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Comprendre et améliorer la prise en charge des benzodiazépines et des Z-drugs en soins primaires

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Understanding and improving benzodiazepines and Z-drugs management in primary care

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Abbreviations

- **AFMPS/FAGG:** Agence Fédérale des Médicaments et des Produits de Santé (Federal Agency for Medicines and Health Products)
- APB: Association Pharmaceutique Belge (Belgian Pharmaceutical Association)
- AVIQ : Agence pour une Vie de Qualité (Agency for Quality of Life)
- **CBIP/BCFI**: Centre Belge d'Information Pharmacothérapeutique (Belgian Center of Pharmacotherapeutical Information)
- **CMP/MFO**: Concertation medico-pharmaceutique (Medical-Pharmaceutical Concertation)
- BELPEP: Belgian Psychotropics Expert Platform
- CBT: Cognitive Behavioural Therapy
- DDD: Defined Daily Dose
- **DSM-V:** Diagnostic and Statistical Manual of Mental Disorders (fifth edition)
- FAGW: Fédération des Associations de Médecins Généralistes de la région Wallonne (Federation of Associations of General Practitioners of the Walloon Region)
- **Féda:** Fédération Drogues Addictions (Federation Dugs Addictions)
- FNRS/FWO: Fund for Scientific Research
- FPS: Federal Public Service
- GLEM/LOK: Groupe Local d'Évaluation Médicale (Local medical assessment group)
- GOC: Goal-oriented care
- GP: General practitioner
- INAMI/RIZIV: Institut National d'assurance Maladie-Invalidité (National Institute for Health and Disability Insurance)
- KCE: Belgian Health Care Knowledge Centre
- LUSS: Ligue des usagers des services de santé (Association of Health Service Users)
- SDM: Shared decision-making
- SSMG: Scientific Society of General Medicine
- SSPF/IPSA: Société Scientifique des Pharmaciens (Scientific Society of Pharmacists)
- **SUD:** Substance use disorder
- **TID:** Thousand inhabitants per day
- **UCD:** User-centred design
- VAD: Vlaams expertisecentrum Alcohol en andere Drugs (Flemish Expertise Centre on Alcohol and Other Drugs)

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Chapter 1

Introduction

Benzodiazepines receptor agonists: Psychoactive Substances

Benzodiazepines and Z-drugs are psychoactive substances prescribed for their sedative, hypnotic, and anxiolytic effects. These medications help individuals fall asleep faster, stay asleep longer, and alleviate stress and anxiety (Gauthier & Nuss, 2015; Gottesmann, 2002). They gained widespread popularity for their psychotropic effects, peaking in the 1970s (López-Muñoz et al., 2011; Wick, 2013). The Rolling Stones wrote a song called 'Mother's little helper' in 1966 about benzodiazepines, in an attempt to highlight the misuse of these 'little helper'. At that time, benzodiazepines were considered to be effective, with more acceptable side effects than barbiturates and a lower risk of addiction (López-Muñoz et al., 2011). Then, Z-drugs (e.g. zolpidem, zopiclone, zaleplon), introduced in the 1990s for insomnia, were initially considered a safer alternative to benzodiazepines. However, despite their different chemical structures, both Z-drugs and benzodiazepines act on the same receptors in the brain and have no efficacy or safety advantages over benzodiazepines (Agravat, 2018; Yu et al., 2017).

Long-Term Use and Prescribing Practices

Research over the years has highlighted significant risks associated with the long-term use of benzodiazepines and Z-drugs (defined in the literature as ≥ 6 months (Kurko et al., 2015), including dependence, cognitive and psychomotor impairment, and an increased likelihood of falls and fractures (Ashton, 2005; Brandt & Leong, 2017; Lader, 2014). Further studies have raised concerns about their potential links to dementia, cancer, and higher suicide rates (Brandt & Leong, 2017; Ferreira et al., 2022; Peng et al., 2022; Sun et al., 2019). Long-term use primarily affects a population that is already vulnerable is associated with factors such as the presence of a DSM-IV disorder, psychiatric comorbidities, older age, lower education levels, feelings of loneliness, and a greater reliance on avoidance coping strategies, compared to short-term use (Zandstra, 2004).

Due to these risks, clinical guidelines recommend that both benzodiazepines and Z-drugs should be used only for short periods, with most guidelines advising use for no longer than four weeks at the lowest effective dose. They suggest one to two weeks for insomnia and two to four weeks for anxiety (Brandt et al., 2024; Centre Belge d'Informations Pharmacothérapeutique, n.d.).

However, studies have shown that the guidelines for benzodiazepine and Z-drugs prescriptions, particularly regarding their duration, are not consistently followed (Davies et al., 2017; Kiridis et al., 2022; Rijksen et al., 2021). In fact, despite these clear guidelines, social dynamics can influence patients' perceptions and behaviour.

For instance, some patientas are reluctant to confide in their social circle about their benzodiazepines and Z-drugs use, except to their partner, while others receive advice from their entourage to avoid using benzodiazepines and Z-drugs but choose to ignore it. Conversely, some children even encourage their elderly parents to take these drugs, believing they will help alleviate their symptoms (Pérodeau et al., 2016). This highlights the extent to which the use of benzodiazepines and Z-drugs not only involves the provider and the patient but also represents a complex family dynamic, where external perceptions and influences significantly shape therapeutic decisions.

From the prescribers' perspective, they may also encounter challenges when prescribing benzodiazepines and Z-drugs. First, some studies suggest that GPs perceive Z-drugs as safer and more effective than benzodiazepines, which contradicts both scientific literature and clinical guidelines (Siriwardena et al., 2006). Certain individuals tend to minimize the potential risks of long-term use and express discomfort with alternative treatment options for insomnia and anxiety (Cook, Marshall, et al., 2007).

On the other hand, communication challenges with patients are well-documented in the scientific literature. Several studies highlight the difficulties clinicians face when addressing withdrawal or dependency management, as they often anticipate patient resistance and fear compromising the therapeutic relationship (Hawkins et al., 2021; Van Ngoc et al., 2024).

In this regard, recent qualitative research further reveals how prescribers navigate these tensions by developing narrative strategies, ranging from strict refusal to compassionate or reluctant prescribing, to justify their decisions while coping with conflicting expectations from guidelines, patients, and institutional contexts (Ceuterick et al., 2023).

Prevalence of benzodiazepines and Z-drugs use

Benzodiazepines and Z-drugs remain widely used worldwide (Donoghue & Lader, 2010; Votaw et al., 2019), including Belgium (Van Der Heyden et al., 2020). Alarmingly, Belgium has consistently ranked among the top global consumers. Belgium had the highest consumption rate in 2008 and remained in the top three by 2018, despite a slight decline. Moreover, the rate of consumption was substantially higher in high-income countries compared to middle-income countries.

This study analysed global, regional, and national trends regarding the use of these molecules from 2008 to 2018, focusing on the Defined Daily Dose (DDD) ("the assumed average maintenance dose per day for a drug used for its main indication in adults" (World Health Organization, 2025)) per thousand inhabitants per day (TID) (Ma et al., 2023) (Figure 1.1).

In Belgium, benzodiazepines and Z-drugs are only available by medical prescription. This pattern reflects broader trends in the Belgian healthcare system where access to prescription drugs is widespread (Van Der Heyden et al., 2020). Although national efforts have led to some reduction, usage levels remain worryingly high, particularly among older adults. A Belgian study covering 2004 to 2013 confirmed this trend, with older adults showing the highest rates of long-term use (Pétein et al., 2021). Current data reveal that 11.9% of people aged 65 and over have taken benzodiazepines and Z-drugs in the last 24 hours (Van Der Heyden et al., 2020). Geographical disparities further underscore this issue. Benzodiazepine and Z-drugs use is significantly higher in the Walloon Region compared to Flanders and Brussels, with Brussels also surpassing Flanders in usage rates, even after adjusting for age differences. In contrast, Z-drugs use remains relatively consistent across regions (Van Der Heyden et al., 2020).

