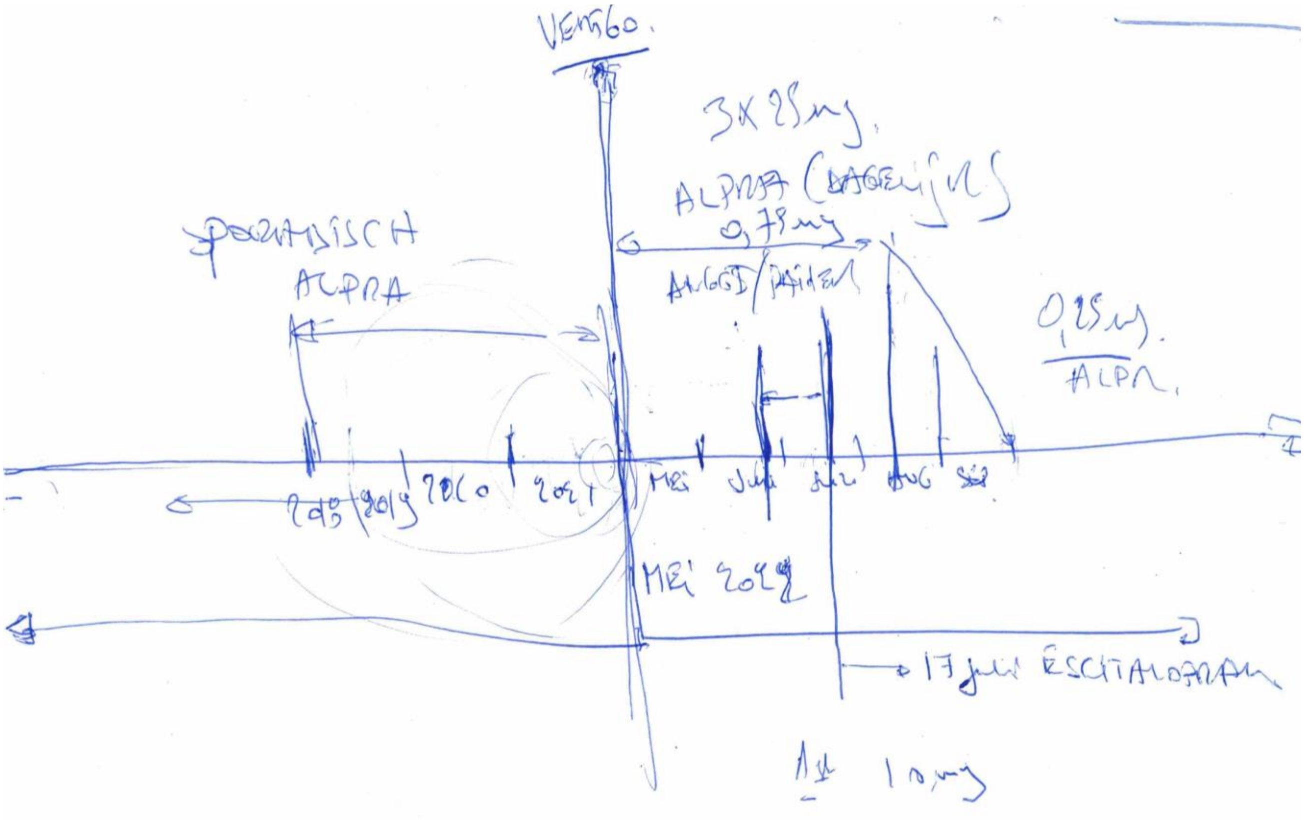
Semi-structured interviews were conducted with long-term BZRA users employing an interview guide developed by three authors— MC, BS, and PV (see annex). The topic guide was structured into several sections focusing on the experience of patients from their initial prescription, their trajectory, the moment they decided to stop, reduce, or stabilize their dose, triggering factors for starting deprescription, and their recovery. This interview guide was first developed in English by the three authors (MC, BS, and PV) based on a previous study conducted by MC (Ceuterick et al., 2021). Subsequently, it was presented to the follow up committee of the research project, comprised of mental health and primary care stakeholders, pharmacists and policymakers to gather their feedback. Following these inputs, the interview guide underwent revisions by the research team until a final version was achieved. The final version was then translated by MC into Dutch and by PV into French.

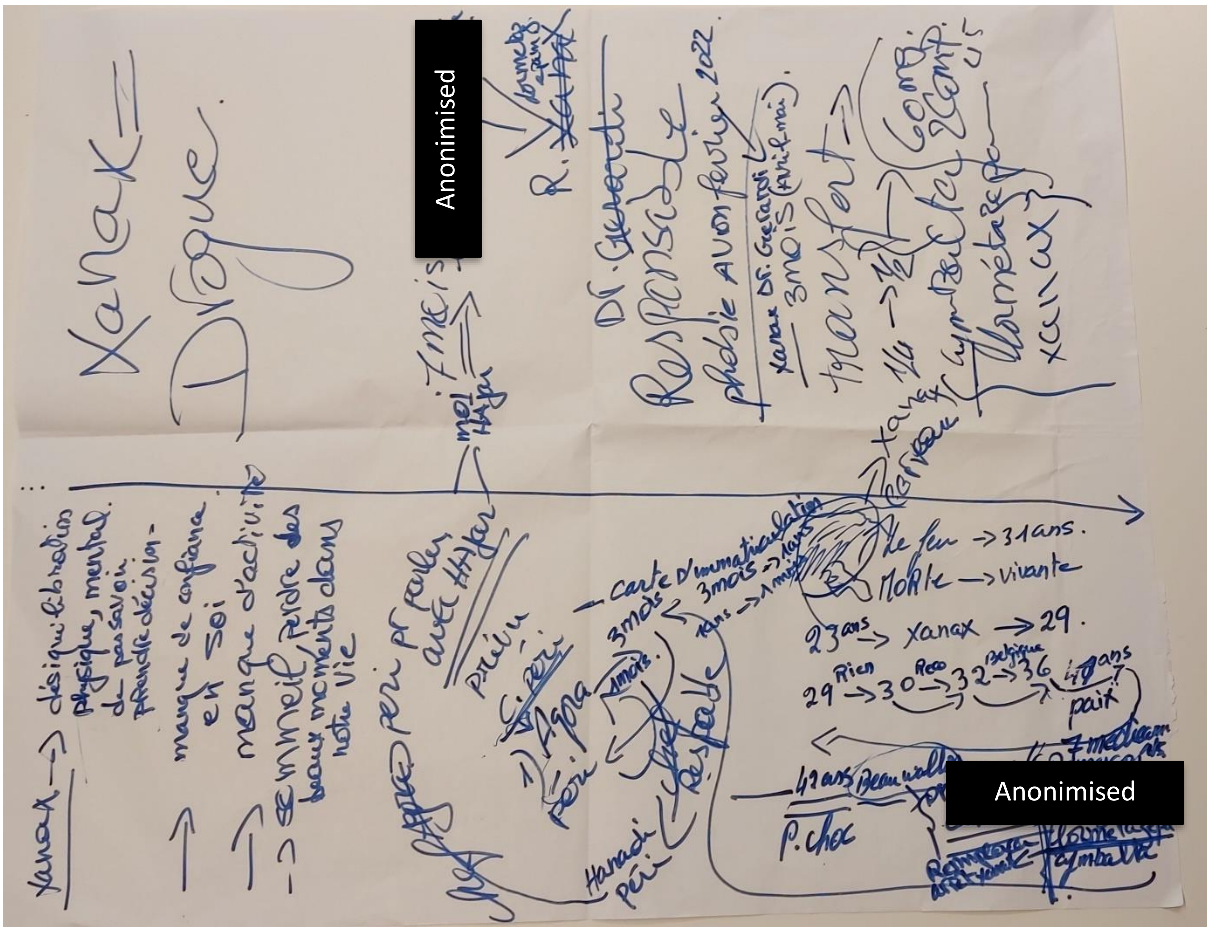
Adaptation of the Life History Calendar Method

In order to facilitate the story telling of what, for some, was a long and complex experience we employed and adapted the life history calendar method. During the interview participants were invited to engage with a 'life history calendar' (LHC) (Nelson, 2010) that we adapted and called Medication Calendar Method (MCM). The classical life history calendar typically covers a specified period, such as a year or several years, and prompts individuals to provide detailed information about various life events. LHC are particularly valuable for studying the timing and sequencing of events in people's lives, and they provide a visual aid that can enhance participants' recall and reporting accuracy (Nelson, 2010). This methodology is a reliable method to help collect retrospective and biographic information, as it allows participants to note various life events and the associated life contexts along a timeline (Freedman et al., 1988) and according to a study published in 2020, this method can improve reports on the experience of certain mental disorders (Axinn et al., 2020). Other studies have used the calendar method to explore the experience of patients during their care using a fixed matrix format (Axinn et al., 2020; Lutaud et al., 2024; Vermeer et al., 2016). After revisiting the literature on this method, the research team decided to integrate a non-structured format. Hence, in our study, participants were invited to draw a timeline on white A3 paper. They were asked to include anything they wanted on the timeline like major life events such as the birth of a child or job changes. This process aimed to help participants to position themselves temporally and to avoid event recall bias, also aimed to facilitate the interviewers understanding of sometimes complex trajectories. Participants could interact with the timeline as much or little as they liked. As illustrated in figure 4, participants engaged in different ways with the method. Overall, using this visual aid generally facilitated the discussion extensively. In the few instances where participants did not feel comfortable using this method, we did not insist on using it. A participant also sent a document on his own initiative before the semi-structured interview, which helped to start the interview on this document. This interview topic guide with the adjusted medication history calendar method was piloted during two interviews, one in French and one Dutch but no adaptions were considered necessary.

Figure 4 Examples of different personalised medication calendars




VERTIGO.
3X 25 mg.
ALPRA (DAGELIJKS
0,75 mg
SPORADISCH
ALPRA
ANGST/PANIEK
0,25 mg.
ALPRA.
2018
2019
2020
2021
MEI
JUNI
JULI
AUG
SEP
MEI 2022
17 juli ESCITALOPRAM
10 mg


Anonimised
Xanax = Drogue.
Xanax → déséquilibration physique, mental, de pouvoir prendre décision
→ manque de confiance en soi
→ manque d'activités
→ sommeil, perdre des beaux moments dans notre vie
7 MEIS →
mei Hajar
Dr.
Responsable
phobie avion février 2022
Xanax Dr. 3 MOIS (avril-mai)
transfert
1/4 → 1/2
comprimés
Xanax
carte d'immatriculation
3 mois → 1 ans
Le feu → 31 ans.
Morte → vivante
23 ans → Xanax → 29.
29 Rien → 30 Reco → 32 Belgique → 36 → 47 ans
paix
P. choc
Anonimised

Interviews

A purposive sample of 19 patients was recruited from the three regions of Belgium (Brussels, Flanders, and Wallonia), the diversity of the sample is presented in table 5. Participants' year of birth spanned from 1948 to 1989. In order to maintain confidentiality, each participant was given a code. Among our sample, 63% of the participants were women and 37% were men, with a median age of 52 years.

Table 5 Overview of interviewees with experience in using BZRA (WP4)

Code	Year of birth	Sex	Professional status	Reason for first prescription	Mode of interview
RESP1	1980	M	Working	Anxiety	In person
RESP2	1964	M	Unemployed	Acute drug-induced psychosis	Online
RESP3	1985	F	On sick leave	Insomnia	In person
RESP4	1989	M	On sick leave	Anxiety	In person
RESP5	1969	M	Working	Stress	In person
RESP6	1971	F	Unemployed	Insomnia	In person
RESP7	1948	F	Retired	Anxiety	In person
RESP8	1948	F	Retired	Pain	In person
RESP9	1969	F	Working	Insomnia	In person
RESP10	1970	M	Unemployed	Anxiety	In person
RESP11	1970	F	Working	Anxiety	In person
RESP12	1949	M	Retired	Insomnia	In person
RESP13	1961	F	Retired	Insomnia	Online
RESP14	1961	F	Working	Insomnia and anxiety	In person
RESP15	1971	F	Working	Anxiety	In person
RESP16	1950	M	Retired	Anxiety	In person
RESP17	1986	F	Working	Anxiety	In person
RESP18	1973	F	Unemployed	Anxiety	In person
RESP19	1976	F	Working	Anxiety	In person

In total 19 interviews were conducted, of which 13 interviews were conducted in French, by the first author (PV, female, PhD student and psychologist by training) and six interviews in Dutch by the second author (MC, female, postdoctoral researcher and medical anthropologist). Almost all interviews (n=17) were conducted in person and two interviews were organised online based on the interviewee's preference. Interviews took place between 27/04/22 and 15/12/22 in a location chosen by the participant (i.e. the participant's home, either one of the two involved universities, or another neutral place). Before the interview, informed written consent was obtained from all participants. All interviews were recorded digitally and transcribed verbatim using Amberscript software, any identifying information was removed. The transcripts were proofread for accuracy. Participants could reread the transcripts if they wished. Monthly team meetings were held to discuss the progress of data collection and data analysis.

Ethical statement

Prior to participating in the study, participants were provided with an information and informed consent letter, as well as a verbal explanation of the study's objectives by the researcher (MC or PV).

They subsequently gave their voluntary and written informed consent and agreed to be recorded. All names and identifying information were removed from the transcription to maintain anonymity.

Data analysis

Interpretative Phenomenological Analysis (IPA) was employed for the data analysis. This approach requires an in-depth exploration of participants' lived experiences, aiming to uncover the ways in which they make sense of their experience. IPA enables exploration of patients' experiences with great depth and detail (Smith and Nizza, 2021). In the context of long-term BZRA use, this could help us to understand the nuances of their experience as a patient. It focuses on the subjective meaning individuals attribute to their experiences. This method recognizes and values the subjectivity and uniqueness of individual experiences.

In the initial phase the first author (PV) thoroughly read and revisited the transcriptions multiple times. Concurrently, detailed exploratory notes were taken to capture the nuances and subtleties within the participants' narratives. To become more immersed in the experiential statements of the participants. An experiential statement is a verbatim that describes a participant's experience as they recounted it and accurately captures and represents the perceptions and meanings that participants attribute to their experiences. PV referenced with each MCM document to get more details and additional elements beyond what the participants had said verbally. Following this, experiential statements were identified for each transcription, clustering them into more comprehensive and overarching statements. The resulting overarching statements were discussed during regular meetings with MC and BS, followed by iterative data discussions. This collaborative process allowed for a thorough exploration of the data and refinement of the analysis. Once the themes were defined, representative quotes were selected to best reflect the participants' shared experiences, enhancing the richness and depth of the analysis. The data analysis process was carried out using Nvivo 14 software (14.23.2).

4.3 Results

Although the participants had different withdrawal goals (stabilisation, reduction or cessation), they shared common experiences in their histories. Five themes emerged from the analysis of the data: (1) “Like sweets”; (2) “When the psychiatrist gives you medication, you must take them.” (3) “I haven't discussed anything with anyone”; (4) “I wasn’t ready [for the withdrawal]”; and (5) “If you want to do it right, you have to go slowly”.

‘Like sweets’

This theme symbolizes the disappointment and dissatisfaction with the lack of comprehensive information about BZRA. This lack of information results in blind trust in healthcare professionals, leading to a limited understanding of the potential consequences of BZRA use. Some patients expressed frustration that the drugs prescribed exacerbated their health problems rather than alleviated them. They reported feeling abandoned and hopeless when their concerns are ignored or downplayed by the prescriber.

> *“And I didn't like that at all because I finally gave up myself, because I said find me something else, I say...[...] I told them straight out eh... I said listen, I sleep 24 hours a day, are you kidding?” “That was after a major event in my life, my mum who committed suicide in fact. […] In fact, also due to abuse of benzos. She took Temesta® and her psychiatrist [name] in [place], who said to her you can take that like sweets. And she said that to us too, from my psychiatrist said you can take that like sweets."* RESP2

In this quote, RESP2 expresses discontentment and mentions the struggle to find an alternative. He seems dissatisfied with the initial treatment, apparently experiencing excessive drowsiness. The mention of the mother's “abuse of benzos,” specifically Temesta®, and the psychiatrist's advice to take them "*like sweets*" highlights the prescription practices and attitudes towards BZRA. These words attributed to the prescriber suggest a lack of awareness or disregard for the associated risks and the patient's real needs and suffering RESP2 draws a connection between his own medication challenges, his mothers’ experience with BZRAs and her tragic outcome.

This is perceived by other participants who also described not receiving enough information. This emphasizes the initial lack of detailed information and demonstrates the lack of awareness and education about these medications.

> *‘Not much, honestly. I didn't know much. I knew what it was because, well, when I was little, I also knew my mother, who used to take that... I remember the bottle that was always on the bathroom shelf. Otherwise, by name, I also knew... I know someone who used to take it...'* RESP10

> *‘I've never been told: "Yes, but this is a medicine you have to be careful with”’.* RESP3

Some quotes reflect the dissatisfaction of patients with a healthcare approach that places a priority on prescribing medications as the primary solution to insomnia and anxiety, often without a thorough understanding of the individual's specific condition and circumstances.

> *‘Well, medications, that was the first thing they gave you before anything else, before, I would say, knowing how you're doing...’* RESP19

RESP19 describes feeling misunderstood or not listened to by the healthcare professional. She believes that the medical approach typically includes prescribing medications immediately, even before fully comprehending or evaluating the person's condition.

> *‘The doctor, it's just to fill you up with medications. It's easy; he writes a prescription; you take the pills. And then... then you feel better, but it's just bypassing the illness; it doesn't cure you.’* RESP7

Another patient expresses a somewhat critical view of doctors, suggesting that they often rely on prescribing medications as a quick and easy solution and encourages a trivialization of benzodiazepines. RESP7 acknowledges that taking the prescribed pills may provide temporary relief, making you feel better. However, he emphasizes that this approach merely addresses symptoms and doesn't address the root cause of the illness, implying that it doesn't lead to a cure.

'When the psychiatrist gives you medication, you must take them.’

Through the patients' stories, they illustrate their profound sense of obligation to strictly follow and adhere to the treatment and prescription guidelines established by their healthcare providers. This feeling leads them to keep their medication management preferences to themselves, and they often feel uncomfortable exploring other avenues that may differ from their doctor's recommendations.

> *'When the psychiatrist gives you medication, you must take them.’* RESP16

In this quote, RESP16 is conveying a straightforward directive regarding psychiatric treatment. His belief is that when a doctor prescribes medication, it is expected or necessary for the individual to take the prescribed drugs. The statement suggests a sense of obligation emphasizing the importance of adhering to the prescribed treatment plan.

Other patients express that they do not fully agree with the treatment proposed by healthcare professionals but refrain from going against it due to fears of potential negative consequences. Additionally, they present an apprehension about straining the doctor-patient relationship or appearing noncompliant. The tendency to blindly trust and strictly follow the provider's prescription often occurs at the expense of voicing concerns. This feeling is shared by RESP7.

> *'But, as my doctor told me, 'You cannot stop that.' So, I think I won't do that without the doctor's advice, because, you know, I don't know where I'll end up.'* RESP7

These accounts highlight a lack of communication and shared decision making between patients and their healthcare providers, underscoring the unequal relationship between the prescriber and the patient. Patients appear to feel obliged to follow prescribed treatments without voicing their own preferences or concerns, indicating a power imbalance where the prescriber's authority outweighs the patient's input.

'I haven't discussed anything with anyone'

From the perspective of some patients, the relevance of involving their healthcare professional in the decision-making process regarding the cessation and stabilisation of BZRA was not clear. Some people decide to take this step with someone close to them, but the involvement of the healthcare professional does not seem to be considered important by patients. It is a decision they have made for themselves. Some patients express pride in having accomplished everything on their own, without assistance from anyone, which leads them to avoid discussing this decision with others. For many, successfully overcoming the difficulties of withdrawal without the help of a healthcare professional or support system was a sign of personal strength and determination. They felt a deep sense of accomplishment. Additionally, they describe the decision as sudden, occurring at a time when they themselves hadn't anticipated making such a choice. They had not premeditated this decision.

> *'"I haven't discussed anything with anyone. I'm not lying to you, you know... you can ask Mr. X [name of the General practitioner] ... he himself was the first surprised... Yes, all alone... Everything and all, everything, everything, everything. (…) "No, no, I really made the decision just like that, all of a sudden. I said no, I have to stop all my medications."*
> RESP8

Some patients also describe a challenging period due to personal events or BZRA adverse effects that led the patient to question their medication and prompted them to stop, reduce, or stabilize their BZRA use. This period is described through the quote from RESP15, who describes going through what she calls a nightmare, a very difficult time that pushed her to take control and start on her own this withdrawal process.

> *'So there, I started the worst period, let's say the nightmare period, and that's when I decided to undergo withdrawal. It was my decision... Now, it's time for me to undergo withdrawal.'* RESP15

While some participants explained that they did not involve anyone in their decision-making and support for discontinuing, stabilizing, or reducing BZRA usage, others included a close family member with whom they planned this withdrawal process. For example, RESP17 established deadlines with her husband to better organize the withdrawal process, drawing from challenging past experiences, without involving a healthcare professional.

> *"So, my ideal goal would have been to stop overnight. But we knew that it hadn't worked the times I had tried. And on top of that, I had researched withdrawal symptoms, so my husband and I had discussed it extensively and set some deadlines."* RESP17

‘I wasn’t ready [for the withdrawal]’

Some patients expressed their hesitance and apprehension regarding the process of BZRA withdrawal. This is outlined by the quote of RESP15.

> *‘We started a withdrawal. I was in a panic when I got out of there. I wasn't ready.’* RESP15

The use of "panic" indicates the high degree of anxiety or stress generated by this situation, highlighting the impact on the patient of feeling unprepared or not ready to start the tapering process. In this quote, the emotional and psychological challenges are made explicit and associated with gradual withdrawal and the reappearance of the symptoms for which she had taken BZRA. Later in the interview she explained that she stopped taking BZRA later, at a time she found more suitable. At that point, her panic was also linked to the fact that she had not been prepared for the withdrawal beforehand and the symptoms it would generate.

Patients may experience strong resistance or reluctance to begin the process of benzodiazepine withdrawal, as the quote indicates. Patients express the need for healthcare professionals to listen to their fears and slow the pace. The testimony of RESP13, who admitted to their doctor that they were taking BZRA through a family member, is another example. They found themselves unable to obtain a prescription from one day to the next following the death of this person. When they explained the situation to their GP, he refused to prescribe it and wanted them to stop without giving more information.

> *‘He [GP] said, “You've got to stop, you've got to stop, that's all”. It wasn't any better, so I tried to get the prescription from the pharmacy. They wouldn't give it to me.’* RESP13

‘If you want to do it right, you have to go slowly’

Some patients emphasize that the withdrawal process is not an easy task and requires prior preparation on the part of the patient. Patients expect the provider to be open to a gradual reduction or personalized stabilization.

> *‘I wanted to gradually decrease until completely stopping. And when my doctor told me in four weeks, I trusted him.’* RESP18

RESP18 initially trusted their doctor's recommendation of a four-week timeframe for tapering off medication. However, in the end, the withdrawal process took over a year. The patient highlights the importance of adapting the pace of withdrawal to the individual's needs and experiences. Other patients underscore the need for a slow and gradual approach to overcoming BZRA substance use disorder. RESP1 thinks that rushing is seen as a common mistake and advocate for a slow tapering off to minimize relapse risk and withdrawal symptoms. Some patients express frustration with the inability to rapidly deprescribe BZRAs, emphasizing that doing it right requires a slow approach. RESP1 elaborates on this frustration, pointing out that rushing the process is often counterproductive. They believe that a hurried withdrawal increases the likelihood of relapse and exacerbates withdrawal symptoms. According to RESP1, the key to a successful tapering off is to proceed slowly and methodically.

> *'That's the frustrating part of all these things; if you want to do it right, you have to go slowly. So, you have to accept right away that if you're taking different products, it's actually a multi-year plan to get rid of everything. In my opinion, the biggest mistake people can make is to quickly say they want to get off benzodiazepines when they hear about them. In my opinion, they often get it thrown back in their faces. It's only by doing a slow tapering that you actually have the least chance, in my opinion, of relapse and the greatest chance of reducing withdrawal symptoms.'* RESP1

4.4 Discussion

In our study on the lived experience of treatment for SUD for BZRA from the patient's perspective, five themes emerged from the analysis. These themes include patients expressing feelings of being insufficiently informed about BZRA, a strong sense of obligation to adhere strictly to prescribed medication, a lack of perceived relevance in involving others regarding cessation and stabilization of BZRA, the importance of respecting the moment when patients are ready to taper off BZRA, and the importance of a personalized approach to tapering off BZRA. These themes are presented separately but they are very much intertwined, in the following paragraphs we attempt to make sense of the complex lived experience of the patients we interviewed.

First, these findings underscore the crucial need for comprehensive information and effective communication in managing long-term BZRA use. In our results, patients expressed dissatisfaction with the lack of detailed information provided about BZRA medication, leading to limited awareness of the associated risks. Other studies have also found that patients reported receiving insufficient information about potential risks and hazards associated with BZRA (Chahal et al., 2023; Lynch et al., 2024; Seddon et al., 2024). A further study revealed that patients' perceptions of the risks linked with BZRAs were influenced by their individual characteristics and beliefs about these medications (Sake et al., 2019). This underscores the importance of transparent and personalised communication between healthcare professionals and patients to ensure informed decision-making regarding BZRA. Communication techniques encouraging patients to voice their concerns and actively participate in decision-making regarding their treatment are warranted. Healthcare professionals are encouraged to explore patients' discourse and to try to understand their real needs and how these evolve, as well as those they may want to hide from them for reasons specific to each patient.

Second, and linked to this need for information, a particular challenge with SUD to BZRA is the fine line between treatment and dependence. Patients are prescribed BZRA in response to certain symptoms but become dependent on the medication. When they decide to stop they must have understood that this is no longer a treatment plan for their symptoms but a dependence. The results presented in theme two, highlight the challenges for individuals with long-term BZRA use to question the 'treatment' plan proposed by their provider. This could be interpreted as a trusting relationship between patient and provider but could also be characterised as 'blind' trust where the patient doesn't dare to question the prescription. The form of 'blind' trust to strictly adhere to the prescription given by the provider, often at the expense of voicing their concerns, presented in theme two is concerning. To maintain the genuine trust established between the provider and the patient when transitioning from a treatment plan to deprescription, it is essential to adopt a collaborative approach with the patient. This is in accordance with the patient's perspective described by Silvernail and

Wright, (2022) which describes a patient's narrative and the essential role of a trusting patient-provider relationship in successfully managing medication tapering. This trust not only provides emotional support but also validates the patient's experiences and concerns. The patient's ability to persist in finding a healthcare provider willing to listen and learn about BZRA dependency highlights the profound impact of trust and communication in achieving positive health outcomes (Silvernail and Wright, 2022).

Moreover, theme three describes how patients hid their attempts to stop taking BZRA from their provider or that they decided to stop without medical support. This is worrying given the complex and unpredictable withdrawal symptoms associated with BZRA (Authier et al., 2009; Pétursson, 1994; Reid Finlayson et al., 2022). The factors that influence patients' confidence in their prescriber are shaped by the prescriber's motivation to understand the patient, their expertise in BZRA, transparent communication, shared decision-making, and the duration of the relationship (Oldenhof et al., 2021). This highlights the need for healthcare professionals to be guided by the patient in setting treatment goals (Van Ngoc et al., 2024). By fostering a supportive and empathetic environment, healthcare providers can enhance treatment adherence and improve patient outcomes. This highlights the importance and inherent challenge of recognising and respecting patient autonomy while ensuring access to comprehensive support and advice throughout the withdrawal process. The withdrawal process can be very difficult for some patients, and they may experience a variety of prolonged and severe symptoms (Authier et al., 2009; Pétursson, 1994; Reid Finlayson et al., 2022). Identifying patients at particular risk of a difficult withdrawal is challenging which further emphasises the need to remain attentive to patients at each prescription renewal. It is therefore important that patients are warned of the adverse effects so that they can be supported and managed appropriately and talk about stopping the molecule at the first prescription.

Third, in order to avoid patients abruptly stopping their medication and or doing so without medical support the timing and the pace needs to be right. As presented in themes four and five and supported by other studies (Ceuterick et al., 2021).(Authier et al., 2009; Pétursson, 1994; Reid Finlayson et al., 2022; Van Ngoc et al., 2024). In Belgium, a new reimbursement programme began in 2023, which proposes three different trajectories for deprescribing within one year. Given the results presented in this paper, it remains to be seen whether this programme will be sufficiently flexible to accommodate the diversity of patients eligible (Institut national d’assurance maladie-invalidité, n.d.). The restricted flexibility of this programme, with its three predefined pathways, constrains the ability to provide personalized care and may result in the deprescribing process being conducted too rapidly for patients.

Finally, adopting a goal-oriented care approach (GOC) could prove advantageous in tailoring care to the individual patient. GOC enables healthcare and social care professionals to collaborate innovatively, placing the priorities and life objectives of patients with complex medical and social requirements at the forefront of their care (Boeykens et al., 2022). Studies have analysed the characteristics associated with the long-term use of BZRA and have shown that users tend to have certain characteristics linked to long-term use, such as advanced age, multiple comorbidities, and psychiatric disorders (Kurko et al., 2015). These users may be considered to require complex medical and social support. Incorporating goal-oriented care principles into the management of BZRA disorders requires actively involving patients in decision-making, acknowledging their treatment preferences, and tailoring interventions to support their goals. This approach fosters a sense of ownership and empowerment among patients, ultimately leading to improved treatment adherence and outcomes (Boeykens et al., 2022; Reuben and Tinetti, 2012). The GOC approach is helpful for patients dealing with multiple parallel care processes for various conditions, which may lead to fragmented care and poor continuity of care (Berntsen et al., 2018). Additionally, it allows for a more effective prioritization of patients' goals, especially for those with a substantial number of prescriptions, by identifying what holds significant importance for them, what are their preoccupations (Boeykens et al., 2022).

Establishing a shared comprehension of treatment goals holds the potential to enhance patient satisfaction (Mold, 2017) and contributes to the satisfaction of healthcare professionals (Salter et al., 2019). The GOC approach is a philosophy directly related to the patient-centered care approach and shared decision-making and, to the best of our knowledge has not yet been applied to deprescribing from BZRA. Given the often complex and unpredictable process of withdrawal for patients and the fact that several outcomes are possible (stabilisation, harm reduction, total abstinence) we believe that GOC may be a helpful approach in this setting.

Strengths and limitations

The study's diverse sampling strategy, combined with the use of multilingual interviewers in both French and Dutch, contributed to comprehensive representation and effective communication with participants. This approach ensured that individuals from various backgrounds and geographic locations were included, enhancing the richness and depth of the data collected. Additionally, the innovative use of the Medication Calendar Method provided a structured framework for participants to recall and report on their experiences with BZRA use within the context of their life events. This visual aid facilitated detailed insights into participants' treatment trajectories, allowing for a nuanced understanding of their journey. However, potential bias in participant recruitment could influence findings. Furthermore, the subjective nature of Interpretative Phenomenological Analysis introduces inherent interpretative bias despite efforts to ensure rigor.

Perspectives

Future research could explore the differences in lived experiences based on gender, as well as examine the experiences of patients within secondary mental health care services, such as psychiatry. These studies could provide valuable insights into the unique challenges and needs of different patient populations and how they are received in different parts of the healthcare system..

4.5 Conclusion

The study emphasizes the importance of transparent communication and comprehensive information in managing long-term BZRA use. Patient adherence hinges on trust and collaboration with healthcare providers. Withdrawal from BZRA requires personalized support and respect for patient autonomy, as some attempt tapering without medical guidance.