The prevalence of benzodiazepines and Z-drugs use varies across populations but remains significant. In Switzerland, the one-year prevalence for Benzodiazepines and Z-drugs prescriptions was 10.5% in 2018, increasing with age (Landolt et al., 2021). In Canada, Z-drug usage increased from 2001 to 2016, with prevalence rising from 2% to 4.8% (Brandt et al., 2019). In the United States, only 2% of the

population misusing benzodiazepines and less than 0.5% misusing Z-drugs in the past year. In France, encouraging statistics show that 86% of new users of benzodiazepines and Z-drugs comply with the guidelines on prescription duration (Bénard-Laribière & Pariente, 2018). In order to determine which group of the population uses benzodiazepines and Z-drugs long-term, a French study identified aging, poor sociodemographic conditions, and depression as significant factors associated with prolonged benzodiazepines and Z-drugs use (Airagnes et al., 2019). Other data also indicate that individuals with lower socio-economic status are more likely to be prescribed psychotropic medication. This is explained by prescribers' perception that patients from lower socio-economic status lack the necessary social, personal, and financial resources for treatments considered more active or expensive, such as Cognitive Behavioural Therapy (CBT) (Colman et al., 2023). These findings underscore a significant pattern of widespread and sustained use of benzodiazepines and Z-drugs, particularly among vulnerable populations. They highlight critical public health concerns associated with aging, mental health conditions, and socioeconomic disparities.

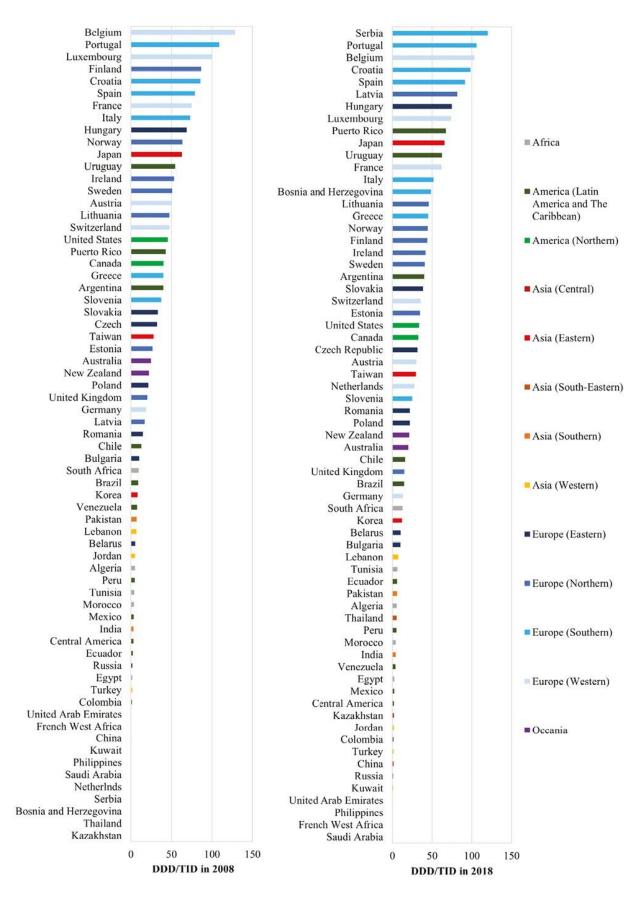


Figure 1.1 Rankings of benzodiazepines and Z-drugs consumption for individual countries and regions in 2008 and 2018 (Ma et al., 2023)

Withdrawal and Barriers to Discontinuation

Long-term use of benzodiazepines and Z-drugs leads to both physical and psychological dependence, making withdrawal particularly difficult. Withdrawal symptoms may develop after just four weeks of daily use and can manifest as psychological disorders, sweating, elevated heart rate, tremors, insomnia, agitation, hallucination, rebound anxiety, nausea or vomiting (Chang, 2005). This includes anxiety and insomnia - the original symptoms that led to the prescription - which may resurface, causing further destabilisation (Ashton, 1991). Indeed, although some withdrawal symptoms may resemble a recurrence of the previously treated anxiety or insomnia disorder, they typically appear more rapidly within 8 to 24 hours after discontinuing the medication and generally subside over time (Chang, 2005). All of this can be extremely challenging for the patient and may significantly impact their quality of life, their family life, careers, and mental health (Reid Finlayson et al., 2022).

There is considerable interindividual variability, making the withdrawal process highly unpredictable. Withdrawal symptoms can be experienced for months, even years, depending on how long the medication was used, even with a gradual tapering process. Withdrawal symptoms tend to be more intense when the medication is stopped abruptly (Ashton, 1991; Reid Finlayson et al., 2022; Socias et al., 2021). A slow and gradual tapering strategy, supervised by a healthcare professional, is the recommended approach to minimizing withdrawal effects (Pottie et al., 2018).

Interventions to support deprescribing

Over the past two decades, many studies have examined the effectiveness of various strategies to discontinue benzodiazepines and Z-drugs (Bashir et al., 1994; Coteur, Henrard, et al., 2022; Gould et al., 2014; Heather et al., 2004; Kuntz et al., 2019; Mugunthan et al., 2011; Parr et al., 2009; Tannenbaum et al., 2014; Vicens et al., 2006, Voshaar et al., 2006). These interventions range from simple, low-resource strategies to more structured, multifaceted approaches.

Minimal interventions can be more effective than routine care. Stepped approaches, starting with simple advice and escalating to more structured discontinuation programs, show positive results (Mugunthan et al., 2011; Voshaar et al., 2006). Indeed, sending informational letters or brief advice and a self-help booklet, have proven effective in reducing long-term benzodiazepines and Z-drugs prescriptions (Bashir et al., 1994; Heather et al., 2004).

Patient education has also emerged as a key strategy. The EMPOWER trial demonstrated that providing information on the risks of long-term benzodiazepines and Z-drugs use and tapering strategies led to significant reductions (Tannenbaum et al., 2014). Furthermore, combining education with pharmacist consultations further enhanced deprescribing outcomes (Kuntz et al., 2019).

More comprehensive interventions, such as blended care models that integrate digital CBT with physician support, have also been tested, but found no significant advantage over usual care, although both methods led to successful discontinuations (Coteur, Henrard, et al., 2022). Meta-analyses focusing on older adults highlighted that supervised withdrawal programs, especially when combined with psychotherapy, are particularly effective in this population (Gould et al., 2014)

Overall, these studies suggest that even simple, low-cost interventions can effectively reduce long-term benzodiazepines and Z-drugs use, with enhanced results when combined with patient education and psychological support.

Comprehensive Personalised Care Model

Deprescribing benzodiazepines and Z-drugs is often a complex and unpredictable process due to significant individual differences in patient responses, withdrawal symptoms, and underlying psychological factors. While some patients may respond well to minimal interventions, others require more intensive and personalized support. This variability highlights the need for multifaceted interventions that address the diverse needs of patients. However, understanding how to effectively tailor these strategies can be challenging for healthcare providers.

The Comprehensive Personalised Care Model (NHS England, n.d.-a) offers a structured framework to guide deprescribing efforts, helping healthcare professionals choose the most appropriate interventions based on the complexity of each case. The model is visualised as a pyramid, with interventions ranging from simple to complex (Figure 1.2).

Paradoxically, benzodiazepines and Z-drugs use, intended as short-term solutions and positioned at the top of the treatment pyramid due to their risk profile, are frequently prescribed and used as if they belong at the base, meant for widespread, long-term use. At the lower levels of the pyramid, brief interventions, such as sending informational letters or conducting short consultations, require minimal resources and expertise, making them accessible to a broad patient population. These simple strategies empower patients to gradually reduce benzodiazepine and Z-drugs use while encouraging self-management. As one ascends the pyramid, interventions become more specialized and resource-intensive.

This framework underscores the need for a range of evidence-based, non-pharmacological options that can be initiated early and at little to no cost, ensuring that patients receive appropriate support (NHS England, n.d.-a).