5 'IT IS OFTEN AN ASSAULT COURSE TO BE ABLE TO BE CARE OF' : ACCESSIBILITY OF SERVICES FOR SUBSTANCE USE DISORDERS TO BENZODIAZEPINES AND Z-DRUGS IN BELGIUM

A manuscript entitled 'It is often an assault course to be able to be care of' : Accessibility of services for substance use disorders to benzodiazepines and Z-drugs in Belgium' is currently being prepared for submission to *BMC Health Services.*

ABSTRACT

Reducing the consumption BZRA is crucial for individual and public health, however, deprescribing is a challenging process. This study explores the accessibility of services for substance use disorders related to BZRA. Accessibility to services involves multiple factors: availability, accessibility, accommodation, affordability and acceptability. This qualitative study was conducted using semi-structured interviews with 19 patients and 24 healthcare professionals to explore their experiences. The data were analysed using the Levesque model of accessibility (2013). The results identified the following elements: lack of Information: patients and professionals noted insufficient information about the risks of BZRA dependence; communication challenges: discussing consumption can be difficult due to the taboo and stigma around the issue; awareness: patients often don't realize the dangers of BZRA addiction, taking years to seek help; logistical challenges: navigating the Belgian healthcare system is difficult; service availability: There are long waiting lists and a shortage of general practitioners and psychiatrists; physical barriers: issues like homelessness and limited public transport make accessing healthcare difficult; costs: psychotherapy is expensive compared to medication, though recent investments have improved access to talking therapies; financial support: social workers help patients manage paperwork and access benefits, but financial difficulties remain especially for patients in precarious circumstances; effective communication: kindness, transparency, and mutual respect are crucial in patient-provider relationships; multi-disciplinary teams: collaboration among healthcare providers and connecting patients with external services are beneficial; long-term engagement: Supporting patients to complete their treatment plans is essential, with activities and support networks playing a key role. In conclusion, improving access to care for BZRA-related substance use disorders requires: at the micro-level, action to improve and maintain the patient provider relationship throughout the process of accessing care; at the meso-level integrated care approaches could help patients navigate the system; at the macro level national interventions have been implemented that respond to a number of the issues raised however universal access across the whole country should be prioritised to avoid exacerbating inequalities. Finally, a whole system approach should be taken to address the problem of BZRAs in its entirety from preventing the first prescription to rapidly managing dependence.

5.1 Introduction

Helping patients deprescribe from medications that are no longer appropriate or to which a person has become dependent is an important public health mission (Reeve, 2017). Reducing the number of medications a person takes has many positive implications including for patient well-being, financial implications for both the patient and the health system as well as environmental implications regarding reduced pollution and wastage (Ailabouni et al., 2021). Correspondingly, deprescribing has attracted a lot of attention from researchers, healthcare providers and policy makers revealing a high degree of complexity and multiple barriers at different levels (Brandt et al., 2024). Accessing care to be able to address issues of dependence and addiction is a first step to developing a proper treatment plan and tapering programme.

Accessibility to healthcare goes beyond simply pushing the door of the healthcare provider's consultation room. It is complex and many factors are at play. In the 1980's Penchansky and Thomas conceptualised access as the five A's: availability, accessibility, accommodation, affordability and acceptability (Penchansky and Thomas, 1981). Healthcare services must be physically available, in a reachable geographic location, easily navigable by patients, at an affordable cost and with a provider they feel comfortable with. In addition to these elements, as described by Andersen (2013) contextual (e.g. neighbourhood) and individual factors (e.g. gender, culture) can also influence an individual's health seeking behaviour (Blackburn, 2024). Levesque et al. (2013) define access as 'the opportunity to reach and obtain appropriate health care services in situations of perceived need for care'. They propose that access to healthcare has both a supply and demand side to it. Patients must have the ability to perceive, seek, reach, pay and engage to achieve access to the services they need. Access is therefore a result of the interface between a person's characteristics, their household, social and physical environments and the characteristics of the health system, the organisations and the providers operating within the system (Levesque et al., 2013).

Benzodiazepines receptor antagonists (BZRA) are a group of medications that are known to provoke tolerance and dependence and for which deprescribing can be difficult (Lader, 2014). BZRA are routinely prescribed, despite the existence of compelling scientific evidence (Airagnes, 2016) and multiple guidelines (Brandt et al., 2024) encouraging doctors to prescribe at the lowest possible dose for the shortest possible duration (see also table 2 on Belgian guidelines in this report). In Belgium the burden of BZRA is high. According to the Health Interview Survey 5,3% of the Belgian population had taken a BZRA in the 24 hours preceding the interview rising to 14.9% among the age group 65+ with higher rates in Wallonia compared to Brussels or Flanders (Sciensano, 2018). Long-term BZRA use is generally considered to be use beyond 6 months (Kurko, 2015) and is associated with side effects such as vertigo, ataxia, cognitive decline, suicide and accidents such as falls and road traffic accidents. Furthermore, long-term use can induce physiological and psychological dependence leading to misuse, abuse or substance use disorder (SUD) (Lader, 2004). The process of deprescribing from BZRAs can be difficult and drawn out. Particularly troubling to patients is that the withdrawal symptoms often mirror the original symptoms they received the initial prescription for. The experience of deprescription from BZRAs varies from relatively simple tapering to challenging and arduous journeys towards total abstinence or a low and stable dose (Lader, 2014). The term 'complex persistent benzodiazepine dependence' has also recently been defined to refer to patients whose experience of deprescribing exceeds the more linear experience of tapering off (Peng, 2022). Furthermore, access to care for SUDs is challenging on many levels due to discrimination and stigma associated with addiction and mental health problems, fragmentation between physical and mental health services as well as the cost of services, especially private services where the waiting list is sometimes shorter but the cost to patients is higher (Kourgiantakis et al., 2023; De Ruysscher et al., 2024).

In this qualitative study we look at accessibility of services for BZRA SUD in Belgium from the perspective of providers and patients through the prism of the conceptual framework of access to health care developed by Levesque and colleagues (2013).

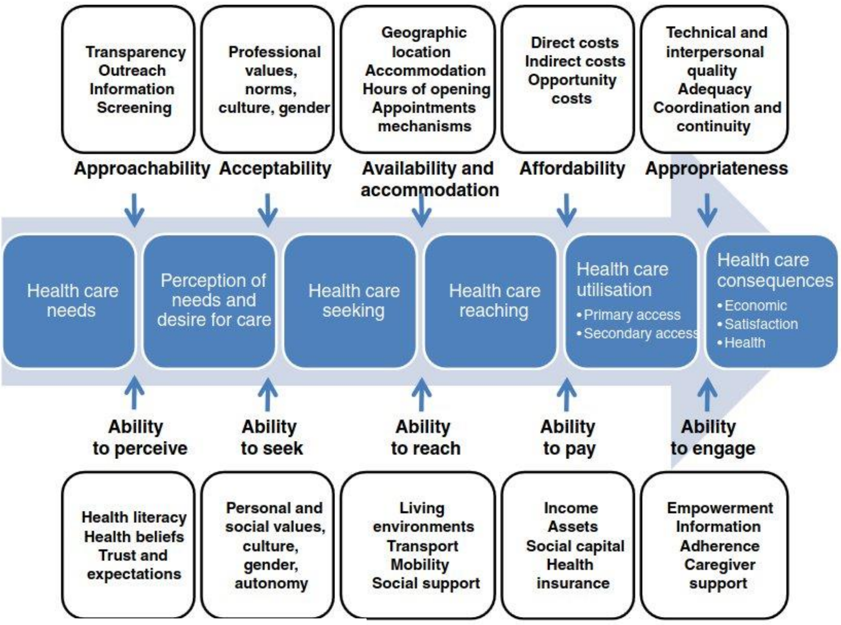
Research question

What are the barriers, facilitators and eventual needs from the perspective of patients and providers concerning accessibility of services for Benzodiazepine and Z drug substance use disorder?

5.2 Method

The methodology employed to collect the data is described in chapter 4 for the patients, and in chapter 2 and 3 for the professionals. The two data sets were analysed by the research team with the help of two interns, using Nvivo 14. A reflexive thematic analysis approach (Campbell et al., 2021) was used and combined with deductive coding based on the model proposed by Levesque et al. (2013) on the accessibility of healthcare (see figure 5). The transcripts were coded using a codebook based on the conceptual model. The different transcripts were then transformed into themes corresponding to the ten elements of the model. These themes were reviewed and reorganised by the research team, working together at regular intervals to achieve a coherent account of the data. The different population groups (patients and professionals) were analysed separately to retain the specificity of each population's perspective. The two sets of themes are presented alongside one-another to demonstrate the correspondence between the two perspectives. The analysis was led by BS who employed an interpretivist approach situating the results in the existing health policy landscape in Belgium. At regular intervals over the project BS, PVN and MC discussed in detail the findings and the conclusions drawn in order to produce a coherent, nuanced and rich reflection of the different themes. The results are therefore interpreted within the context of our multi-disciplinary backgrounds of public health, primary care and health policy (BS), occupational psychology (PVN) and anthropology and medical sociology (MC).

Figure 5 Conceptual model of access to healthcare (Levesque et al., 2013)



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5.3 Results

A purposive sample of 19 patients and 24 professionals was recruited from the three regions of Belgium (Brussels, Flanders, and Wallonia), the diversity of the sample is presented in tables 1 and 5 (earlier in this report). The results of the analysis and their categorisation into the different elements of the Levesque model are presented in brief in table 6 and in more detail in the text below.

Table 6 Overview of accessibility of care according to professionals and patients

THEME	LEVESQUE DEFINITION	OUR RESULTS PROFESSIONALS	OUR RESULTS PATIENTS
APPROACH-ABILITY	• That people facing health needs can actually identify that some form of services exists, can be reached, and have an impact on the health of the individual. • Services can make themselves more or less known among various social and geographical population groups • Elements such as transparency, information regarding available treatments and services and outreach activities can contribute to the approachability of services	• (lack) of information given at first prescription warning of dependence to BZRA (but improving according to some participants) • Professionals appear to fear advertising their services in case this should provoke unmanageable demand. • Challenge for professionals to explore their patient’s consumption	• Lack of information given in Emergency dept. • Possibility to change doctors to change approach - reset relationship
ABILITY TO PERCEIVE	• Determined by factors such as health literacy, knowledge about health and beliefs related to health and sickness	• Challenge for patients to differentiate between the medication as a treatment and as a problem in itself. • Perception challenges of risk of BZRA compared to illegal drugs • Challenge for professionals to draw patients' attention to the problematic use due to risk they go elsewhere • Time lag before a problem is perceived and time lag before help is sought	• Waiting for a solution • Intervention of family members that identify the problem • Patient not feeling ‘themselves’ • Patient knowing their bodies • Patients feel that the GP doesn’t understand their suffering and that it is linked to benzodiazepine withdrawal • Difficult to convince prescriber that the symptoms experienced were due to benzodiazepine withdrawal – invalidation/dismissing

			symptoms and patient's explanations
ACCEPTABILITY	• Cultural and social factors determining the possibility for people to accept the aspects of the service (e.g. sex or social group of providers, the beliefs associated to systems of medicine) E.g. cultural difficulties for women from some cultures to consult a male doctor • Inequitable organisation of services making them unacceptable to some sections of the community they are intended to serve	• Negative social representation on the part of patients associated with mental health services – taboo, shame and stigma. • Negative social representation on the part of professionals – reluctance to take on patients with certain profiles - discrimination • Patient selection by over-subscribed services	• Increasing acceptability of psychological follow-up over the years. • Acceptability of talking therapy on the part of the doctor – influence on the patient • Communication challenges with HCPs • Varying degrees of acceptability on the part of the doctor concerning the wishes/ expectations and the knowledge of the patient • Patients not accepting younger GPs with less experience and shorter work hours
ABILITY TO SEEK	• Personal autonomy and capacity to choose to seek care • Knowledge about healthcare options • Knowledge about individual rights that would determine expressing the intention to obtain healthcare • Different groups may judge appropriateness and quality differently – this is an important challenge	• Difficult to understand the system make it challenging for patients to seek care • Demands a lot of autonomy and certain skills such as assertiveness etc.	• Choice • Encouraged by family member – but disappointed by follow up
AVAILABILITY AND ACCOMMO-DATION	• Health services can be reached in a physical and timely manner • Physical existence of health resources with sufficient capacity to to produce services • Characteristics of facilities: density, concentration, distribution, building accessibility etc • Characteristics of providers: presence of appropriate health professional, qualifications, modes of provision of services	• Challenges associated with mobility in rural areas – accommodated by home visits offering a unique perspective into patient's lives • Lack of capacity in the system (GPs, psychiatrists) rural urban disparities • Potential but challenges in building collaborative networks • Timeliness of availability of services – when a patient identifies their need for help	• Lack of GPs • Lack of psychiatrists • Availability of GPs • Lack of help for psychological problems • Pharmacist nearby and accommodating facilities

	(contact procedure, possibility of virtual consultations)		
ABILITY TO REACH	• Personal mobility and availability of transportation • Occupational flexibility • Knowledge to enable a person to physically reach service providers • Restricted mobility of elderly and handicapped • Inability of casual workers to be absent from work to consult providers	• Public transport provision • Particular challenges for vulnerable populations (homeless, patients living in poverty, unemployed etc) • Challenges linked to addiction itself • Presence of social workers can facilitate access	• Mobility • Availability of other profiles (e.g. psychiatrist) at the primary care centre
AFFORDABILITY	• Economic capacity for people to spend resources (€) and time to use appropriate services • Direct price of services, indirect costs (e.g. travel time and cost), opportunity costs (e.g. loss of income)	• Financial challenge for patients to invest in therapy when BZDs are cheaper • First-line psychologists improve access • Universal healthcare insurance facilitates affordability – nevertheless there is a system of out-of-pocket payments that the patient must assume.	• Cost of medication compared to cost of other treatments including alternative therapies
ABILITY TO PAY	• Capacity to generate economic resources through income, savings, borrowing or loans • Ability to pay for healthcare services without catastrophic expenditure of resources such as sale of home . Poverty, social isolation or indebtedness would be examples of factors restricting the capacity of people to be able to pay	• Role of social worker to ensure that patient's ability to pay • Particular challenge for this population due to potential indebtedness associated with drug use	• Cost of pharmacist prepared pills dependent on health insurance status (higher reimbursement for certain socio-economic groups)
APPROPRIATENESS	• Fit between services and client's needs, timeliness, amount of care spent in addressing health problems and determining correct treatment, technical and interpersonal	• The way care is established to address an SUD includes communication styles including reassurance, kindness and transparency in order to fully understand the patient's situation.	• Different policies in different institutions – hospital, psychiatrist etc • Primary care as coordinating party – to avoid unnecessary hospitalisation • Follow up that corresponds to the

	quality of services provided • Adequacy relates to the appropriateness (what services are provided) and quality (the way they are provided) - integration and continuous nature • One should not have access to healthcare based on geographical and organisational availability and affordability alone – access encompasses the possibility to choose acceptable and effective services	• Working in (multidisciplinary) networks helped professionals identify patients suffering from SUD, a lack of structured network hindered this. • Services outside the health system could also provide helpful resources • Coherent approaches between different professionals helped deal with complex problems – conversely differing approaches among professionals were challenging such as over-prescribing BZRA or abandoning patients. • Different approaches to deprescribing (harm reduction, total abstinence) offer patients choice and autonomy.	expectations of the patient • Inappropriate medicalisation of issues such as insomnia • Communication techniques
ABILITY TO ENGAGE	• Participation and involvement of the client in decision making and treatment decisions • Capacity and determination to participate in care and commit to its completion • Capacity to communicate as well as health literacy, self-efficacy, self-management • Access to optimal care ultimately requires the person to be fully engaged in care and this is seen as interacting with the nature of the service on offer.	• Holistic approach to dependence helps patients engage • Group therapy described as a useful way to help patients engage with the process of withdrawal • The connection between the patient and the therapist was considered an important element in accessibility. • Providing information for patients helped them engage with the process. • Barries identified in terms of committing to completing care due to either lack of motivation or capacity.	• Other activities outside the health issue (holistic approach) • Complementary and alternative therapies • Support of occupational therapist • Psychologist for encouragement • Self-control • Discouragement by doctor • Encouragement by doctor

Approachability

> *"We talk a lot about addiction to cannabis and alcohol, but when it comes to addiction to sleeping pills and benzos, we don't see a lot of information on television or leaflets lying around..."* (professional, RESP12)

Participants, both patients and professionals, described a general lack of information concerning the risks of dependence to BZRA – both within the context of the consultation but also at a wider society level. Though some see a change in the information being given to patients, an improvement over the years. *"It used to be taken for granted, but now you get a whole explanation. What's more, if you go to the chemist, you get this explanation again."* (professional, RESP13).

From the patient's perspective this was challenging since the lack of information was perceived to have contributed to their subsequent dependence which further complicated their trajectory. *"I repeated what the [other doctor's] assistant had told me, that benzodiazepines don't really cause dependence. And he said Ah yes, Ah right, that's nice, there you go [sarcasm]. That's when I realised that he knew. So I felt confident...* (patient, RESP18). In this case the understanding on the part of the new doctor the patient had found was met with relief that *'he knew'.* This is also echoed in the following quote : *"I think we can do a lot around prevention, you know, if you start it (preferably don't start it) and then, if you have started it, you also have to communicate the message that it's not a disaster"* (patient, RESP1). Here we see different tiers of prevention mentioned underlining the importance of acknowledging the current situation and making the best of it.