Beyond structured deprescribing programs, support from healthcare professionals is also vital. Indeed, a significant challenge during withdrawal is the perceived lack of support from healthcare professionals. Reid Finlayson et al. (2022) found that patients felt they did not receive adequate support from healthcare professionals, who downplayed their distress and failed to take their suffering seriously (Reid Finlayson et al., 2022). This lack of recognition from medical professionals can push patients to seek help online, as highlighted in Fixsen's studies (Fixsen, 2016; Fixsen & Ridge, 2017). Online support forums play a crucial role in the recovery process for some patients, providing a space where individuals can share their experiences, find validation, and receive emotional support from others who understand their struggles (Fixsen, 2016; Fixsen & Ridge, 2017). Many patients describe their withdrawal as a deeply isolating and traumatic experience, often using metaphors such as "hell" or "walking through fire" to express their suffering. These forums not only serve as a refuge for those in distress but also as a source

of hope, with former users sharing success stories to reassure others that recovery, while unpredictable and lengthy, is possible (Fixsen & Ridge, 2017). Another study also indicates that patients should receive more information about withdrawal symptoms and methods (Lynch et al., 2024).

Despite the significant distress they experience, very few studies have focused on the perspective of benzodiazepine users during withdrawal (Ceuterick et al., 2021a; Cook, Biyanova, et al., 2007; Fixsen, 2016; Fixsen & Ridge, 2017; Gabe & Lipshitz-Phillips, 1982).



Comprehensive Personalised Care Model All age, whole population approach to Personalised Care

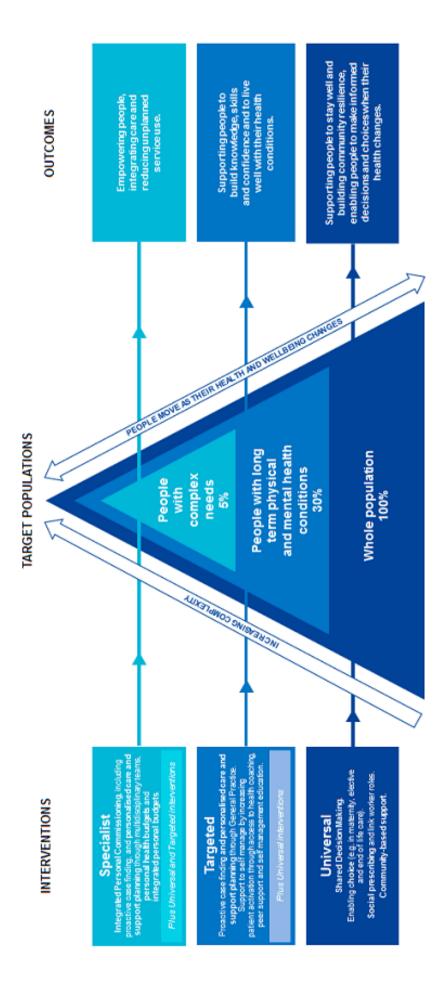


Figure 1.2 Comprehensive Personalised Care Model (NHS)

Primary Care in Belgium: Structure, Challenges, and Ongoing Reforms

Belgium's healthcare system operates within a federal structure, with responsibilities divided between the federal government and the federated entities. While the federal level oversees health insurance, hospital care, and financing, the federated entities are primarily responsible for primary care, mental health, elderly and disability services, prevention, and health promotion (Belgian Federal Public Service Health, Food Chain Safety and Environment, n.d.; Gerkens & Merkur, 2020a).

Primary care is mainly delivered through private practices, where GPs have significant autonomy. Most work in solo or small group settings under a fee-for-service model. A minority of patients with around 3.4% in 2016 receive care through community health centres which operate under a capitation-based model and involve multidisciplinary teams (Gerkens & Merkur, 2020b). However, the sector faces mounting pressure due to a growing shortage of GPs and increasing difficulties in accessing care. In 2022, one in five GPs in Wallonia reported no longer accepting new patients (Beerslans et al., 2023).

In response to these challenges, Belgium launched the "New Deal for General Practice" in 2022. This reform promotes a shift towards more coordinated and team-based care, supported by changes in professional roles and financing. New professions such as practice assistants are being introduced to handle administrative and basic technical tasks under GP supervision, while pharmacists now contribute more actively to public health through vaccination and medication review for patients with polypharmacy. The payment model is also being reconsidered, aiming to increase the role of capitation and performance-based incentives, while reducing dependence on fee-for-service (Gerkens et al., 2024). Recent qualitative findings also highlight that while GPs generally support the integration of nurses and receptionists into their practices, concerns remain regarding professional autonomy, task delegation, and the practical feasibility of team-based models (Jamart et al., 2025).

These transformations are particularly relevant in the context of addressing complex medication use, such as that of benzodiazepines and Z-drugs. Studies

have shown that three out of four benzodiazepine prescriptions are written by general practitioners (GPs) (Lader et al., 2009; Vicens et al., 2006) and Belgian GPs prescribed 83% of benzodiazepines and Z-drugs (Federal Public Services, n.d.), highlighting their central role in both initiating and potentially deprescribing such treatments. However, the current structure of care, with limited coordination and fragmented information flows, can hinder appropriate follow-up. As patients in Belgium can access secondary care without GP referral (Anthierens, Tansens, et al., 2010), medications are sometimes initiated or modified in hospitals or by specialists without informing the GP, further complicating continuity of care.

Improving interprofessional collaboration and information sharing, both within primary care and across care levels, is therefore essential. GPs' longitudinal relationship with patients makes them well-positioned to address inappropriate prescriptions, but structural support, such as integrated records and multidisciplinary practices, is needed to ensure holistic and coordinated care.

Belgian Initiatives

In Belgium, specific initiatives have been introduced to promote deprescribing and encourage safer alternatives to benzodiazepines and Z-drugs, aligning with international recommendations. One such initiative is the public awareness campaign launched by the Federal Public Service (SPF) Health, titled "Somnifères et calmants: pensez d'abord aux autres solutions." (Service Public Fédéral, 2018). By raising awareness, the initiative seeks to reduce reliance on Benzodiazepines and Z-drugs for managing insomnia and anxiety.

Additionally, the National Institute for Health and Disability Insurance (INAMI) has introduced a reimbursement program for compounded preparations. This program financially supports the use of lower-dose formulations prepared by pharmacists as part of a structured trajectory.

These initiatives reflect Belgium's commitment to addressing the problem of benzodiazepines and Z-drugs through both public education and structural healthcare programs. However, their long-term impact on prescribing behaviours and patient outcomes remains to be fully evaluated.

Objectives

This thesis pursued several objectives. First, it aimed to understand the perspectives of healthcare professionals who support long-term users of benzodiazepines and Z-drugs, with a particular focus on how they define patient care goals. The focus then shifted to the patients themselves, exploring their perspectives and, more specifically, their lived experiences with benzodiazepines and Z-drugs withdrawal.

By integrating the views of both patients and professionals, policy recommendations targeting the primary, secondary, and tertiary prevention of long-term benzodiazepines and Z-drugs use were collected and assessed in terms of feasibility, support, importance, and the conditions necessary for their implementation. The main objective was to propose Belgian policy recommendations that are well adapted to real-world practices, benefiting both patients and healthcare professionals.

One key recommendation that emerged was the need to provide patients with information about the risks and potential for dependency at the time of the initial benzodiazepines and Z-drugs prescription. To address this, a support tool for first-time prescriptions was co-developed in collaboration with healthcare professionals and patients, intended for use in general practice and pharmacies. This tool was piloted and evaluated by users to assess its acceptability.

Dissertation Outline

The following outline presents the structure of the dissertation:

- Chapter 1 introduces the issue of long-term benzodiazepines and Z-drugs use, its public health risks, and the gap between guidelines and real-world prescribing.
- Chapter 2 explores how 24 healthcare professionals set treatment goals for long-term benzodiazepines and Z-drugs users. Findings reveal a lack of standardized criteria, varied approaches (abstinence vs. harm reduction), and limited patient involvement. Highlights the need for clearer withdrawal guidelines.
- Chapter 3 analyses 19 patient experiences of benzodiazepines and Z-drugs withdrawal. Key issues include poor information, strict adherence, lack of involvement in tapering plans, and the need for personalised approaches.
- Chapter 4 presents a Policy Delphi study evaluating 27 policy recommendations to prevent long-term benzodiazepines and Z-drugs use.
 Consensus supports awareness campaigns and provider training, while some recommendations need further refinement and evaluation.
- Chapter 5 describes the co-development of a patient education leaflet to improve initial benzodiazepines and Z-drugs prescribing. This tool is codeveloped with professional and patient input and promotes shared decision-making and alternative treatments.
- Chapter 6 synthesises findings, discusses implications for clinical practice and policy, and highlights the need for collaborative, goal oriented care approach to benzodiazepines and Z-drugs management.

Chapter 2

Professionals' treatment goals for long-term benzodiazepine and Z-drugs management: a qualitative study

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Abstract

Introduction: Benzodiazepines and Z-drugs (BZD/Z) are frequently prescribed for longer than recommended. Through their interactions with patients taking BZD/Z, primary care and mental health professionals play a key role in the management of this medication.

Aim: To explore how primary care and mental health care professionals set treatment goals with users of long-term BZD/Z

Method: A qualitative study using semi-structured interviews with professionals from mental health, addiction care, and primary care practices in Belgium. Semi-structured interviews were conducted, online and in person, with 24 professionals working in mental health and primary care. Inductive thematic content analysis was performed.

Results: Seven themes were identified from the analysis. Professionals tended not to use the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) standard to diagnose a BZD/Z substance use disorder. They described criteria based on their experience. They identified diverse types of patients that influence their choice of treatment goals. Professionals appeared 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 reported feeling trapped into continuing to prescribe and considered BZD/Z withdrawal to be difficult. Some were 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, perceiving the current recommendations to be too broad.

Conclusion: Whether primary care or mental health care professionals are more in favour of a total abstinence or a harm reduction approach to BZD/Z, professionals should be guided towards greater patient participation in setting and evaluating goals with patients taking BZD/Z.

Introduction

Benzodiazepines and Z-drugs (BZD/Z) are broadly prescribed, and inappropriate consumption constitutes a major public health concern (Airagnes et al., 2016; Lader, 2011). Belgian guidelines recommend prescribing BZD/Z as a last resort at the lowest possible dose for a period of 1–4 weeks (Centre Belge d'Informations Pharmacothérapeutique, n.d.; Vlaams expertisecentrum alcohol en andere drugs, n.d.). Nevertheless, in 2018, the results of the National Health Interview Survey showed that 14.9% of participants aged ≥65 years had taken a BZD/Z in the 24 hours preceding the survey (Van Der Heyden et al., 2020). Long-term usage of benzodiazepines (>6 months) (Kurko et al., 2015) can lead to adverse side effects such as psychological, cognitive, and physical effects including vertigo, ataxia leading to falls, and dysarthria (Lader, 1999). Furthermore, physiological and psychological dependence can be induced (Lader, 1999, 2011), which can lead to misuse, abuse, or to a substance use disorder (SUD), as described in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (American Psychiatric Association, n.d.). Likewise, Zdrug use is also associated with adverse effects such as delirium, dementia, fractures, or road traffic accidents (Kang et al., 2012; Lai et al., 2014; Pin-Liang Chen et al., 2012). Even short-term use can engender side effects, including impairment in psychomotor and cognitive functioning, and can lead to tolerance (Gudex, 1991).

In 2020, a Belgian report showed that guidelines are not being followed appropriately, especially in terms of prescription duration (Kiridis et al., 2022). These gaps between guidelines and practice illustrate the difficulties professionals face regarding long-term BZD prescriptions and deprescribing (Mokhar et al., 2019). An alternative approach to address these difficulties could be to prioritise patient goals.

While biomedicine is founded on the disease—outcome paradigm, where each disease is treated separately following guidelines and population goals, the goal-oriented care (GOC) approach is part of a dynamic process of collaboration and co-creation between the patient and the professional based on the patient's needs, preferences, and values (Boeykens et al., 2022; Reuben & Tinetti, 2012). This approach can be divided into three steps during a consultation (Boeykens et al.,

2022). The first is goal elicitation where professionals and patients work on understanding each other's expectations. Then goal setting is defined based on the patient's needs and preferences. This is followed by goal evaluation, which requires working on measurable common goals (Boeykens et al., 2022). Both parties must be prepared to change their paradigm of care; this may require professional training on how to define the objectives of care with their patients (Franklin et al., 2019) and on how to help them share their needs and preferences (Reuben & Tinetti, 2012). This approach has been predominantly employed and studied among patients with chronic conditions (Boeykens et al., 2022).

Given the challenging nature of BZD/Z withdrawal and the high likelihood that these types of patients already have complex physical and mental health needs (Cook, Biyanova, et al., 2007; Heather, 2006), a GOC approach seems appropriate. Nevertheless, as described above, the process is not necessarily easy and greater understanding of the current state of affairs would be helpful. We therefore posed the research question: how do primary care and mental healthcare professionals in Belgium currently set treatment goals with users of long-term BZD/Z?

Methods

A semi-structured interview study was conducted among healthcare professionals using an interview guide (Additional File 2.1) based on the model of healthcare accessibility by Andersen (Andersen, 1995). The guide was developed by three researchers (MC, BS, PV) and was piloted with two interviews, one in each language.

Participants were recruited via Belgian mental health care and primary care networks and via a Belgian medical professional newspaper. Efforts were made to achieve a diverse sample in terms of geographical regions, sex, type of profession, and practice (Table 2.1). We aimed to recruit at least two participants per profession (GP, nurse, social worker, psychiatrist, psychologist). Only professionals who were interested in participating contacted the research team; therefore, we have no information on those who refused to participate. One interview per participant was held, one-to-one, at the participant's workplace or by

video conference. The interviews took place between July 2021 and January 2022, and the average duration of the interviews was 68 minutes.

Interviews were conducted by the first author (PV, female, PhD student and psychologist by training, n = 11), the second author (MC, female, postdoc researcher and medical anthropologist, n = 8), and a research team member (AV, retired GP, female, n = 5). All three had been trained in interviewing.

Participants signed a consent form before the interview. All the interviews were audio-recorded and transcribed, and identifying information was removed. Transcripts were proofread for accuracy; they were not returned to participants for comments or correction. Field notes were taken but did not add anything new to the dataset.

Team meetings were held every fortnight to discuss progression of data collection.

| Code | Date | Sex | Professional background | Type of practice | Location | Region | Interviewer | Online or in person |
|-----------|-------------------------|-------------------|-------------------------|--------------------|-------------|----------|-------------|---------------------|
| RESP1 | 14-07-21 | Female | GP | Addiction care | Urban | Flanders | MC | Online |
| RESP2 | 20-09-21 | Male | GP | Addiction care | Urban | Flanders | MC | In person |
| RESP3 | 13-10-21 | Male | Social worker | Addiction care | Urban | Flanders | AV | In person |
| RESP4 | 20-10-21 | Male | GP | Addiction care | Urban | Flanders | MC | In person |
| RESP5 | 22-10-21 | Male | Psychiatrist | Addiction care | Urban | Flanders | MC | In person |
| RESP6 | 03-11-21 | Female | GP | Addiction care | Urban | Flanders | AV | In person |
| RESP7 | 04-11-21 | Female | GP | Addiction care | Urban | Flanders | MC | In person |
| RESP8 | 17-11-21 | Female | GP | Primary care | Urban | Flanders | MC | Online |
| RESP9 | 30-11-21 | Female | Psychiatrist | Addiction care | Urban | Flanders | MC | Online |
| RESP10 | 09-12-21 | Female | GP | Primary care | Urban/rural | Flanders | MC | Online |
| RESP11 | 29-12-21 | Female | Nurse | Mental health care | Urban | Flanders | AV | In person |
| RESP12 | 07-01-22 | Male | Psychologist | Mental health care | Urban | Flanders | AV | In person |
| RESP13 | 07-01-22 | Male | Psychiatrist | Mental health care | Urban | Flanders | AV | In person |
| RESP14 | 08-07-21 | Female | GP | Primary care | Rural | Wallonia | PV | In person |
| RESP15 | 05-08-21 | Male | GP | Primary care | Urban | Wallonia | PV | In person |
| RESP16 | 23-08-21 | Female | Psychologist | Addiction care | Urban | Brussels | PV | In person |
| RESP17 | 23-08-21 | Female | GP | Addiction care | Urban | Brussels | PV | In person |
| RESP18 | 06-09-21 | Female | Social worker | Addiction care | Rural | Wallonia | PV | In person |
| RESP19 | 09-09-21 | Female | Nurse | Addiction care | Urban | Brussels | PV | In person |
| RESP20 | 10-09-21 | Male | Psychiatrist | Mental health care | Rural | Wallonia | PV | In person |
| RESP21 | 13-09-21 | Male | GP | Primary care | Urban | Brussels | PV | In person |
| RESP22 | 21-09-21 | Male | Psychologist | Addiction care | Rural | Wallonia | PV | In person |
| RESP23 | 22-09-21 | Male | Psychiatrist | Addiction care | Urban | Brussels | PV | In person |
| RESP24 | 19-11-21 | Female | Social worker | Addiction care | Rural | Wallonia | PV | Online |
| Date form | Date format = DD-MM-YY. | - / Y. | | | | | | |

Data analysis

Inductive thematic content analysis was performed using NVivo (version 12). A first code matrix with recurring themes was produced and 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, two interviews in each language were coded by both coders 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 & Clarke, 2006).