However, exploring their patient's consumption was described as difficult by professionals: *"... sometimes with velvet gloves, applied in such a way that you don't lose your client's trust."* (professional, RESP7). Misunderstanding or lack of information on the addictive nature of these molecules on the part of the patients is likely to contribute to this complex situation where patients don't realise they are dependent on the medication and professionals don't dare to probe too far for fear of putting the patient –doctor relationship in jeopardy. Professionals also identified the challenge of taboo within the issue of BZRA – the taboo of addiction leading patients to hide or deny their dependence. Moreover, the drug itself was somewhat trivialised and this challenge to find a way to draw attention to the seriousness of the issue while remaining sensitive to avoid taboo or stigmatisation. In terms of outreach, professionals referred to a fear that advertising their services would provoke unmanageable demand.

Ability to perceive

> *"The danger is that patients are often unaware of the dangers of this addiction or are in complete denial. Because it's a prescribed drug, there's this notion of need... otherwise I'll have a panic attack or I won't sleep. There's a complete lack of awareness of the paradox."* (professional, RESP17)

Perception of need for care is complex. Patients need time to realise that they are becoming, or have become, dependent on the medication, at which point it is even more difficult to stop. "*It takes a long time before it becomes a serious addiction problem. It also takes a long time to ask for help. I think it* *takes an average of ten to fifteen years before a person can talk about it (professional, RESP11).* The difficulty to fully understand the mechanism of the medication was also described by this patient who reflected on how difficult this must be for 'the average person' *"In October, not last year, but the year before, I even went from two to three milligrams of Xanax, so I didn't really understand how it worked then, otherwise I wouldn't have done it. It's only been in the last year or so that I've really understood how it works. And then I am not the average person, I have a university degree, I am reasonable, I am intelligent, I think..."* (patient, RESP1)

Professionals mention the challenge for their patients to differentiate between the medication as a treatment while understanding that it may become a problem in itself. Likewise, professionals struggle to fully evaluate consumption and describe walking a fine line between questioning their patients on their consumption and exacerbating things. "*The evaluation of consumption with patients is sometimes extremely difficult because when they see that we are a little strict on the criteria. They may go elsewhere and see doctors who are less scrupulous, or they may go medical shopping. We are not always well placed to make this assessment."* (professional, RESP21)

Here we see how freedom to choose your provider in Belgium has positive and negative connotations. While professionals fear losing their patients to unscrupulous colleagues, patients (in our sample) report positively on the ability to change providers. "*So I thought I'd better change doctors. So I phoned Dr X, from X who is younger. He's in his forties. And I explained it to him in two words." (patient, RESP18).* This patient also described how their complaints concerning withdrawal symptoms were also not fully understood by professionals. "*They say oh no, it's in you, it was underlying. Yes, yes, that's for sure... Every week, I'd have convulsions in bed, sweating like a cow, without having slept, of course (sarcasm)"* (patient, RESP18). This complexity extends to the possibility that the patient begins to view the prescriber as the source of their addiction. "*The complaint against the prescriber, that they were eh... They often saw the GP or psychiatrist who prescribed the drug as the cause of their addiction. (professional, RESP1)".* Beyond the provider patient relationship, the role of the family and friends was mentioned by the patients as helping identify the problem. *"But I didn't do it to stop. It was my son who told me 'Mum, stop taking the Xanax, please, you'll go gaga'"* (patient, RESP7).

Acceptability

> *"Because there's a whole lot of the population who would never have consulted a psychologist. And they even think that psychologists are for loonies."* (professional, RESP20)

Professionals spoke of taboo, shame and the representation by some parts of the population that mental health care was *'for loonies'.* Furthermore, the social representation associated with drug use and of mental health care was cited by several participants as a barrier for patients to access care. *"..taboo, of all the negative representations of addiction, mental health issues and drug use."* (professional, RESP18). One of the patients reflected on the acceptability of mental healthcare and how this has evolved over the years recounting how he had started to see a psychologist but had trivialized the impact of his experience when talking to the psychologist until he began to suffer from post-traumatic stress disorder. "*And so I decided, after reading about it, to take care of myself psychologically, by talking about it, trivializing my crash, talking about it all the time in such a way as* *to get rid of it until 2000 ... and in 2000, I really started to lose it. That's when I really went into post-traumatic shock"* (Patient, RESP12).

Additionally, professionals spoke of the challenges associated with the social representation, on the part of healthcare professionals, to dependence to BZRA and the breadth of reactions from taboo to trivialisation. One participant recounted the story of a pharmacist who dispenses a box of BZRA to patients without a prescription and of a GP who upon finding out that their patient had become heavily dependent on the medication they had prescribed abruptly stopped the prescription. Professionals also mentioned how some services were reluctant to take on certain members of society – effectively discriminating against certain groups, in this case prisoners: "*Well...the reluctance of many, many institutions to deal with people who are subject to the law and with people who are drug addicts, also addicted to benzo, addicted, seriously addicted ... it's frightening, it's very, very frightening. An ex-convict who also takes drugs. Frankly, it's scary [referring to the discrimination]."* (Professional, RESP20)

In reaction to this perceived discrimination some professionals indicated how, in response to the cultural challenges patients face, being accompanied, such as by social workers, while accessing services could *'open doors'. "And often, once they have the support of our colleagues or psycho-social counsellors, it opens doors. That's clear. It opens doors, which shows that there are barriers and this is undoubtedly cultural."* (Professional RESP19)

Professionals also spoke of services being over-subscribed leading to a degree of selection by providers to accept patients with 'appropriate behaviour'. "*We find access to care a bit difficult. There are enough candidates for residential care, so our clients who don't always show appropriate behaviour are not a priority for many services."* (professional, RESP3) On the other hand some professionals spoke of growing flexibility for acceptability to residential care for certain groups: "*At one point we looked at the issue of women with children... who found that they didn't have access to residential maternity homes because they were drug addicts and they didn't have access to therapeutic communities because they had a child. Here too, I mean, we really tried to open up. We also accept women with children in X."*(professional, RESP24)

Participants also spoke about acceptability of services and from the patient's perspective and how they perceived some GPs to be incompetent but that they can't find a new one because all the 'good ones' don't take anymore patients. *I don't like him... He doesn't do anything, he's a bureaucrat, He's got set hours and doesn't follow patients very well. They took a blood test that seems more than suspicious. We don't tell him anything. So here we are, trying. We'd like to find a new GP who's competent, but all the good ones in quotation marks don't take on any more patients because they're so overstretched"* (patient, RESP14). Here we see the conflict between a more modern way of practicing medicine, for example with shorter work hours, and the patient's perspective of how doctors 'should' practice.

Ability to seek

> *"It was a medical desert for a long time because I was really looking for people who could help me. And it's been pretty hard to find. And I don't find that normal. I don't*

> *think it's normal that people who are suffering psychologically can't find a centre..."*(patient, RESP4)

Patients and professionals indicated the logistical challenges patients face accessing care. That the system was difficult to understand and that patients don't know where they should go. "*Yeah, gosh, yeah, I felt like I had nowhere to turn with my problems."* (patient, RESP4) That the match between people's organisational skills and the organisation of the system was not aligned. "*Does it have anything to do with the skills of these people? In part, but it also depends on the way the help is organised, the way professional help is organised and the way it approaches people, and so on."*

This is connected to the degree of autonomy required to be able to seek the care patients need. Professionals indicated how the process was complicated (more complicated than before) including online and offline actions, particularly difficult for older people. "*In fact, you need to be able to do a lot of things yourself to receive care. You have to apply online. You have to come in for an interview. They ask a lot more - but I think that's the case everywhere...Especially older people and people who aren't very good at online things. They fall by the wayside. You used to have a connection with someone who could do it for you, but that ..."* (professional, RESP11) In addition, professionals spoke of soft skills a patient must have to access the care they need such as assertiveness. "*There's a certain degree of assertiveness. You have to be strong, you have to ask for help and you have to be a bit - I think a lot of people fall by the wayside because they don't dare or are ashamed of what an addiction is."* (professional, RESP11).

Availability and accommodation

> *"I took the phonebook and looked for a place where I could get hospital treatment, and it was very close to where I lived. I phoned up. On Monday they took me straight away, 3 days later they took me..."* (patient, RESP16)

In this theme patients and professionals paint a mixed picture of waiting lists and over-booked practitioners. The quote above is somewhat positive in terms of timeliness of care received. However, it is striking that a patient must turn to the *phone book* to seek hospital care without a referral from a primary care physician or other provider. This degree of patient isolation indicates that patients must develop their own motivation to access care which means that there are likely to be many who do not. Professionals also refer to the motivation and the need to act quickly when people suffering from SUD ask for help. *"There are indeed waiting lists and two days later, people are no longer motivated to be admitted... You need to be able to get them in immediately."* (Professional, RESP13) but also positive experiences of getting the care they, or their client, needed in a reasonable time-frame *"I had looked for a psychiatrist in July and he was- There was one free at the end of August, so 30 August there is a psychiatrist in [XX] who- I had already called him in June, July about, because he was not free until August. Those psychiatrists in the area who are only free after two, three, four months. So that was, I called all the psychiatrists like that, but again, all this was all a totally new experience for me. I have never had to go to the psychiatrist, never been in that situation before, never seen such black snow, such sword-wielding, such wicked thinking."* (patient RESP5) The quote above expresses the challenge patients experience in finding care while experiencing severe and frightening symptoms of psychological distress, in this case for the first time. This highlights the dual element of this theme –

that services must be available but must also accommodate the patients' needs at that moment. The role of the social worker emerged as an important resource to support patients in this way.

This participant, a social worker, describes how they manage challenges such as mobility and accommodate patient’s particular circumstances, for example by organising home visits or finding providers that consult on weekends. *“So we found someone who was available on Saturdays and so we put in place a psychiatrist, a GP who is now really looking after him medically and an independent psychologist with the help of the CPAS.”* (professional, RESP18) Here, the participant indicates how in addition to providing a tailored approach to their patient’s care they invoke a multi-sectoral approach by involving the CPAS to help finance the care the patient receives. There are also hidden positives associated with these work arounds – such as home visits that allow healthcare professionals to get a unique perspective into the lives of their patients that are obscured when the patient is in the clinic. *“It's also often necessary, because you can often bring a unique perspective because you get into people's homes and can often see things that aren't noticeable in a department. Like the fact that certain situations can be distressing, you don't notice it in a department. You can see how people arrive and they can tell you about it, but when you actually visit people in their homes, it's a different matter. Our psychiatrist has also chosen to make home visits from time to time, to benefit from this unique perspective.”* (professional, RESP12)

Nevertheless, despite these more positive stories, a lack of capacity in the system was also identified. In terms of a lack of beds in residential facilities : *“The network is overbooked... whether it's for residential homes or inpatient places for cures, it's hell. So yes, I can see a deterioration in the number of places and the number of people who could be cared for*”. (professional, RESP19) a lack of general practitioners and psychiatrists was also mentioned and a generational challenge of GPs unable to find replacements after retirement. *“As I was saying, access to healthcare is easy for nobody...My GP is supposed to have been retired for ten years, his wife for six years and he's staying because there's no other doctor to replace them. And that's really a big problem here in the south; a big problem. We don't have enough psychiatrists, and it takes a long time to get an appointment. It's very complicated.” (professional RESP 18).* This shortage of GPs was described as present in both rural and urban areas. *“In this urban context, it's increasingly difficult to find a GP surgery or a GP who doesn't say that he's full, that he can't take the patient, or who can only devote five or ten minutes to him, after which he's out on the street. It doesn't help.”* (professional, RESP13)

Participants mentioned territorial collaborations - working in geographically delimited networks as a feature of the current system. “*There's a good atmosphere in the province of Luxembourg. There's a mutual benevolence between the various services that means we can really work together for our population.”* (professional RESP18). For this participant this was a positive element, however for others it is time-consuming (*“We don't have the time to network and collaborate.” (professional RESP23)).* If the network was not yet fully established or integrated into the working patterns of the professionals working in that region. “*So perhaps the obstacles also lie in the interactions between the places that could provide access to care.”* (professional RESP17)

Some very simple things were also mentioned by patients as an indication of how provider can provide an accommodating environment. *“My pharmacist, who was a great support, I often went to her. I didn't know what to do all day, so I went there because there were chairs. I'd sit down and talk to her so I wouldn't be left all alone…”* (patient, RESP15).

Ability to reach

> *"... not being able to keep an appointment because someone lives on the street, has no fixed schedule, is exhausted or has had to work all night to earn money and therefore can't keep an appointment."* (professional, RESP19)

The complex lives of many patients struggling with precarity, unemployment etc was cited as a challenge for them to physically reach heath service. "*In any case, as the years go by, we're dealing with a population that is becoming increasingly marginalised. That's one thing, so we now have people who no longer have a home. We have people who are increasingly out of work."* (professional, RESP24) In addition, the challenge of limited public transport is also relevant here.

Furthermore, undocumented migrant populations were identified as encountering serious challenges reaching care due to their highly complex and unpredictable lives as well as the location of residential facilities for migrants: "*I arrived in Belgium and they put me in a very remote place. There were no trains, buses or anything."* (patient, RESP11).

This challenge was also identified as strongly linked to addiction itself and patients being too strongly intoxicated to be able to maintain appointments and little by little becoming more and more discouraged. *"On the other hand, it's also about getting there, because they're so intoxicated that it's difficult to get to appointments or they have little confidence in the treatment. They have often tried so many times and relapsed so often that they have lost the courage to do anything."* (professional, RESP12)

The presence of social support was identified as a significant positive factor for patients. "*If people still have a network of their own or family ties to which they feel attached, they also receive a certain amount of support."* (professional, RESP3) as was the integrated nature of some services, such as multi-disciplinary primary care centres (medical homes) "*I saw a psychologist at the medical centre."* (patient, RESP19)

Affordability

> *"Benzos are still cheaper than psychotherapy. So it's cheaper to buy a benzo than to go to the psychologist. It's all very well to explain that things won't get better until something is put in place on the side. It's too expensive and medication is still the cheapest option."* (professional, RESP14)

Providers and patients talk of the cost of psychotherapy and commented on the challenge in terms of comparative costs for BZRA and talking therapy. *"The financial aspect is also very important. They all say 'psychologists', but ultimately, a psychologist costs you at least seventy euros, of which now in totality you pay twenty euros, but that's still fifty euros. And the mutual insurance company who sponsor only eight sessions, so and the rest you have to- If you already go ten times, then you already spend seven hundred euros even so."* (patient, RESP5). However, they indicated how the recent investment in first line psychologists was a positive improvement in accessibility of talking therapies. *"You see, front-line psychologists, that's one major thing that has really helped, and that's affordability."* (professional, RESP15)

Participants also commented on the different funding mechanisms employed by general practitioners – fee for service and capitation and how this impacts the way they manage their patients prescribing and deprescribing. "*Ideally, they should be seen on a recurring basis. It's like taking charge. He's stopping drinking. I don't just let him go. It would be nice to see him again in 15 days. It's complicated to say that when you're paid on a fee for service basis. People always have the impression that you're trying to make money off them."* (professional, RESP14) Others described how for patients with certain statuses (giving them the right to greater intervention from their health insurance) they felt more comfortable asking those patients to come back for a follow up appointment. "*On the fact that fee-for-service work like mine, we can ... we're obliged to use direct billing to the mutual insurance companies. The people who have status (e.g. increased allowance status).. They pay one euro. So I'm no longer reluctant to ask them to come back and see me."* (professional, RESP21) Some services are free to access due to direct subsidies from regional agencies. "*It's important to know that the sessions are free. Our service is subsidised by the COCOF, so it's free and easy to access."* (professional, RESP23)

Participants also spoke positively of the Belgian health insurance system in general, and the investments made to ensure accessibility. *"Everyone is insured. If you do something, you don't go bankrupt. Even if it's your own fault, you'll still get help. There are no insurance companies that immediately exclude you for anything and everything. You don't get thrown out of the mutual if you don't take responsibility."* (professional, RESP13) Nevertheless, as the patients indicate the participation of the health insurance in care costs is not necessarily enough. *Y: "Yes, indeed and I am also fortunate and I also realise that and I am also grateful for that, that I have the intelligence and the determination and perseverance to figure that out. Also, the financial thing, me going to healing, that costs so much." X: "Is that reimbursed?" Y: "No".* (patient, RESP1)