Results

A purposive sample of 24 participants from the three regions of Belgium (Brussels, Flanders, and Wallonia) was recruited from different professional backgrounds (Table 2.1). In total, 11 interviews were carried out in French and 13 in Dutch with GPs (n = 11), psychologists (n = 3), psychiatrists (n = 5), nurses (n = 2), and social workers (n = 3).

The following seven themes emerged from the data about the treatment goals:

- 1. Diagnosis and recognition of a BZD/Z SUD;
- **2.** Position concerning their treatment goals;
- **3.** Goal of abstinence:
- 4. Harm reduction;
- **5.** Feeling trapped;
- **6.** Patient participation;
- **7.** Targeted recommendations.

1. Diagnostic and recognition of a SUD to BZD/Z

Participants did not always use criteria, such as those described in the DSM-V (American Psychiatric Association, n.d.), to diagnose a BZD/Z SUD. The participants spoke rather of a 'feeling' and identified a change in the patient's behaviour to obtain more prescriptions, a non-respect of the prescribed dose, and where the BZD/Z 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.' (RESP14, GP, primary care, rural)

'We really speak of extreme use when people regularly 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.' (RESP12, psychologist, mental health care, urban)

The participants explained how they differentiate between the different types of patients, for example, an older person who takes a BZD/Z every evening or a person who takes BZD/Z in addition to other drugs to become 'high'. This classification influenced the choice of professionals in the patient's treatment goals. Indeed, the older person who takes their BZD every night will be less likely to be associated with a SUD 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.' (RESP1, 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." (RESP19, nurse, addiction care, urban)

2. Position concerning their treatment goals

Most of the participants positioned 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 BZD/Z to maintain the relationship with patients who needed 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 [one advocating total abstinence versus one advocating harm reduction], there was sometimes a bit of a cold war ...

Today, there is a situation of coexistence between those different visions.' (RESP1, GP, addiction care, urban)

Professionals promoting complete abstinence and those supporting harm reduction strategies seemed somewhat distinct. One participant mentioned a dogmatic vision for those who believed in abstinence and a 'cold war' between these approaches. There seemed to be a coexistence between these distinct beliefs, or for some even 'professional identities' concerning what was possible for patients who have been taking BZD/Z for long time.

'I don't know if we can really believe in that "harm reduction".' (RESP10, GP, primary care, urban/rural)

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.' (RESP5, 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.' (RESP24, 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?' (RESP18, Social worker, addiction care, rural)

4. Harm reduction

For participants in favour of harm reduction, they mentioned the intention that their patients achieve a degree of stability in their BZD/Z consumption. Some explained their experience of patients taking high doses of benzodiazepines with high tolerance. Some of them did not consider taking BZD/Z 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' (RESP21, 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, familially with their use.' (RESP15, GP, primary care, urban)

Some participants described the importance for them to maintain the therapeutic relationship with the patient and that they welcomed patients unconditionally, whatever their consumption or their condition. They considered this to be more valuable than following the recommendations on BZD/Z 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.' (RESP17, 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.' (RESP17, 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.' (RESP2, GP, addiction care, urban)

5. Feeling trapped

Some participants reported feeling stuck with BZD/Z deprescription. They observed 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 reported that withdrawal is, in itself, very difficult for the patient:

'Benzodiazepine withdrawal is a dreadful mess. We're stuck.' (RESP21, GP, primary care, urban)

'A small decrease often takes an implausible turn.' (RESP23, Psychiatrist, addiction care, urban)

Some participants described difficulties talking with their patients about their long-term BZD/Z use owing to fear of breaking the trusting relationship with their patients, or of upsetting the status quo established with the drug (particularly for older 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...' (RESP14, GP, primary care, rural)

6. Patient participation

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

'We accompany them wherever they want to go.' (RESP16, Psychologist, addiction care, urban)

'You need to know where they start from and where they want to go.' (RESP21, 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.' (RESP13, Psychiatrist, mental health care, urban)

7. Targeted recommendations

Concerning the withdrawal, some participants described their difficulties applying guidelines that they considered were not appropriate for their patient group. Some changed the molecules to the equivalent of diazepam and decreased more slowly than the recommendations, depending on the patient's profile. In addition, some prescribers mentioned the need to keep the BZD/Z for a long time, without being able to stop 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.' (RESP17, 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, benzodependent people who do not fit into the current frameworks.' (RESP2, GP, addiction care, urban)

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 favouring abstinence and others 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 felt 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 users of long-term BZD/Z.

Strengths and limitations

This study is part of a larger project, BENZOCARE, focusing on the experience of professionals and patients regarding the use of BZD/Z and the accessibility of care. The results presented here were collected in the context of that study, which in its essence was not focused exclusively on GOC. The interview guide was therefore somewhat broad and these results represent a part of the data collected. If we had created an interview guide tailored to GOC, we may have had different results but there may also have been a tendency towards social desirability bias given the push towards GOC in Belgium at the moment. We feel, therefore, that our results reflect the way BZD/Z are managed in primary care and mental health services. The study was conducted in Belgium and data were collected in French and in Dutch (sometimes in local dialect). In order to facilitate comparability and discussion within the team and develop a global understanding of the data, the Dutch transcripts were translated into French after having been analysed separately by two coders in the original language. 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. This gave us a richness in terms of experiences 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 BZD/Z and a social desirability bias in the answers they gave.

Comparison with existing literature

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. 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 proposed a paradigm shift for professionals to view treatment and recovery differently (Gallagher et al., 2019). The authors conceptualised recovery on a spectrum that is determined by patients and that is not a projection of professional or institutional values.

In our results, patients' expectations appeared not to be the starting point for setting treatment goals. Some professionals appeared to find it difficult to start a conversation about BZD/Z. Previous research has demonstrated that prescriber behaviour is influenced by assumptions concerning patients' expectations, motivation, and adaptability, such as anticipating patient resistance to initiating a deprescribing process (Cook, Marshall, et al., 2007; Sirdifield et al., 2013). This has also been described for 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 seemed to be present in our sample as well and is also experienced on the other side of the desk, with some patients feeling stuck or imprisoned during their withdrawal from BZD/Z (Fixsen & Ridge, 2017; Mokhar et al., 2019). Patients are unaware of the potential problems associated with their BZD/Z use and do not realise that they are addicted to these drugs, until the day they try to stop (Mokhar et al., 2019).

Furthermore, in our study, some prescribing participants mentioned their fear of breaking the trusting relationship if they initiated the conversation about BZD/Z. This is consistent with other studies about users of BZDs, where physicians were reported to have experienced the same discomforts (Cook, Marshall, et al., 2007; Hawkins et al., 2021). While communication between doctor and patient is positively correlated with patient adherence to treatment (Zolnierek & DiMatteo, 2009), prescribers seem to be struggling to know how to engage the talk about BZD/Z (Oldenhof et al., 2019). They declared having insufficient time, and need training for communication and negotiation skills to discuss BZD (Bendtsen et al., 1999). The challenges professionals face communicating with patients regarding this problem is understandable and models have been developed to structure such discussions and help develop goals together. The 'three-talk model' proposes three stages in the consultation: first, 'team talk' where the professional and the patient

work together to describe the possible choices, offer support, and describe the objectives; second, 'option talk' where alternatives are discussed, and third 'decision talk' where decisions are made based on patient preferences (Elwyn et al., 2017).

As some participants mentioned, tapering off BZD/Z can be very difficult. However, one of the benefits of withdrawal mentioned by professionals is the opportunity for the patient to get to know themselves 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 & Hoffer, 2012). Patients 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 professional (Schlosser & Hoffer, 2012). This underlines the need for the two parties 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.

In general, our results point to a lack of patient-centred care in the management of BZD/Z SUD. Indeed, in a systematic review in 2018, the authors did not find any studies that included a BZD tapering intervention that was defined as specifically using the concept of patient-centred care. Nevertheless, among their results 20 interventions were based on patient-centred dimensions of the approach, focusing on patient information, professional—patient communication, and provider characteristics (Mokhar et al., 2018). Among them, a study of an educational intervention had a positive impact on shared decision-making for benzodiazepine overuse in older people (Tannenbaum et al., 2014).

Today, primary care literature is increasingly focusing on the GOC approach; however, less focus is afforded in the literature to GOC and BZD/Z use. Similarly, GOC or elements of it, were rarely mentioned by our participants. GOC requires working in partnership with users, families, healthcare professionals, and other service providers (Boeckxstaens et al., 2020). The approach can have a positive

impact on the patient experience, the wellbeing of professionals, lead to a reduction in healthcare costs, and improve population health (Boeykens et al., 2022). In light of our results and the burden of BZD/Z prescribing and deprescribing, it appears important to explore and study the GOC approach in the context of both initial prescriptions of BZD/Z and deprescription.

Implications for research and practice

Total abstinence appeared to be complex to implement universally given the diversity of patients taking BZD/Z, especially regarding complete withdrawal within a few weeks. Some professionals asked for recommendations for specific populations for BZD/Z tapering off. Implementing the GOC approach in the BZD/Z guidelines by taking into consideration the challenges faced by clinicians and integrating needs, preferences, and values of patients could be considered in future studies and in practical guidance.

Professionals reported feeling trapped by the issue of BZD/Z, 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 article is one of the first to study the experiences of professionals concerning BZD/Z use through the prism of the GOC approach.

Our results have concluded that the DSM-V does not appear to be used by professionals to diagnose a BZD/Z SUD and instead they use their instincts. Participants clearly positioned themselves between an abstinence or harm reduction goal. They described feeling trapped in the prescription of BZD/Z and patient involvement in decision making is not clear. Participants requested recommendations that were specific to certain patient groups. We feel that by recognising or diagnosing a BZD/Z SUD using criteria already defined in the DSM-V could increase transparency between the patient and professional. Co-creating goals according to the patient's needs, preferences, and values could help navigate the challenges professionals feel concerning harm reduction or total abstinence making them feel less trapped.

Renewed emphasis in professional training on the patient experience of BZD/Z could be undertaken to promote patient empowerment in the context of BZD/Z prescription and deprescription. Ongoing training in the GOC approach and in communication techniques for healthcare professionals is also important. Future studies should focus more on the patient's lived experience of BZD/Z dependence and withdrawal and the relationship with professionals.

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Ethical approval

Participants were informed on the goal of the study and gave their written informed consent. The two Ethics Committees (Comité d'Éthique Hospitalo-Facultaire Universitaire de Liège with the approval number: 2021/121 and Ethics Committee of the Faculty of Political and Social Sciences of Ghent University with approval number: EC-2021–22) have given their agreement for the study.

Additional File 2.1

Conceptualization and diagnosis of substance use disorder (SUD) to benzodiazepines and Z-drugs (BZD/Z)

In your general practice how do you diagnose SUD to BZD/Z drugs?

What criteria to do you use?

Length of time dependent / dosage

Does this approach differ from how you diagnose dependence to other substances?

Do you involve other healthcare professionals in the diagnostic process? If so who?

Types of patients with BZD/Z SUD

What would you say is a typical patient profile? For SUD to BZD?

What is their typical trajectory - how do typical patients you care for end up with an SUD to BZD?

Do you have many patients that have multiple addictions?

Do you have many patients that also suffer from mental health problems in addition to their SUD?

Treatment of BZD/Z SUD

What is your general approach to treating SUD to BZD?

How do you approach the issue with your patients?

Goal oriented care, shared-decision making, patient education...?

Do you struggle to address the issue with patients?

What stops you?

What encourages you?

What is your usual course of action?

 Tapering-off? Substitution with other medication? Supportive therapies/treatments?

How do you choose between these options? What influences your choice?

What are the advantages and disadvantages of each?

How do you manage relapses?

How do you see the role of the patient in the decision making?

Vision on successful treatment

What does successful treatment look like to you?

Do you feel there is a tension between you and colleagues on what successful treatment should look like?

Is there a tension between you and your patients concerning what successful treatment looks like?

Do they want to reach total abstinence?

Do they feel reaching total abstinence is impossible?

Is there a tension for you between total abstinence and harm reduction?

Vision on prescription of BZD/Z

How do you view prescription of BZD/ Z drugs?

Is there ever justification for prescribing BZD?

In what circumstances?

How should prescription be managed? Safeguards?

Does your institution have a policy concerning prescription for BZD/Z drugs?

Do you agree with it?

How do colleagues within the facility view the policy?

What about other colleagues? Other professions/institutions?

Numbers of patients with a BZD/Z SUD (treated), estimate of successful treatment

How successful do feel treatment is? What proportion of your patients go on to successfully complete treatment?

Estimate of possible treatment gap

How many patients do you feel need treatment but are not getting it?

Out of 10 patients who need treatment how many do you think are receiving treatment?

Perception of barriers and facilitators / protective factors (

In your view what facilitates the access to care for patients in Belgium - protective factors? (Health beliefs, social structure, stigma etc

What hinders it? (Financial means of the patient, geography etc.)

In your view what facilitates the role of the provider in the providing treatment to patients with SUD to BZD?

What barriers may the provider encounter to providing treatment?

In your view what elements of the Belgian health care system (or the regional offer) promote access to care among typical patients with a SUD to BZD?

What elements of the system hinder access to care?

Some statistics about your practice

How many patients are you responsible for?

What type of practice are you working in?

What would you say is the socio-economic situation of patients in your practice? Living in poverty, poor, comfortable

Final reflective question: on impact of recent reforms in the mental health/addiction care sector on prescribing/ deprescribing of BZD/Z

How do feel the recent reforms in mental healthcare have impacted the addiction care sector?

How has this impacted prescribing BZD/Z?

How has this impacted deprescribing of BZD/Z?

Chapter 3

'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

Introduction: 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.

Methods: 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.

Results: 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.

Conclusion: 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.

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, Pasteels, 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, Henrard, et al., 2022) and examining facilitators and barriers at provider and system level (Linsky & 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 (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 & 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 & 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 & Done, 2021; Wangensteen & 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, Habraken, Petrovic, et al., 2007; Cook, Biyanova, 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, Habraken, Petrovic, et al., 2007), factors influencing older patients' willingness to consider stopping benzodiazepines (Cook, Biyanova, 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 (J. A. Smith & Nizza, 2021). This method delves into how participants construct meaning from their experiences, perceptions and perspectives (J. A. Smith & 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 (J. A. Smith & 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?

Methods

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 (Additional File 3.1). 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., 2021b). 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) (Image 1). 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 Image 1, 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.

Interviews

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 6 interviews in Dutch by the second author (MC, female, postdoctoral researcher and medical anthropologist). 18 interviews 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 to 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 (J. A. Smith & 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).