Ability to pay

> *"In this respect, all the social work that is taken care of, that is done from the outset, facilitates access to care. Because that's the first thing, if we have people going through withdrawal at the XXXX clinic. We're already going to go and see them, and try to regularise their health insurance situation so that their stay is obviously reimbursed. If that's not the case, we'll help them apply to the CPAS..."*
> (professional, RESP24)

Ensuring that patients are able to pay for their care is one of the roles of the social worker. Professionals described how that was one of the first steps with a new patient to get their paperwork in order. Correspondingly, other healthcare professionals recognise how difficult it is for their patients to get things in order without the support of a social worker. *"I know that here, we sometimes get applications from people who don't have their insurability in order... so they have to do a lot of work to get their affairs in order before they can apply, and these are people who are quite destitute..."* (professional, RESP20)

Participants also made reference to specificities of this population in terms of potential indebtedness due to drug consumption and how this was an important consideration concerning their ability to pay. *"Financially, it's a great thing, but often these are people, as I said, who are below the poverty line. Admission costs money. Even if they get all the benefits, it's still not enough because they're often in debt from consumption. So, in all cases, the financial aspect is an important consideration."* (professional, RESP12)

The different cost experiences for patients with and without specific health insurance interventions (beneficiary of increased assistance) is perceptible in the data. One patient describes how little it cost to have small doses prepared by the pharmacist (due to his specific health insurance status. "*My pharmacy does that [small dose preparation] and I pay 30 cents or so. So it costs nothing. Now, Redomex is a very cheap medicine in itself, huh. But they have my box there, and I ask them to make thirty tablets of three mg and they do that with that medication standing there and then- All I pay for are the capsules that they have used. I don't even have to pay for the work they have done. X: Is that through increased allowance maybe? Y: Yes."* (patient, RESP3) Another patient, who appears not to have the same status, described paying for smaller doses *"X: But you do have a pharmacy that can provide you with that [smaller doses]? Y: Yes. Pharmacy [X]. They are very accommodating, and I am lucky that financially for me it is not a problem. But I can imagine for many people, if you go for a preparation and it costs you thirty or forty euros, for me okay, that's OK, that's not a problem. For someone who is already struggling and many of those benzo people are already sitting at home, may not have a job already. That is not so obvious."* (patient, RESP1) Here we see how the system is somewhat accommodating to different financial circumstances, whether this is enough, and if the fit between the needs of the population and the support provided remains to be seen. From this data we do not have a detailed enough picture. Also, since this data was collected a new scheme has started to support patients deprescribing from BZRA via reimbursed small dose preparations at the pharmacy.

Appropriateness

> *"Being reassuring with the patient also helps him or her to get over the difficult period. When the doctor says: we're going to put something in place, I'll ring you tomorrow to see how things are going, and if they're not, we'll make adjustments."*
> (professional, RESP18)

The appropriateness of care is a very complex element of accessibility because the lived experience of each patient is different. The degree to which the care offered is deemed appropriate by the patient can influence their ability to engage with their care or treatment plan. The long trajectory (as described above in the theme 'ability to perceive') and the interaction between different professionals at different moments means that patients have a variety of needs over the life-course.

Participants, both professionals and patients, expressed the need for effective communication styles, kindness, transparency, mutual respect, promoting autonomy, realism and honesty. Professionals insisted on the importance of kindness and transparency. "*I'm really attentive to transparency, to being kind to people and to maintaining a relationship of trust."* (professional, RESP18) They also spoke of how they remain transparent with the patient concerning what is shared with other healthcare professionals and that they try to empower the patient as much as possible to take control of the information shared. *"If we share something, it's always with the patient's permission. So, we always* *say, this looks like something to share with your doctor. Then we ask them to do it themselves or to do it with us. Sometimes it's done at the kitchen table. They call the doctor together...These are things they know. When we make home visits, they know that we work as a team, that we have a psychiatrist, that we have regular meetings, but they are also invited to these meetings, for example."* (professional, RESP13) Likewise, patients describe important elements of the provider patient relationship such as respect and kindness and feeling understood. *"I also respect him, it's mutual respect and a bond you build.", "Feeling understood is actually a big one too."* (patient, RESP1) They described the value of enduring relationships between patient and provider, once patients had found a good provider, they recognised the importance of the enduring relationship and were reluctant to change. "*When I go there, I always feel better. That's also why I don't plan to change or find another one as long as he keeps doing it, because I have a good one."* (patient, RESP2) This highlights the importance of relational continuity of care for patients so they have the chance to get to know their provider and vice versa. Conversely, one participant described how she hadn't really clicked with her provider but that she would persevere with the treatment.

In terms of transparency the patients expressed a need for honesty on the part of providers to properly address the issue at hand and how difficult it can be to deprescribe. *"You have to be made very aware that stopping such medication is a huge drain on your body."* (patient, RESP3) The patients and providers talked of promoting patient autonomy. *[describing an exchange with the provider] "'If you feel okay with it, then it probably works well. If you want to stop it, then we'll stop it and do a phase-out.' But he puts it a bit in my hands."* (patient, RESP2) For professionals, the autonomy of the patient to choose their own trajectory and the people they want to work with was also mentioned. *At the end of the day, it's up to the client to decide who they want to work with and who they're going to work with. And this contact, this individual, human contact, is so important."* (Professional, RESP3) Within this desire to support patient autonomy professionals also describe ethical tensions *"But with as much respect as possible for the autonomy of the individuals themselves. But this is true in many areas, around contraception, pregnancy, other psychiatric drugs and suicidal behaviour. Sometimes, unfortunately, we reserve the right to assume that this autonomy doesn't really exist at the time and that we take over a little. So ethically it's not easy."* (professional, RESP7)

The value of multi-disciplinary teams was also mentioned by professionals to promote unity concerning the objectives and transmitting the same message. *"Being supported by the other providers. And that everyone has the same message to reassure the patient, to support him, to be attentive. And that everyone agrees on the objectives."* (professional, RESP14) The participant below describes similar benefits and alludes to how much investment it is to build networks but that this investment pays off. *"The network has really enabled us to get to know each other better, to work together to,... Well, that's time and energy to devote but after 3-4 years of working together, I think we've reached a bit of a steady rhythm as we each have expertise in the field. We're really good to each other. We're in tune with what's happening in the field."* (Professional, RESP18). Conversely, multiple professionals working around the same patient but not communicating well amongst themselves was identified as a serious challenge. "*this multiplicity of caregivers. I think it's also one of the risk factors in the development of addictions, to have several people involved who don't talk to each other. Yes, but also seeing a psychiatrist on one side, a GP on the other, another specialist on the other. You could still be getting prescriptions left and right, with no one really playing a coordinating role. I'm very, very reactive to people leaving hospital with benzos, or to specialists prescribing benzos to patients they can't follow up. Yes, it's annoying, it really pisses me off."* (professional, RESP15). In this case the participant highlights the risk of developing addictions but the same lack of concertation could be a challenge during the deprescribing process.

Beyond inter-professional collaboration within the health sector professionals also spoke of the value of connecting patients with services outside it. Activities implemented as part of the social cohesion plan were identified as being a helpful resource for some patients, such as elderly or those struggling with loneliness. The impact of holistic working on patients was seen as being positive due to the complexity of the problem and the need for patients to feel supported by a team of people. *I think it's very important to approach patients in a holistic and multidisciplinary way, which is often possible in a mental health setting, because you have people who need to get over their benzo addiction, for example, and if there's still an alcohol addiction or if there's an underlying problem with depression or anxiety or a sleep problem. So yes, I think integrated care is necessary anyway to have any chance of success."* (professional, RESP8)

Ability to engage

> *Participant: I spoke to Mr X, who helped me 1,000% because it was thanks to him too. I said doctor... I was in the street, I said doctor... I'm feeling bad, I'm feeling bad... but I didn't know how to manage it, I said to him you can't take me between two clients...? Yes, yes, [he said] I will take you. And he could see I was in trouble. And the lady could see it too. I say... I'm going to take another Xanax I say... I can't take it anymore. No, no, no, no, no, no,' he said." (patient, RESP7)*

In connection with appropriateness of the care proposed is the notion of the ability to engage with that care - the capacity and determination to commit to care and to complete a treatment plan. In the context of deprescribing there is a lot of overlap with the theme appropriateness because of the long-term nature of the treatment plan proposed. Many of the points highlighted in appropriateness are therefore also applicable to ability to engage but perhaps at a later phases in the process such as the appearance of withdrawal effects or the reappearance of insomnia and anxiety. In this theme therefore we are referring more to how the system can support patients to complete the process of deprescribing fully or reducing their dose of BZRA. "*So there you have it. It involves getting back into sports, which means walking, cycling and swimming. There are self-hypnosis exercises. Sometimes I can't do it, sometimes I can. But letting go of being able to sleep is still very difficult because it's all about letting go."* (patient, RESP10) Patients and professionals mentioned the role of other activities in the patient's life as helping them to manage and overcome their addiction. "T*o go some way towards supporting the work she is going to do around her addiction in other aspects of her life."* (professional, RESP18)

Professionals refer to the 'human touch' (professional, RESP13) and a climate of 'shared understanding and trust' being important for their patients during the process. This, while maintaining a framework of control over the situation. *"I think that a climate of shared understanding and trust is necessary to be able to work in the long term while respecting a framework that I set myself and I don't want, while waiting for him to become aware [of his dependence], to throw benzos around as much as he wants."* (professional, RESP15) Notions of negotiation and collaboration were also mentioned by professionals. *“Yes, it's not just me who thinks that but we're going to reduce together... and that's when we negotiate the reduction and how we're going to operate. Therapy is a collaboration. It's a two-way process...”* (professional, RESP20)

The utility of group therapy was also described by one participant concerning the engagement of patients in their care and how the group in residential therapy can *‘Nourish hope and faith over time’* (professional, RESP24) This was also seen as a positive reinforcement by the group when they point out to their peers successes and progress. *“I think that within the group, they will point out to each other what they have achieved and their skills, and that's really important. Their new experiments sober will be recognised.”* (professional, RESP24) Likewise, the support of a group or network of professionals was also seen to be important to initiate and maintain the engagement of the patient. *“Being supported in a course of treatment by a network or a doctor”* (professional, RESP19), *“That there are several people, ... around, to feel counted and cared for.”* (professional, RESP20) Patients also expressed similar thoughts, in the following quote we also see an example of the length of time we are talking about. *“In my case, the first thing I had was medication, and then mainly occupational therapy and psychological help. I had a psychologist for 17 years” (patient, RESP16).*

Information availability was also discussed and how this reduced the incidence of secondary dependencies as well as facilitated shared –decision making. *“When they [the patients] are given information about what to watch out for and the associated risks, I have very few addictions that are secondary.” (Professional, resp. 15)*

In terms of committing to the completion of care, challenges were identified regarding access to ‘post-cure’ due either to patient motivation or lack of capacity. “*Some people undergo withdrawal cures in hospital. Ideally, they are followed by aftercare services, but often they are not. They don't go or there's no room.” (professional, RESP17)”* Similarly, this patient describes how he felt he was not followed up at the hospital so abandoned his care after three or four years. *“And my wife, at that time, tried to get me treated at hospital X... I went for... three or four years I can no longer remember. Then I realised that I wasn't getting any treatment... I wasn't being followed up, nothing at all. So I stopped going.”* (patient, RESP16). It is not clear what it was that made this patient feel he was not being sufficiently followed up, but it is interesting to note that he was sufficiently invested for three or four years before giving up.

The evolution of the relationship between healthcare professional and patient over time was also described as going further and further towards autonomy. *“I notice that at the beginning of such a process, there's a lot of work for us, but towards the end, the patient actually works harder than we do”* (professional, RESP 13)

5.4 Discussion

This paper explores the issue of accessibility to healthcare services for patients suffering from SUD to BZRAs, from the perspective of healthcare providers and patients. The results indicate the presence of many factors that map well to the different elements of the Levesque model. The deductive analysis allowed a nuanced presentation of different factors and how they fit into the rich picture of the patient and provider experience of deprescribing from BZRA. We identify multiple, complex and long trajectories among patients and diverse perspectives among professionals. Many of the known barriers came out in the results such as mobility, rural - urban differences, financial constraints, system capacity etc. In addition, factors such as communication techniques, provision of patient information, alternative therapies, inter-professional networks were also identified. In the following paragraphs we discuss the implications of these results for the Belgian context at the micro level – patient provider relationship, meso level – interprofessional networking.

Patient – provider relationship

The results presented demonstrate the importance for patients to feel reassured and informed by their provider in terms of the symptoms the experience, the process they are going through. This is in line with the literature on the subject. Authors such as Lynch et al in 2022 (Lynch et al., 2022) found similar results reflecting the findings of a meta synthesis of qualitative studies on the topic in 2017 (Sirdifield et al., 2017). Clearly, communication around the issue of BZRA, prescribing and deprescribing needs to improve but given the number of studies that conclude that providers need more training and patients need to be made more aware of the risks. Perhaps an approach that goes deeper, more to the roots of the problem is what is required. The results presented in chapters 2 and 3 present the difficulties providers experience faced with their patient' suffering and being asked to solve their problems. Problems that stem from factors far beyond their or their patients' control (such as global inflation, financial hardship, grief and childhood trauma). In the field of opioid prescribing a German study, published in 2022, identified a link between negative emotions and non-compliant behaviour following guidelines or, in other words, 'Not having negative emotions appeared to protect physicians from prescribing and patients from receiving an opioid medication that is not indicated.' (Schulte et al., 2022) A potential avenue to address this issue may be to focus on the emotional intelligence and clinical reasoning of providers to help them to better control their anxiety in the face of (perceived) patient demands that run counter to evidence-based guidelines. A similar mechanism has been identified for prescribing antibiotics, (Sergent, 2017) opioids, (Schulte et al., 2022) and unnecessary diagnostic tests (Michiels-Corsten and Donner-Banzhoff, 2018) thus such courses could provide transversal benefits to complex issues in prescribing.

Similarly, among patients at least two interesting avenues seem worth exploring. The first addressing the trivialisation of the medication as illustrated, for example, in the use of the diminutive name (alpra, zolpi, 'slapertje',… etc). Patients in this study expressed their need for honesty and transparency regarding deprescribing and the medication itself. There have been public health campaigns run by the SPF-FOD (Health Belgium, 2018) and the federal agency for medication and health products concerning the correct use of BZRA (AFMPS, 2011). These campaigns attempt to challenge the trivialisation of such medication. However, adapting societal norms and the (re)normalisation of emotions such as stress and anxiety and difficulties such as insomnia at certain moments over the life-course could also be helpful to reinforce the resilience of patients to face these problems without turning immediately to pharmacological solutions.

Fragmented care

In Belgium, as elsewhere, a major challenge for healthcare systems is the fragmentation of services which is especially difficult when things become complex for patients (Stange, 2009). The results presented in this study demonstrate the diversity of experiences and the complexity of accessing care for BZRA SUD, in part, as a result of fragmented care creating confusion for both patients and providers. Addressing fragmentation can be done by promoting integration vertically, between different levels of care, and/or horizontally, within the same level of care (Valentijn, 2013). Promoting greater horizontal integration between actors in primary care within a defined area such as a municipality or the neighbourhood of a city could be a way to improve access by providing guidance to the services (governmental and non-governmental) available in close proximity. Similar networks already exist for mental health through the 107 programme, but with mixed success due primarily to governance challenges (De Ruysscher, 2024). Ongoing efforts to strengthen primary care by structuring the meso level in Belgium through the Primary Care Zones in Flanders, the 'Bassins d'Aide et de Soins' in Brussels and the Local-Regional Organisations for health in Wallonia (Proxisanté) could be important vehicles to promote horizontal integration for this issue. By embracing complexity and taking a broad approach to health and social care patients could be put in contact, not only with appropriate healthcare providers such as psychiatrists and GPs but also social workers. These, in turn, could direct patients to the diverse services beyond the health sector such as sports or social programmes (e.g. for loneliness) that are provided by many of the municipalities in Belgium.

Macro-level interventions

Several recent macro level interventions were alluded to in our analysis. Such as first-line psychologists, financed by the RIZV-INAMI that aim to increase affordability of therapy within primary care appear to be improving access to care at community level (Willems et al., 2024) Additionally a programme also financed by the RIZV-INAMI financially supports tapering off from BZRA in collaboration with GPs and pharmacists. The latter was found to have been relatively successful with a success rate of 42% among patients enrolled. However, marked regional differences indicate that uptake to this programme is not universal. Indeed 70% of patients enrolled were from Flanders, 27 % from Wallonia and 3% from Brussels (Mutemberezi, 2024). Whereas the usage statistics indicate insignificant differences, in terms of usage of these medications, between the three regions (Sciensano, 2021). These two examples demonstrate how the macro level can support the accessibility of care in this field but that the interventions must consider regional inequalities and develop interventions that benefit the whole country.