Results

Description of the study sample

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 3.1. 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.

| Code | Date of the interview | Year of birth | Gender | Professional status | Reason for first presciption | Online or in person |
|--------|-----------------------|---------------|--------|---------------------|--|---------------------|
| RESP1 | 27-04-22 | 1980 | М | Working | Anxiety | In person |
| RESP2 | 22-07-22 | 1964 | М | Unemployed | acute psychosis due to drug abuse | Online |
| RESP3 | 29-07-22 | 1985 | F | On sick leave | Insomnia | In person |
| RESP4 | 31-08-22 | 1989 | М | On sick leave | Anxiety | In person |
| RESP5 | 02-09-22 | 1969 | М | Working | Stress | In person |
| RESP6 | 15-12-22 | 1971 | F | Unemployed | Insomnia | In person |
| RESP7 | 09-05-22 | 1948 | F | Retired | Anxiety | In person |
| RESP8 | 25-05-22 | 1948 | F | Retired | Pain | In person |
| RESP9 | 07-06-22 | 1969 | F | Working | Sleep | In person |
| RESP10 | 23-06-22 | 1970 | М | Unemployed | Anxiety | In person |
| RESP11 | 11-07-22 | 1970 | F | Working | Anxiety | In person |
| RESP12 | 08-09-22 | 1949 | М | Retired | Sleep | In person |
| RESP13 | 09-09-22 | 1961 | F | Reitred | Sleep | Online |
| RESP14 | 14-09-22 | 1961 | F | Working | Sleep and anxiety | In person |
| RESP15 | 16-09-22 | 1971 | F | Working | Anxiety | In person |
| RESP16 | 21-09-22 | 1950 | М | Retired | Anxiety | In person |
| RESP17 | 30-09-22 | 1986 | F | Working | Anxiety | In person |
| RESP18 | 05-10-22 | 1973 | F | Unemployed | Anxiety | In person |
| RESP19 | 10-10-22 | 1976 | F | Working | Anxiety | In person |

Table 3.1. Socio demographic data

Interviews findings

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 (table 3.2): (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».

5 themes

- 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]'
- 5. 'If you want to do it right, you have to go slowly'

Table 3.2. Themes

1. '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.

2. 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.

3. '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.

(…)

"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

4. '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

5. '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

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 decisionmaking 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 & 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., 2021b).(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.-b). 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 goaloriented 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 & 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.

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.

Implementing a GOC approach could address these challenges by involving patients in decision-making and tailoring interventions to their preferences. This approach, relatively novel in BZRA deprescribing, aims to prioritize patient goals, enhance treatment satisfaction, and improve outcomes. By establishing shared treatment goals, patient satisfaction and healthcare professional fulfilment can be enhanced.

Overall, the findings underscore the significance of communication, collaboration, and personalized support in managing long-term BZRA use. Adopting a GOC approach holds promise for optimising care delivery, particularly for patients managing multiple conditions, by aligning treatment strategies with individual goals and preferences.

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Declaration of interest statement

The authors report there are no competing interests to declare.

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Ethical Statement

This study received approval from the Ethics Committee (Comité d'Éthique Hospitalo-Facultaire Universitaire de Liège with the approval number: 2021/121 and a positive response from the Ethics Committee of the Faculty of Political and Social Sciences of Ghent University with reference number: EC-2021-22). Prior to participating to the study, participants were provided with an information and informed consent letter, as well as a verbal explanation of the study's objectives. 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.

Additional File 3.1

Topic guide

Demographic and socio-economic background

- 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/retired/ sick leave/ other: fill in

Where are they in the cycle of Prochaska and Diclemente¹?

- Are you currently (tick all that apply): completely stopped, actively tapering-off/reducing doses, at a stable dose (no plans to reduce)
- Choose an answer that corresponds to your situation:
 - I stopped taking sedatives and/or tranquilizers.
 - I started to reduce the number of sedatives and/or tranquilizers.
 - I did not plan to reduce the number of sedatives and/or tranquilizers.

Type of medication

- What kind(s) of sedatives and/or tranquilizers have you taken regularly?
- What kind(s) of sedatives and/or tranquilizers do you take regularly?

INTRODUCTORY QUESTION

Tell me about your experiences **recovering from** using sedatives and/or tranquilizers?

Aim: get basic background history

Pertinent additional questions can be asked, for example to explore overarching concepts and definitions.

CALENDAR METHOD

For this question we will employ an adjusted life history calendar method (Nelson, 2010) ² centered on the participant's medication and cessation history. The participant will be invited to draw a timeline of his/her medication and cessation history. We will allow the participant to fill this in freely. We will ask them to indicate the following major event points (in line with the different phases outlined by DiClemente and Prochaska, 1998) ¹:

- 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)

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 do 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? Marriages? Deaths?

- Professional life? (work?)
- Stressful 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...

RECOVERY (stabilization, stop, reduce, satisfactory situation)

- What was the first step? (Did the decision come from yourself or did someone else suggest it (e.g. Health Care Professional)? Probes (based on BENZONET study³):
- What/who helped to take that first step?
 - 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)
 - o 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?
 - 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

- o 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? (Refer to previous responses)

Who was supporting you? What exactly was supportive about their help? (Here we will show a list of possible sources of help, accompanied by an icon)

- 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
- Optional question: are you a believer?
- Whose help were you missing?
- How did your recovery evolve? Can you describe the process?
- How did you experience that part of the treatment?
 - o Physical effects?
 - o 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?

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Chapter 4

Primary, secondary and tertiary prevention of long-term benzodiazepine receptor agonists use in Belgium: a Policy Delphi

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Abstract

Background: 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.

Methods: 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.

Results: 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 peer support, "benzo-buddy" system, garnered less agreement, suggesting that these proposals require further refinement.

Conclusion: 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 use 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.

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 & 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.-a).

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?

Methods

Policy Delphi Process and recruitment

To answer the research 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:

1. 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) (Additional File 4.1). For the interviews conducted in the initial phase, healthcare professionals and patients were recruited through Belgian mental health and primary care networks, as well as a walloon and Flemish professional medical newspaper. To ensure diversity among healthcare professionals, factors such as geographic location, gender, professional roles, and practice settings were considered, aiming to include at least two participants from each profession (general practitioners, nurses, social workers, psychiatrists, and psychologists). For the patient group, long-term BZRA users (≥6 months) were targeted, with recruitment through various Belgian mental health networks, primary healthcare channels, social media, and by inviting individuals featured in a French-speaking Belgian television documentary on long-term BZRA use. Eligible patients had prior BZRA experience and had stabilized, reduced, or discontinued usage. A diverse patient sample was ensured by considering variations in experiences, geographic locations, and stages of cessation.

The interviews with healthcare professionals explored various aspects of managing patients using BZRAs, with questions such as, "What does successful treatment look like to you?" or "In your view, what elements of the Belgian healthcare system (or the regional offer) promote or hinder access to care for typical patients with a substance use disorder related to BZRAs?" The complete interview guide is included in Additional File 2.1. Similarly, patient interviews focused on their experiences from the initial prescription of BZRAs, their usage trajectory, decisions to stop, stabilize, or reduce use, and the recovery period. At the end of the interview, patients were asked, "What would you do to make this process easier for others, if you could do anything, in an ideal world?" to identify policy recommendations. This interview guide is also included in Additional File 3.1. All interviews were transcribed and analysed using thematic analysis (Dusi &

Stevens, 2022) by the research team (PV, MC, BS) in order to identify policy recommendations. These recommendations underwent thorough discussion and revision within the team to ensure accuracy in their formulation.

Each recommendation was then categorised by the research team (PV, MC, BS) according to prevention tiers via the following definitions (Leavell & Clark, 1953):

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

This structured approach ensured that the policy recommendations were firmly grounded in the experiences and insights of both healthcare professionals and patients.

2. First round

For the policy Delphi process, an expert panel consisting of healthcare professionals and patients was assembled 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. Participant selection aimed to gather professionals in mental health care, addiction care, primary care, or pharmacy who have a connection to the topic of BZRAs, whether through direct practice or health policy perspectives. For patients, the criterion was having taken or currently taking BZRAs.

A total of 111 participants took part in the first round (Table 4.1 and Table 4.2). It took place over two weeks in March 2023 with an online questionnaire via the LimeSurvey platform (Additional File 4.2). In this first round, the participants completed the online questionnaire. The participants were asked to evaluate (1) the feasibility and (2) the extent to which they supported each recommendation. Feasibility and support were assessed via a five-point Likert scale ranging from 'completely disagree' to 'completely agree' for the categories 'feasibility' and 'support'. 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'. The scale to measure support was developed in a similar manner. Since these participants were different from those in the initial phase of compiling and identifying policy recommendations, the participants had the opportunity to add additional recommendations in an open text box: "If you have any suggestions for additional recommendations, please indicate them here."