Strengths and limitations

The topic of accessibility to care is vast, as captured by the Leveque model used in this study. Our attempt to use these ten themes to explore the process of BZRA deprescribing using qualitative data provides a nuanced presentation of the different issues at play in this complex problem. Nevertheless, some limitations should be considered. First, it is difficult to achieve a sample that covers the breadth of experiences within this issue. As the results show, many different healthcare professionals are mentioned, by both patients and professionals, as being involved in this issue. It would have been interesting to be able to broaden our sample and to interview more and different healthcare professionals to diversify the data set. This was sadly not possible given the resources available. Similarly, there are many patient trajectories present in this issue and though our sample of patients is diverse it does not fully cover the breadth of experiences. As above, it would have been interesting to be able to collect more date and broaden our scope. Second, the data collection took place in 2021 for professionals and in 2022 for patients whereas the data analysis was done in 2024. This time lag as well as the sometimes very long patient trajectories makes it difficult to apply with precision the relevance of our findings to the health system as it is organised today. Nevertheless, many of the transversal issues such as communication, inter-professional collaboration, mobility and financial accessibility remain stubbornly relevant. Third, applying a qualitative approach to this topic is helpful in terms of the details provided, however, these details and nuance can sometimes be overwhelming in the complexity they describe. The last thing we want to do is to paralyse the discussion by insisting too heavily on the complexity of the issue. These results should be followed-up by a more quantitative analysis of the state of affairs concerning the prevalence of the problem in terms of population groups and geographic prevalence – this would help policy makers to direct resources to populations and regions that need it most and tailor public health approaches to match patient needs.

5.5 Conclusion

The results presented here paint a complex picture for patients and providers to navigate the emotional, physical and structural challenges to access care for SUD to BZRA. Improving access resides in multiple actions at multiple levels to address communication, social norms, a lack of providers and capacity in the system, greater integration between services etc. However, above all, addressing access to care for SUD to BZRA is not addressing the root cause. Attention must also be turned towards preventing the first prescription for BZRA which, on a positive note, probably requires the same multi-level interventions presented above. By taking an in-depth and integrated preventative approach: primary – preventing the first prescriptions; secondary – preventing SUD to BZRA, and tertiary – implementing deprescribing; we could finally address this problem in all its complexity.

6. PRIMARY, SECONDARY AND TERTIARY PREVENTION OF LONG-TERM BENZODIAZEPINE RECEPTOR AGONISTS USE IN BELGIUM: A POLICY DELPHI

One of the study's objectives is to develop well-informed, tailored, and practical policy recommendations for addressing dependence on benzodiazepine receptor agonists. In this chapter we summarise the results of the Delphi study. Additionally, a full length report is also available on the BELSPO website (Van Ngoc, P., Scholtes, B., Anciaux, M., Desmecht, L., Pais, D., Degroote, P., Bracke, P., Belche, J-L., Ceuterick, M. (2024) The BENZOCARE Study Policy Delphi Report. Brussels : Belgian Science Policy Office 2024 – 67 p. (Federal Research Programme on Drugs.) The Delphi report offers a comprehensive overview of the policy Delphi study conducted as part of work packages 5 and 6. Within that document, we outline the methodological approach in detail, present the study's findings, and situate the recommendations within the context of existing literature. It thus serves as an in-depth analysis for those seeking to explore the recommendations from the BENZOCARE study in greater detail. It can be read independently or as a supplement to the present final report, providing additional insights and background for specific recommendations. It can be especially useful for policy makers. Furthermore, a manuscript entitled 'Primary, secondary and tertiary prevention of long-term benzodiazepine receptor agonists use in Belgium: a Policy Delphi' is currently under review with *Archives of Public Health.*

ABSTRACT

The long-term use of benzodiazepine receptor agonists (BZRAs) poses a significant public health challenge in Belgium because of the associated risks of physical and psychological dependence. Despite guidelines recommending short-term use, BZRAs are frequently prescribed beyond the recommended duration, leading to chronic use and associated harm. To address this issue, a policy Delphi study was conducted to assess targeted strategies for preventing long-term BZRA use through the lenses of primary, secondary, and tertiary prevention. The study involved a panel of experts, including healthcare professionals and patients, who participated in two rounds of questionnaires to evaluate 27 policy recommendations. These recommendations were assessed for feasibility, support, and importance, and participants were also asked whether the necessary conditions were in place to implement each recommendation. This approach aimed to identify areas of consensus and divergence among participants. Key findings reveal a strong consensus on the need for awareness campaigns aimed at healthcare professionals and the general public to highlight the risks associated with BZRA withdrawal. There was also significant support for implementing training programs to equip healthcare providers with the skills needed to manage BZRA withdrawal effectively. However, some recommendations, such as increasing remuneration for long follow-up consultations and establishing a "benzo-buddy" system, garnered less agreement, suggesting that these proposals require further refinement. This study highlights the complexity of addressing long-term BZRA use and advocates for a comprehensive, multifaceted approach. This approach should integrate education, awareness, and tailored healthcare practices to increase prevention efforts. The findings emphasise the importance of coordinated interventions across different levels of prevention to effectively mitigate long-term dependence on BZRAs in Belgium. By refining and implementing these strategies, the likelihood of achieving meaningful improvements in the management and reduction of chronic BZRA use could be significantly increased, contributing to better public health outcomes.

6.1 Introduction

Owing to their adverse effects, the long-term use of benzodiazepine receptor agonists (BZRAs) represents a significant public health concern. These drugs are primarily employed for their anxiolytic and sedative properties. However, their use can result in both short- and long-term adverse effects, including physical and psychological dependence, dizziness, an increased risk of falls, drowsiness, road accidents, and withdrawal difficulties (Lader, 1999, 2011, 2014). Therefore, guidelines in Belgium recommend that these medications be prescribed for very short periods ranging from 1-4 weeks at the smallest possible dose and as a last resort (Centre Belge d'Informations Pharmacothérapeutique, n.d.). Nevertheless, these drugs are widely prescribed and are often used beyond the recommended duration. In fact, a Belgian report showed that the duration of prescriptions was longer than what is recommended in the guidelines, with 67% of participants having been using them for more than 1 year (Kiridis et al., 2022).

In this context, the prevention of long-term use of BZRAs becomes crucial and requires a structured, multilevel approach. The concepts of primary, secondary, and tertiary prevention, first articulated by Leavell and Clark (Leavell and Clark, 1953), provide a foundational framework for addressing health issues at different stages. Primary prevention concentrates on preventing the initial onset of disease by addressing risk factors and promoting healthy behaviours. Secondary prevention aims to identify and treat emerging health problems at an early stage. Tertiary prevention involves action taken after the onset of a disease to minimise complications, prevent further deterioration and improve the quality of life of those affected. When applied to long-term use of BZRAs, primary prevention seeks to avoid unnecessary initial prescriptions, secondary prevention focuses on identifying and reducing long-term use, and tertiary prevention aims to minimise harm in chronic users. These levels of prevention necessitate both specific and coordinated interventions in terms of public health policy and clinical practice.

In Belgium, several policies have been implemented in recent years to address the problem of BZRA use. These policies range from information for patients and the general public, training courses for clinicians and, more recently, a reimbursement programme to help patients taper off the medication. This pilot program launched in February 2023 aimed at reimbursing compounded BZRA preparations for patients undergoing withdrawal (Centre Belge d'Informations Pharmacothérapeutique, 2023; Institut national d'assurance maladie-invalidité, n.d.).

In recent years, Belgium has also undertaken campaigns to prevent the long-term use of BZRAs among both patients and healthcare professionals (Service Public Fédéral, 2018). A systematic review highlighted that effective public health campaigns need to be well targeted, clearly communicated, and sustained over time to bring about meaningful behavioral change (Ranjbar et al., 2017). Some studies have demonstrated that awareness campaigns on medicine use have had limited impacts (Giordano et al., 2013; McNulty et al., 2010; Ranjbar et al., 2017), particularly those conducted through social media, which often focus on immediate engagement rather than long-term behavioral change (Ghahramani et al., 2022). This underscores the importance of a multilevel approach that incorporates primary, secondary, and tertiary prevention strategies with an evaluation of the impact of these strategies and, furthermore, is adapted to the population it is intended to serve. This article explores various prevention strategies in the context of long-term benzodiazepine receptor agonist use in Belgium, utilising a policy Delphi method to assess and recommend further preventive actions. This approach allows us to explore the opinions of patients, health care professionals and policy-makers familiar with the Belgian context to formulate practical recommendations tailored to Belgium. Our research question is as follows: how can primary, secondary, and tertiary prevention of long-term BZRA use be improved under the current circumstances in Belgium?

6.2 Method

To answer this question, a policy Delphi was carried out to establish policy recommendations adapted to current Belgian circumstances. In contrast to the conventional Delphi method, which aims to achieve consensus, the policy Delphi method is intended to uncover the most divergent perspectives and examine a broad spectrum of policy options (de Loë et al., 2016). This methodology was used to give equal voice to the patients taking part in the study. The policy Delphi was developed in four phases.

Initial compilations and classifications of recommendations

Initially, interviews were conducted with a sample of healthcare professionals (N=24) and patients who had either taken or were currently taking BZRA (N=19). From these interviews, the research team (PV, MC, and BS) identified 20 initial policy recommendations. These recommendations underwent thorough discussion and revision within the team to ensure accuracy in their formulation. Each recommendation was then categorised according to prevention tiers via the following definitions (Leavell and Clark, 1953):

1. Primary prevention involves strategies aimed at preventing healthy individuals from starting BZRA use by targeting at-risk populations and promoting alternative treatments.

2. Secondary prevention focuses on early detection and intervention to stop the development of long-term BZRA use. Our study included efforts to prevent patients from moving from short-term BZRA prescription to chronic use.

3. Tertiary prevention typically involves rehabilitation; in our study, it involves strategies to reduce and discontinue long-term BZRA use safely while managing any negative effects that may result from prolonged usage.

First round of online Delphi panel

The first round took place over two weeks in March 2023 with an online questionnaire via the LimeSurvey platform. In this first round, the participants completed the online questionnaire. The participants were asked to evaluate (1) the feasibility, (2) the extent to which they supported each recommendation and (3) the importance they addressed to the recommendation for each recommendation. Feasibility, support and importance were assessed via a five-point Likert scale ranging from ‘completely disagree’ to ‘completely agree’ for the categories ‘feasibility’ and ‘support’ and from ‘unimportant’ to ‘very important’ for the category ‘importance’. The response scales were presented in ascending order to avoid inflated data, acquiescence bias and social desirability bias (the tendency of some respondents to agree with statements or choose positive answers) (Chyung et al., 2018). The feasibility and importance scales were adjusted from Turoff (Turoff, 1970), adding a fifth option, ‘neither agree nor disagree’, in line with Meskell et al. in 2014 (Meskell et al., 2014). The scale to measure support was developed in a similar manner. At the end of the questionnaire, the participants had the opportunity to add additional recommendations in an open text box.

Analysis of additional recommendations

The ideas for new policy recommendations put forward by the participants in the first round were analysed by the team of researchers (BS, MC and PV) to merge the common ideas and remove the elements that were not coherent. This resulted in seven additional policy recommendations, which were compiled and incorporated into the existing set of 20 recommendations.

Round 2 of online Delphi panel

The second round took place over two weeks in April 2023 with an online questionnaire via the LimeSurvey platform. In this second round, 62 participants completed the online questionnaire. During this round, the seven new recommendations that were proposed by participants in the first round were evaluated in terms of (1) feasibility, (2) the extent to which participants supported each recommendation and (3) the importance they assigned to the recommendation. Similarly, in the first round, feasibility, support and importance were assessed via a five-point Likert scale ranging from ‘completely disagree’ to ‘completely agree’ for the categories ‘feasibility’ and ‘support’ and from ‘unimportant’ to ‘very important’ for the category ‘importance’. A small information box was included to explain the meaning of the importance scale (Turoff, 1970).

Additionally, for all 27 recommendations, participants were asked if conditions were met to implement each recommendation with multiple choices: ‘yes’, ‘I don’t know’ and ‘no’. Finally, they were asked to prioritise each recommendation classified per tier of prevention (primary-secondary-tertiary prevention). The participants were asked to select three recommendations among each level of prevention and to rank them in order of importance for implementation given the current circumstances in Belgium.

Recruitment

An expert panel consisting of healthcare professionals and patients was assembled for the Policy Delphi study via various recruitment strategies. These included a call for participants at a Belgian healthcare conference and the distribution of flyers within the research team's network and through the project’s follow-up committee of stakeholders. Interested individuals were invited to express their initial interest and provide contact information through an online registration form.

6.3 Results

Panel characteristics

The policy Delphi panel included 65.8% health professionals, 28.8% patients, and 5.4% considered themselves both. The majority were female (69.4%), aged mainly between 18 and 60 years. Geographically, 21.6% were from Brussels, 53.2% were from Flanders, and 25.2% were from Wallonia. Among professionals, various specialties were represented, with most having 0-10 years of experience. Patients had diverse employment statuses. In terms of their experiences with BZRA, 50% had stopped taking BZRA. Table 7 shows the sociodemographic data of the expert panel. In the first round, 111 people took part in the online questionnaire. In the second round, 62 participants completed the questionnaire. The response rate was 100% for the first round and 55.85% for the second round.

The study yielded 27 policy recommendations, as shown in table 8, categorised and aligned within three tiers of prevention.

Table 7 Sociodemographic characteristics of participants Delphi panel

		N	**%**
Responding as	Patient	32	28,8
	Professional	73	65,8
	Both	6	5,4
Gender	Female	77	69,4
	Male	34	30,6
Age	18-40	46	41,4
	41-60	50	45,0
	>60	15	13,6
Regions	Brussels	24	21,6
	Flanders	59	53,2
	Wallonia	28	25,2
Current professions among participants responding as professionals or as a professional who has taken or is taking BZRA	General Practitioners	23	29,1
	Nurse	1	1,3
	Pharmacists	18	22,8
	Psychiatrists	8	10,1
	Psychologists	12	15,2
	Social workers	3	3,8
	Other	14	17,7
Years of experience	Between 0 – 10 years	27	34,2
	Between 11 – 20 years	24	30,4
	Between 21- 30 years	16	20,3
	> 30 years	12	15,2
Current occupation among participants responding as patient	Student	2	6,3
	Unemployed	2	6,3
	Worker	5	15,6
	On sick leave	9	28,1
	Retired	3	9,4
	Other	11	34,4
Current BZRA use among professionals and patients	Using 1 or more BZRA for the long term	6	15,8
	In the process of tapering off ≥1 BZRA	5	13,2
	Completely tapered off ≥1 BZRA	19	50,0
	Other	8	21,1

Table 8 Overview of the 27 recommendations

Primary prevention	
1	Implementing an awareness raising campaign among the general public on tapering off BZRA.
2	Implementing an awareness raising campaign for patients on the challenges of withdrawing BZRA from multiple medications.
3	Implementing an awareness raising campaign for professionals on the challenges of withdrawing from multiple medications.
4	Implementing an awareness raising campaign of the risks of BZRA in empathetic and non-stigmatising way.
5	Adding warnings of the risk of dependence on the BZRA package.
6	Undertake further research on the mechanisms surrounding the first prescription of BZRA.
Secondary prevention	
7	Increase the price per BZRA package.
8	Create smaller packages of BZRA.
9	Provide information by the prescriber to the patient regarding the risks of dependency of BZRA at first use.
10	Provide higher remuneration for prescribers for long follow up consultations dedicated to BZRA.
11	Give access to other BZRA prescribers/providers to the part of the medical file related to prescriptions.
12	Allow the carer to dispense one or two doses of BZRA at the same time to provide the correct dose.
Tertiary prevention	
13	Encourage prescribers to add the indication for substance use disorders next to insomnia/anxiety to patient records when use exceeds guidelines.
14	Establish an agreement between the prescriber, the pharmacist and the patient to keep the same prescriber and pharmacist throughout treatment.
15	Creating a shared policy position between different professionals groups in addiction care concerning the management of BZRA.
16	Create an inter-professional communication channel at local level, between pharmacists and GPs to discuss common patients
17	Implementing a training course on difficult tapering-off processes related to BZRA for professionals.
18	Establish and providing a list of healthcare providers specialised in tapering off of BZRA.
19	Establish a support and advice line for people who want to taper off of BZRA.
20	Develop a 'Benzo-buddy' system.
21	Share patient testimonials about BZRA tapering-off.
22	Develop culturally appropriate patient materials.
23	Create an ombudsperson for healthcare practitioners to report other practitioners who over-prescribe, prescribe or delivered unsafely BZRA.
24	Extend the patient inclusion criteria of the new reimbursement scheme for the compounding of smaller doses of BZRA to residents living in nursing homes.
25	Extend the patient inclusion criteria of the new reimbursement scheme for the compounding of smaller doses of BZRA to patients who are taking more than one type of BZRA.
26	Offer group therapy to ambulant patients to support the tapering off process.
27	Tailor residential addiction care programmes, specifically to BZRA withdrawal.

Level of consensus

Among the recommendations, a level of consensus was established according to Meskell et al. (Meskell et al., 2014) to explore the diversity of agreements and disagreements among the panel of experts in the first and second rounds. To analyse the results, graphs were produced showing the percentage of responses in each response option for each recommendation in terms of its feasibility, the extent to which participants supported each recommendation, the importance they assigned to the recommendation and whether conditions were met to implement each recommendation.

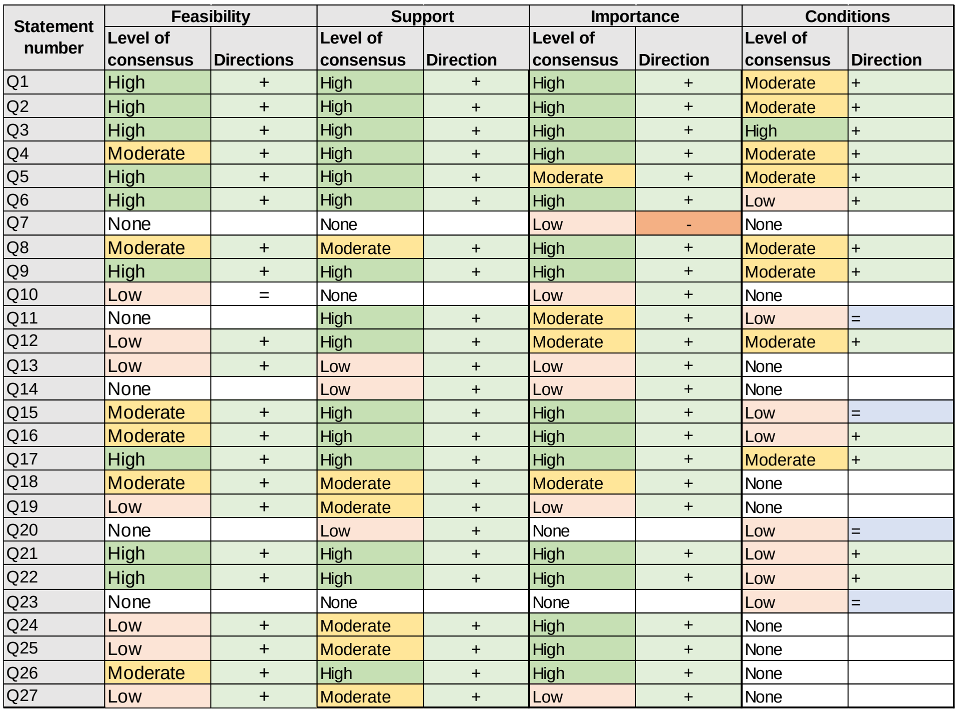
The level of consensus was then calculated and classified using a 4-point scale of high, moderate, low and none (see table 9). The level of consensus is defined by the percentage of agreement within a response option on the basis of the Likert scale proposed for each category (feasibility, support, importance, or conditions). For example, "high," a consensus occurs when a minimum of 70% agreement is attained for the same response option.

Table 9 Level of consensus and direction

Level of consensus for feasiblity and support columns	
Categorisation of the percentages of agreement in each category of the scale.	
High consensus	≥ 70% in completely agree or completely disagree or agree or disagree or neither agree nor disagree
	≥ 80% in completely agree and agree; disagree and completely disagree
Moderate consensus	≥ 60% in completely agree or completely disagree or agree or disagree or neither agree nor disagree
	≥ 70% in completely agree and agree; disagree and completely disagree
Low consensus	≥ 50% in completely agree or completely disagree or agree or disagree or neither agree nor disagree
	≥ 60% in completely agree and agree; disagree and completely disagree

Level of consensus for importance column	
Categorisation of the percentages of agreement in each category of the scale.	
High consensus	≥ 70% in important or very important or slightly important or unimportant or neither important nor unimportant
	≥ 80% in very important and important; slightly important and unimportant
Moderate consensus	≥ 60% in very important or important or slightly important or unimportant or neither important nor unimportant
	≥ 70% in very important and important; slightly important and unimportant
Low consensus	≥ 50% in very important or important or slightly important or unimportant or neither important nor unimportant
	≥ 60% in very important and important; slightly important and unimportant

Direction of consensus		
The direction of consensus indicates the prevailing opinion on the statement, whether in favour or not.		
Direction of consensus	+	In favour
	-	Not in favour
	=	Consensus in the "neither agree nor disagree" category



Statement number	Feasibility		Support		Importance		Conditions	
	Level of consensus	Directions	Level of consensus	Direction	Level of consensus	Direction	Level of consensus	Direction
Q1	High	+	High	+	High	+	Moderate	+
Q2	High	+	High	+	High	+	Moderate	+
Q3	High	+	High	+	High	+	High	+
Q4	Moderate	+	High	+	High	+	Moderate	+
Q5	High	+	High	+	Moderate	+	Moderate	+
Q6	High	+	High	+	High	+	Low	+
Q7	None		None		Low	-	None	
Q8	Moderate	+	Moderate	+	High	+	Moderate	+
Q9	High	+	High	+	High	+	Moderate	+
Q10	Low	=	None		Low	+	None	
Q11	None		High	+	Moderate	+	Low	=
Q12	Low	+	High	+	Moderate	+	Moderate	+
Q13	Low	+	Low	+	Low	+	None	
Q14	None		Low	+	Low	+	None	
Q15	Moderate	+	High	+	High	+	Low	=
Q16	Moderate	+	High	+	High	+	Low	+
Q17	High	+	High	+	High	+	Moderate	+
Q18	Moderate	+	Moderate	+	Moderate	+	None	
Q19	Low	+	Moderate	+	Low	+	None	
Q20	None		Low	+	None		Low	=
Q21	High	+	High	+	High	+	Low	+
Q22	High	+	High	+	High	+	Low	+
Q23	None		None		None		Low	=
Q24	Low	+	Moderate	+	High	+	None	
Q25	Low	+	Moderate	+	High	+	None	
Q26	Moderate	+	High	+	High	+	None	
Q27	Low	+	Moderate	+	Low	+	None	

High consensus

Of the 27 recommendations, only one, recommendation 3 (*for the implementation of an awareness-raising campaign for professionals on the challenges of withdrawing from multiple (psychotropic)* *medications*), was evaluated with a high level of consensus in terms of its feasibility, support, importance and necessary conditions.

Other recommendations have high levels of consensus, with three categories among the categories of ‘feasibility’, ‘support’, ‘importance’ and ‘conditions’, which have a high level of consensus, and only one is considered moderate. These are the following recommendations: 1 'Implement an awareness raising campaign among the general public on tapering off BZRA’; number two, ‘Implement an awareness raising campaign for patients on the challenges of withdrawing BZRA from multiple medications’; number 9, ‘Provide information by the prescriber to the patient regarding the risks of dependency of BZRA at first use’; and number 17, ‘Implement a training course on difficult tapering-off processes related to BZRA for professionals’.

Moderate level of consensus

No recommendation was assessed as having a moderate level of consensus for all 4 categories. Among the recommendations that had moderate consensus in three of the categories, 8 ‘Create smaller packages’ and 18 ‘Establish and provide a list of local healthcare providers trained in tapering off BZRA for healthcare providers and patients’ are recommended. For the recommendations that had 2 categories that were evaluated as a moderate level of consensus, recommendation 4 ‘implement an awareness raising campaign on the risks of BZRA in an empathetic and non-stigmatising way’, recommendation 5 ‘Add warnings of the risks of dependence on packages’ and recommendation 12 ‘Allow the carer to dispense one or two doses of BZRA at a time to provide the correct dose’.

Low level of consensus

Among the recommendations that were evaluated with a low level of consensus, no recommendation was evaluated with a low consensus for all categories. One recommendation obtained a low level of consensus for 3 categories. This is recommendation 13 ‘encourage prescribers to add the indication for substance use disorders alongside insomnia/anxiety to patient records when use exceeds guidelines’. Among the other recommendations, which have a low level of consensus for two of the four categories, are recommendation 10 'Provide higher remuneration for prescribers for long follow-up consultations dedicated to BZRA', recommendation 14 'Establish an agreement between the prescriber, pharmacist, and patient to keep the same prescriber and pharmacist throughout treatment, recommendation 19 'Establish a support and advice line for people who want to taper off from BZRA', recommendation 20 'Develop the 'benzo-buddy system' and recommendation 27 'Tailoring specific residential addiction programs to BZRA'.

No consensus

None of the recommendations were evaluated with zero consensus in all 4 categories. Some had 3 categories with no consensus: recommendation 7 'Increase the price per package' and recommendation 23 'Create an ombudsperson for healthcare practitioners to report other practitioners who overprescribe or deliver unsafely'. There are also recommendations with 2 categories assessed as having no consensus, but the participants were nonetheless in favour of these recommendations, namely, recommendation 10 'Provide higher remuneration for prescribers for long follow-up consultations', recommendation 14 'Establish agreement between prescriber, pharmacists and patients to keep the same prescriber and pharmacists throughout the treatment' and recommendation 20 'Develop the benzo-buddy system'.

Direction of consensus

The direction of the consensus was assessed to indicate whether the consensus was in favour, against or without taking a position (see table 9). There is a direction of consensus only if the level of consensus is high, moderate or low. With respect to the 'feasibility' category, all recommendations with a high, moderate or low level of consensus are included as being in favour of the recommendation, with the exception of recommendation 10, ‘Provide higher remuneration for prescribers for long follow-up consultations’, where the consensus is at the level of the 'neither agree nor disagree' response option.

For the 'support' category, all the recommendations are considered favourable. For the 'importance' category, all are considered favourable, except recommendation 7 'Increase the price per BZRA package'. For the 'conditions' category, the assessments are favourable to the recommendation, with 4 recommendations where the consensus is in the 'do not know' category.

Prioritisation of recommendations per level of prevention

The participants were invited to select and rank the most important recommendations to implement in the current circumstances. Among the class recommendations at the primary prevention level, recommendation 4, ‘Implementing an awareness raising campaign of the risks of BZRA in an empathetic and non-stigmatising way’, was cited 22 times in the first position. For secondary prevention, recommendation 9, ‘Provide information by the prescriber to the patient regarding the risks of dependency of BZRA at first use’, was cited 22 times. For tertiary prevention, recommendation 17, ‘Implementing a training course on difficult tapering off processes related to BZRA for professionals’, was cited 11 times.

6.4 Discussion

Twenty-seven policy recommendations were evaluated on the basis of their feasibility, support, importance, and conditions required for implementation. Among them, only one recommendation, which focused on raising awareness among professionals about the challenges of withdrawing from multiple psychotropic medications, achieved a high level of consensus across all evaluation categories. Other recommendations, such as those aimed at public awareness, patient education, and professional training, also garnered strong consensus in most categories, while some showed varying degrees of agreement, with certain recommendations reaching only moderate or low consensus across different areas, indicating, for example, high support but low feasibility due to a lack of necessary conditions present.

Awareness-raising campaigns are generally considered to be feasible, supported, important and necessary. These findings may indicate that participants feel that these types of campaigns are underutilised in Belgium. Indeed, several studies on public health campaigns specifically about medicine use awareness have shown a significant effect of public health campaigns on medication adherence and medicine knowledge. However, while awareness campaigns aim to influence public health behaviour, it is important to recognise that a single message may not be suitable for a diverse population (Wakefield et al., 2010). To achieve this, it is important that the campaign message is clear and tailored to the target group (Gupta et al., 2016; Huang et al., 2006; Ranjbar et al., 2017; Shen et al., 2006; Wen et al., 2007). To enhance their effectiveness, it is crucial to adopt a comprehensive approach that ensures sufficient funding, incorporates various intervention strategies, conducts thorough research and testing and evaluation of campaign messages tailored to specific audiences, and provides access to supportive services and policies (Wakefield et al., 2010). In addition, while social media can improve the reach and engagement of health promotion efforts, their impact on long-term behaviour change remains uncertain, highlighting the need for more robust methodologies to measure sustainable outcomes (Ghahramani et al., 2022).

Given the importance of tailoring awareness campaigns to diverse populations, ensuring that these campaigns are non-stigmatising is equally important, especially when sensitive issues such as BZRA withdrawal are addressed. Stigma, particularly in the context of substance use, can significantly hinder individuals from seeking help and accessing treatment. Research highlights that the language used in public health messaging plays a vital role in either perpetuating or reducing stigma. For instance, terms such as "substance abusers" can evoke punitive attitudes and reinforce negative stereotypes, whereas person-first languages, such as "individuals with a substance use disorder," help promote more empathetic and supportive public perceptions (Zwick et al., 2020). Therefore, any campaign designed to address BZRA withdrawal should prioritise non-stigmatising language and narratives that emphasise support, recovery, and understanding rather than blame or judgement.

Furthermore, our study demonstrates a high level of consensus on the importance of prescribers providing information to patients about the risks of dependency associated with first use. This finding aligns with results from another study that highlighted that patients receiving their first prescription for BZRA are often unaware of the potential risks and rarely ask for additional information, relying instead on the trust they place in their physicians (Anthierens et al., 2007). This lack of awareness, coupled with patients' ambiguous feelings about using such medications, underscores the need for prescribers to proactively communicate the risks and benefits from the outset (Anthierens et al., 2007). By setting clear expectations and discussing potential dependency issues early, prescribers can play a crucial role in preventing unintentional long-term use (Anthierens et al., 2007). Additionally, another study underscores the importance of the physician's role in shaping patient attitudes, particularly among patients with little experience with the medication, who are more influenced by their prescriber's perceived norms. This highlights the need for careful consideration of how prescribers' attitudes and advice may impact patients’ medication behaviour and long-term use, ensuring that patients are better equipped to make informed decisions about their treatment (Van Hulten et al., 2003).

Our results also support the implementation of a training program for professionals on the challenges of BZRA withdrawal. These recommendations received strong consensus regarding their feasibility, support, and importance, with participants expressing their approval. In Belgium, several e-learning initiatives on BZRA have already been launched, including the Federal Public Service (SPF) (Service Public Fédéral, n.d.), which focuses on patient complaints and nonpharmacological approaches. Additionally, the Belgian Centre for Pharmacotherapeutic Information (CBIP) (Centre Belge d’Informations Pharmacothérapeutique, 2024) has introduced a specific training course on benzodiazepine withdrawal for pharmacists and doctors as part of a broader campaign promoting the responsible use of psychotropic drugs. The recommendation for additional training on benzodiazepine withdrawal, despite existing programs in Belgium, may highlight the need for more comprehensive support for healthcare professionals, ensuring that they are well equipped with up-to-date knowledge, practical skills, and tailored guidance to effectively assist patients through the withdrawal process. This finding may also indicate dissatisfaction with the current training courses offered.

On the other hand, certain policy recommendations were characterised by a low level of consensus, such as those aimed at better remunerating prescribers for long follow-up consultations; encouraging prescribers to add the indication for substance use disorders to the record; establishing a tripartite agreement to keep the same prescriber and pharmacist; and developing a ‘benzo-buddy’ system, which is the subject of low consensus in multiple categories, including feasibility, support, importance and conditions. However, insights from studies suggest that adopting a more patient-centered approach, particularly through shared decision-making and the collaborative definition of treatment goals (Mokhar et al., 2018; Van Ngoc et al., 2023), could enhance the effectiveness and acceptance of such strategies. They emphasise the importance of aligning treatment plans with patient expectations and needs, which may address some of the concerns that led to the lower levels of support observed in our study (Mokhar et al., 2018; Van Ngoc et al., 2023).

In addition, other recommendations, such as increasing the price of BZRA packaging, received low consensus, and participants were in disfavour of this recommendation. Creating an ombudsperson for healthcare practitioners to report unsafe practices is a source of debate among the participants. There was no consensus on feasibility, importance or support, and participants did not take a position in favour or in disfavour. The prioritised implementation of highly consensual recommendations is advisable, given their broad support and feasibility, whereas the less consensual recommendations may require further review and modification to address concerns regarding their feasibility, support, importance, and necessary conditions. It is also important to be able to bring forward recommendations that may not have had a high level of consensus but that stand out because of their originality, which means that they are less obvious to implement but could be just as effective and inspiring.

6.5 Strengths and limitations

This study has several strengths that contribute to the robustness and relevance of its findings. First, the use of the policy Delphi method allowed for the inclusion of diverse perspectives from both healthcare professionals and patients, which enhanced the comprehensiveness of the policy recommendations. This method also facilitated the identification of areas of consensus and disagreement, providing a nuanced understanding of the complex issue of long-term BZRA use. Additionally, the study's multilevel approach, which focuses on primary, secondary, and tertiary prevention, ensures that the recommendations are well rounded and address the problem from multiple angles.

However, the study also has several limitations. The response rate decreased between the first and second rounds of the Delphi process, which may have impacted the overall consensus and representativeness of the findings. The self-selected sample could also introduce bias, as those with strong opinions or experiences related to BZRA use might be overrepresented.

6.6 Conclusion

The diversity of recommendations and the levels of consensus underscore the complexity of addressing long-term BZRA use in Belgium. Nevertheless, developing a comprehensive approach that includes education, raising awareness, and training in healthcare practices seems feasible and well supported by the community. This includes raising public awareness to inform and educate patients, ensuring that healthcare providers are adequately trained to manage and support patients through withdrawal, and creating a supportive healthcare environment where informed decisions are encouraged and facilitated. To make significant improvements, it is essential to integrate multiple strategies that collectively address different aspects of the issue (including structural elements such as package size). Employing concepts from implementation science, such as the behaviour change wheel and the theoretical domain framework, to carefully structure public health interventions is an important avenue to explore in Belgium (Michie et al., 2005). By adopting a multifaceted approach and gaining a better understanding of the facilitators and barriers that influence behaviour change around the issue of BZRA through the use of the Theoretical Domains Framework, we will be better equipped to identify, prioritise, and implement future policy strategies.

7 DISSEMINATION: THE BENZOCARE PODCAST

7.1 Why a podcast?

At the start of the project we envisioned to create a podcast to disseminate the results of the study to a broad audience of patients and health care providers, as well as people who are not familiar with BZRA (yet), in Belgium. The goals of this podcast are threefold: 1) to inform the general public about BZRA, 2) to raise awareness on (de)prescribing and tapering off from BZRA and 3) to reduce the stigma that patients and providers might experience when (de)prescribing this medication. Hence, we planned to create a podcast miniseries in both French and Dutch, which captures the perspective of someone who has tapered off from BZRA, and from a health care professional with experience in (de)prescribing.

7.2 The creation process

We collaborated with a professional partner for the creation and production of the podcast: https://lesvisions.com/ and https://lvdt-studio.com/accueil/). We schematically present the flow of the process in table 10.

Table 10 Steps in the creation of the podcast

Steps	Description
1. Workshop storytelling	September 30 2024: a first (digital) storytelling workshop (attended by members of each partner institution) to create a storyline for the recording of the podcast episodes + creation of a topic guide to structure the discussion during the recordings, translated into French and Dutch.
2. Recordings	October 8 2024: French episodes at ULiège studios October 30 2024: Dutch episodes at UGent studios
3. Rushes review	After the recordings, the team listened to the recorded discussions and indicated the segments they wanted to keep. Afterwards the podcast maker created a 'rough cut' of these fragments for feedback.
4. Workshop voiceovers	After providing feedback on the 'rough cut', the edit is used for writing the voiceovers. The voiceovers are created together in a workshop with the podcast maker.
5. Voice coaching and recording of voice-overs	December 3 2024: recording of voice overs in French and Dutch at lvdt studios in Liège, with the team
6. Finalisation	Sound Design, Mixing, and Mastering, sending of final edit with voiceovers for validation and delivery of final audio

Figure 6 Podcast artwork (designed by Octavia Roodt)

The podcast can be accessed here: https://urls.fr/JQJiL1 or by scanning this QR-code:

8 CONCLUSION

Long-term use of BZRA is a so-called wicked problem. It begins with the hidden contrast between the initial efficacy of the medication, which soon turns, almost unnoticed, into side effects that mirror the initial symptoms for which the medication was prescribed. As reflected in patients' medication histories (in Chapter 4), these symptoms of insomnia and anxiety are generally just the figurative tip of an iceberg of underlying problems that are often more systemic and therefore beyond the reach of individual practitioners and prescribers. As a result, however, the latter often feel compelled to prescribe (albeit to varying degrees). This explains the continuing role of BZRA in clinical practice (as outlined in Chapter 3). On the other hand, deprescribing, as discussed in Chapter 4, poses a whole new set of challenges for patients who struggle with physical, mental and practical difficulties along the way. Professionals, in turn, struggle with diagnosing dependence, motivation and follow-up (as shown in Chapter 2). Chapter 5 further describes the various possible hurdles that patients and providers often have to overcome at multiple levels (intrapersonal, interpersonal, and organisational) before they are able to achieve actual goal-directed care in de-prescribing. The recommendations that emerge from these findings (and that are described in Chapter 6 and in detail in a separate report on the policy Delphi) are therefore necessarily complex, nuanced, and multilevel. They range from preventing the first prescription (primary), over preventing a potential first prescription from developing into long-term use (secondary), to tackling actual habitual use (tertiary prevention). Finally, by disseminating our findings through a bilingual podcast series, in which patients with tapering experiences, go into a constructive dialogue with prescribers, we aim to tick the box of raising public awareness.

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10 ANNEXES

10.1 ANNEX 1 INTERVIEW TOPIC GUIDE (PROFESSIONALS-WP3)

BEFORE THE INTERVIEW The pre-interview phase will take place via phone or email prior to the interview; if this is not possible, it can also be asked during the interview as a warm-up. This allows the interview guide to be adjusted in advance to the profile of the interviewee.	
1. Some statistics about your role/practice	1.1. Where do you work? What kind of practice/organisation? 1.2. Can you briefly describe your function? 1.3. For how many patients are you responsible? 1.4. What is the socioeconomic situation of your patients, in your opinion? 1.5. Do your work in a rural or urban setting? 1.6. What kind of patients with a SUD to BZRA do you generally see in your (clinical) practice?
INTERVIEW PART I: MICRO At the beginning of the interview, the researcher summarizes what was discussed during the pre-interview to check if she has understood all the information correctly.	
2. Conceptualisation and diagnosis of a BZRA related dependency/use disorder/addiction	2.1 **PRESCRIBER:** How do you determine that a patient is dependent on BZRA? **NON-PRESCRIBER:** How do you recognise that a patient is dependent on BZRA? 2.2 How do you define a dependency/addiction/SUD related to BZRA 2.3 Which criteria do you use? Probes: length of dependence, dose,… 2.4 How does this differ from diagnosing other forms of substance use (such as alcohol)? 2.5 **PRESCRIBER:** Do you involve other colleagues or professionals in making this diagnosis? **NON-PRESCRIBER:** Do you share this information with other professionals? Probes: Who? In what way? (phone, letter, sharing medical files, multidisciplinary meetings,...)
3. Patients with a BZRA related dependency/use disorder/addiction	3.1 If any, what is the typical profile of a patient with a BZRA related dependency/use disorder/addiction (age, gender, background,…) 3.2 What does a standard/typical trajectory look like? How do these patients typically develop a BZRA related dependency/use disorder/addiction? 3.3 How many clients/patients have a BZRA SUD/dependence? 3.4 How many clients/patients do you treat for a BZRA SUD/dependence? 3.5 Do you have many patients with multiple dependencies? Which kinds are these usually? 3.6 Do you treat many patients who also have psychological complaints/problems, besides their SUD? What are these complaints typically?
4. Treatment	4.1 How do you usually treat a dependence on BRZA?

	4.2 What is your role in the treatment of patients with a BZRA related SUD? What is your role compared to those of other professionals? 4.3 How do you address this issue with patients/clients? Probes: *Goal-oriented care*? Shared decision making? Psycho education? 4.4 Do you fin dit difficult to address this problem with patients? 4.5 What is it that you find difficult? What hinders? 4.6 What encourages? **4.6 - 4.8 only for PRESCRIBERS** 4.7 How do you usually work? Probes: gradual taper, substitution medication, maintenance therapy, therapy Onderhoudstherapie? Therapie? 4.8 How do you choose between those options? What influences that choice? Probes: Physical/ psychological/social/familial situation of patient 4.9 What are the advantages and disadvantages of these treatment options?
5. Vision on treatment	5.1 What does a treatment usually look like? 5.2 Which goals do you usually set? Probes: Total abstinence? Harm reduction? 5.3 In which cases is that not the goal you aim for? 5.4 In which cases do you think it is appropriate or justifiable to prescribe (or continue prescribing) a BZRA as part of the treatment? 5.5 How do your patients see their treatment? 5.6 How do you motivate them? 5.7 Which aids do you have for this? Is that sufficient? 5.8 What do you consider relapse? 5.9 How do you address relapse? Probes: During treatment? After recovery? 5.10 What is recovery according to you? 5.11 When do you consider patients to be recovered?
INTERVIEW PART II: MESO-MACRO The second part of the interview is conducted either after the first part or during a second interview.	
6. Policy in your organisation	6.1 Is there a vision/policy/agreement framework within your organization regarding the treatment of BZRA dependency? 6.2 Does this align with your personal vision on the treatment of BZRA dependency? 6.3 How do your colleagues view this policy/agreement framework? And colleagues from other organisations?
7. Assessment of the treatment gap	7.1 How many patients do you think need treatment for BZRA dependency but do not receive it? In other words, out of ten patients/clients who need treatment, how many do you think actually receive it?
8. **Perception of barriers, levers, and protective factors (at the patient, provider, and organizational level):** "In	8.1 At the patient level, what do you think promotes finding appropriate care for BZRA dependency in Belgium? Probes: health literacy? network? 8.2 What barriers do patients experience in finding appropriate care for BZRA dependency in Belgium? What are the hindering factors at the

this section, we want to focus on both levers and potential barriers to accessing care, at the level of the patient, care or service provider, the organization or facility, and the healthcare system.	patient level? Probes: stigma, financial situation, location/distance to a facility? 8.3 What promotes the provision of appropriate care for BZRA dependency by healthcare providers? 8.4 What barriers do healthcare providers encounter in offering appropriate care for BZRA dependency? 8.5 Which elements of the Belgian healthcare system (or regional offerings) do you think promote access to care for patients with BZRA dependency? 8.6 Which elements of the Belgian healthcare system (or regional offerings) do you think hinder access to care for patients with BZRA dependency?
9. Concluding reflective question: What is the impact of the recent reforms in mental healthcare/addiction care on the treatment of BZD/Z dependency?	9.1 What impact do you think the recent reforms in mental healthcare have had on addiction care? 9.2 What impact do you think these reforms have had on accessing care for individuals with BZRA dependency? 9.3 What impact do you think these reforms have had on treating patients with a BZRA dependency?

10.2ANNEX 2 Interview topIC guide (Patients- WP4)

Demographic drop-off

- Gender M/F/X
- Year of birth
- Postcode (if applicable)
- Household composition:
    - I am… living alone
    - Living with partner
    - Living with children, living with partner and children, other: fill in
- What do you do in daily life:
    - I work
    - I am unemployed
    - I am retired
    - I am on sick leave
    - Other: fill in
- Are you currently (tick all that apply):
    - completely stopped taking sedatives and/or tranquilizers.
    - actively tapering-off/reducing doses taking sedatives and/or tranquilisers.
    - at a stable dose (no plans to reduce) taking sedatives and/or tranquilisers.
- Type of medication
    - What kind(s) of sedatives and/or tranquilisers have you taken regularly?
    - What kind(s) of sedatives and/or tranquilisers do you take regularly?

CALENDAR METHOD

For this question we employed an adjusted life history calendar method (Nelson, 2010) centred on the participant's medication and cessation history. The participant is invited to draw a timeline of their medication and cessation history. We allow the participant to fill this in freely. We ask them to indicate the following major event points (in line with the different phases outlined by DiClemente and Prochaska, 1998):

- ONSET: starting point of medication (=precontemplation phase)
- USE TRAJECTORY: evolution of medication use (=precontemplation phase)
- DECISION TO STOP/STABILISE OR REDUCE: turning point (contemplation + preparation phase)
- RECOVERY : cessation, stabilisation (action + possible relapse(s) + maintenance phases)

At each point, the following questions are asked:

ONSET

- When did you start taking the medication?
- What was or were the reason(s) for the first medication? (sleep problems, anxiety, chronic pain,…)
- Who prescribed it? / How did you access your sedatives and/or tranquilizers?
- What were the circumstances in your personal life related to the need to start medication?
- Personal life (Children? How old at that time? Marriage? Losses?
- Professional life? (work?)
- Stressfull life events?

USE TRAJECTORY

- How did your use of this medication evolve over time?
- In what dosage did you use it?
- How did you obtain it?
- How did you manage to get more?
- Did you combine this with other substances (e.g. alcohol, medication, drugs,…)? If so, which ones?
- What were the benefits of using this medication for you? What were the positive impacts?
- What were the disadvantages of using of this medication for you?
- What were the interaction with professionals? On your own?

DECISION TO STOP/STABILISE/REDUCE

- At what point did was your use was becoming problematic to you? What was the turning point for you?
- At what point did you decide to stop?
- What were the context and reasons behind your decision?
- Who played a role in that (health care professionals)?

- What were your objectives?
- What do you consider to be recovered? What do you consider a satisfactory situation?
- Prompt into how they describe the experience, and take the liberty to go a bit deeper into what they say… How was it to X or Y… Can you elaborate a bit on X or Y.. Give an example of X or Y…

<u>RECOVERY (stabilization, stop, reduce, satisfactory situation)</u>

- What was the first step? (Did the decision come from yourself or did someone else suggest it (e.g. Health Care Professional)?
- What/who helped to take that first step? Possible probes (based on Ceuterick et al. (2021)):
    - Alternatives for the underlying anxiety/sleeping problems (sleep therapy in a sleep clinic or through a physiotherapist, psychotherapy, meditation (self-taught through online videos), sports, natural remedies (herbs, melatonin)
    - Peer support
    - Support of family and informal network
    - Change in context and daily schedule (for example due to retirement, change of career,…)
    - Moral support of the attending physician
    - Recognition of the patient's experiences during withdrawal are (validation)
    - Accessibility to (small) correct taper dosages (taper strips, pharmaceutical preparations)
    - Tapering at own pace/rhythm (mutual agreement on treatment)

- What/who hindered? Possible probes:
    - Stigma/shame to seek help
    - No feasible alternatives for the underlying anxiety/sleeping problems
    - Unsupportive family and informal network
    - Invalidation of withdrawal effects by treating health care professional
    - No accessibility to (small) correct taper dosages (taper strips, pharmaceutical preparations)
    - Limited knowledge on support for cessation options
    - When under medical supervision: unrealistic tapering schedule

- At that point, when you decided to seek help, did you experience problems to access the care you felt you needed?
- What were the circumstances in your personal or professional life?
- Who was supporting you? What exactly was supportive about their help? Possible probes:
    - Pharmacist
    - GP
    - Psychologist (where did you consult with them)
    - Psychiatrist
    - Nurse
    - Peer support (off-or online), coach
    - Informal network: partner, family member, friend…
    - Physiotherapist
    - Alternative therapist

- Whose help were you missing?
- How did your recovery evolve? Can you describe the process?
- How did you experience that part of the treatment?
  - Physical effects?
  - Psychological effects?
- How was your interaction with the health care system during your recovery?
- Can you describe the role of each professional?
  - What helped?
  - What hindered?
- At what point did you consider yourself to be recovered? And how do you describe recovery?
  - What are the benefits and disadvantages of stopping/ to be stabilised?
  - Are you currently still doing things to maintain this balance?

CLOSING QUESTIONS

- What would you do to make this process easier for others, if you could do anything, in an ideal world?
- Is there anything else you want to mention?