3. Analysis of additional recommendations

The ideas for new policy recommendations put forward by the participants in the first round were reviewed 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 revised by the fourth author (JLB) and incorporated into the existing set of 20 recommendations. Seven additional recommendations from the first-round participants were added to the initial 20 derived from interviews with healthcare professionals and patients, resulting in a total of 27 recommendations evaluated in the second round.

4. Round 2

The second round took place over two weeks in April 2023 with an online questionnaire via the LimeSurvey platform (Additional File 4.3). 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 and support 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.

Data analysis

The consensus level analysis was conducted on the Policy Delphi technique based on the technique developed by Meskell et al., 2014. This approach is particularly appropriate as it captures both the extent of consensus and the direction of opinions, offering a more comprehensive understanding of agreement and disagreement. The classification of consensus is based on both agreement scales, providing a structured framework to evaluate consensus levels and the underlying direction of opinions. Responses are categorized into distinct levels of agreement and importance, which are subsequently classified into high, moderate, or low consensus according to predefined thresholds:

High consensus:

- ≥ 70% agreement in a single category (completely agree, agree, neither agree nor disagree, disagree, completely disagree OR very important, important, neither important nor unimportant, slightly important, unimportant,).
- ≥ 80% agreement in grouped categories (completely agree & agree OR disagree & completely disagree OR very important & important OR slightly important & unimportant).

Moderate consensus:

- ≥ 60% and <70% agreement in a single category (completely agree, agree, neither agree nor disagree, disagree, completely disagree OR very important, important, neither important nor unimportant, slightly important, unimportant).
- ≥ 70% and <80% agreement in grouped categories (completely agree & agree OR disagree & completely disagree OR very important & important OR slightly important & unimportant).

Low consensus:

- > 50% and <60% agreement in a single category (completely agree, agree, neither agree nor disagree, disagree, completely disagree OR very important, important, neither important nor unimportant, slightly important, unimportant).
- ≥ 60% and <70% agreement in grouped categories (completely agree & agree OR disagree & completely disagree OR very important & important OR slightly important & unimportant).

Consensus direction (in favour, against, or neutral) was determined based on the highest level of agreement.

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 4.1 shows the sociodemographic data of the patients from the expert panel and Table 4.2 shows the sociodemographic data of the professionals from 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 4.3, categorised and aligned with tiers of prevention.

| Responding as | N | % |
|---|----------|-------|
| Gender | | • |
| Female | 27 | 84,38 |
| Male | 5 | 15,63 |
| Age | • | |
| 18-40 | 11 | 34,38 |
| 41-60 | 14 | 43,75 |
| >60 | 7 | 21,88 |
| Regions | <u> </u> | • |
| Brussels | 3 | 9,38 |
| Flanders | 25 | 78,13 |
| Wallonia | 4 | 12,50 |
| Current occupation among patients | <u> </u> | • |
| Student | 2 | 6,25 |
| Unemployed | 3 | 9,38 |
| Worker | 10 | 31,25 |
| On sick leave/invalid | 11 | 34,38 |
| Retired | 4 | 12,50 |
| Other | 2 | 6,25 |
| Current BZRA use among patients | <u> </u> | • |
| Using 1 or more BZRA for the long term | 6 | 18,75 |
| In the process of tapering off 1 or more BZRA | 5 | 15,63 |
| Completely tapered off one or more BZRA | 16 | 50 |
| Other | 5 | 15,63 |
| Round participation | | |
| Patients who took part in the first round | 32 | 28,83 |
| Patients who took part in the second round | 17 | 27,42 |

Table 4.1: Sociodemographic Data of the Patients

Percentages are calculated based on the total number of patients, except for the "Round Participation" category, where percentages are based on the total number of participants within each round.

| Responding as | N | % |
|---|-------|--------|
| Gender | | l |
| Female | 50 | 63,29 |
| Male | 29 | 36,71 |
| Age | | |
| 18-40 | 35 | 44,30 |
| 41-60 | 36 | 45,57 |
| >60 | 8 | 10,13 |
| Regions | 1 | I |
| Brussels | 20 | 25,32 |
| Flanders | 46 | 58,23 |
| Wallonia | 13 | 16,46 |
| Current professions among participants res | spond | ing as |
| professionals or as a professional who has | taker | or is |
| taking BZRA | | |
| General Practitioners | 22 | 27,85 |
| Nurse | 1 | 1,27 |
| Pharmacists | 17 | 21,52 |
| Psychiatrists | 8 | 10,13 |
| Psychologists | 11 | 13,92 |
| Social workers | 4 | 5,06 |
| Other | 16 | 20,25 |
| Years of experience | | |
| Between 0 – 10 years | 27 | 34,18 |
| Between 11 – 20 years | 24 | 30,38 |
| Between 21- 30 years | 16 | 20,25 |
| > 30 years | 12 | 15,19 |
| Current BZRA use among professionals who | cons | idered |
| themselves as professionals and BZRA users | | |
| Using 1 or more BZRA for the long term | 2 | 2,53 |
| In the process of tapering off 1 or more BZRA | 0 | 0 |
| Completely tapered off one or more BZRA | 4 | 5,06 |
| Other | 0 | 0 |
| Round participation | • | • |
| Professionals who took part in the first round | 79 | 71,17 |
| professionals who took part in the second round | 45 | 72,58 |

Table 4.2: Sociodemographic Data of the Professionals

Percentages are calculated based on the total number of professionals, except for the "Round Participation" category, where percentages are based on the total number of participants within each round.

| | Primary prevention | Initial recommendation (IR) or new recommendation (NR) |
|----|--|--|
| 1 | Implement an awareness raising campaign among the general public on tapering off BZRA. | IR |
| 2 | Implement an awareness raising campaign for patients on the challenges of withdrawing BZRA from multiple medications. | IR |
| 3 | Implement an awareness raising campaign for professionals on the challenges of withdrawing from multiple medications. | IR |
| 4 | Implement an awareness raising campaign of the risks of BZRA in empathetic and non-stigmatising way. | IR |
| 5 | Add warnings of the risk of dependence on the BZRA package. | IR |
| 6 | Undertake further research on the mechanisms surrounding the first prescription of BZRA. | NR |
| | Secondary prevention | |
| 7 | Increase the price per BZRA package. | IR |
| 8 | Create smaller packages of BZRA. | IR |
| 9 | Provide information by the prescriber to the patient regarding the risks of dependency of BZRA at first use. | IR |
| 10 | Provide higher remuneration for prescribers for long follow up consultations dedicated to BZRA. | NR |
| 11 | Give access to other BZRA prescribers/providers to the part of the medical file related to prescriptions. | NR |
| 12 | Allow the carer to dispense one or two doses of BZRA at the same time to provide the correct dose. | NR |
| | Tertiary prevention | |
| 13 | Encourage prescribers to add the indication for substance use disorders next to insomnia/anxiety to patient records when use exceeds guidelines. | IR |
| 14 | Establish an agreement between the prescriber, the pharmacist and the patient to keep the same prescriber and pharmacist throughout treatment. | IR |
| 15 | Create a shared policy position between different professional's groups in addiction care concerning the management of BZRA. | IR |
| 16 | Create an inter-professional communication channel at local level, between pharmacists and GPs to discuss common patients | NR |
| 17 | Implement a training course on difficult tapering-off processes related to BZRA for professionals. | IR |

| 18 | Establish and providing a list of healthcare providers specialised in | IR |
|----|---|----|
| | tapering off of BZRA. | |
| 19 | Establish a support and advice line for people who want to taper off of | IR |
| | BZRA. | |
| 20 | Develop a 'Benzo-buddy' system. | IR |
| | * The 'benzo-buddy system' refers to a mentorship and peer support | |
| | system among individuals with lived experience withdrawing from BZRA | |
| | (after long-term use). | |
| 21 | Share patient testimonials about BZRA tapering-off. | IR |
| 22 | Develop culturally appropriate patient materials. | IR |
| 23 | Create an ombudsperson for healthcare practitioners to report other | IR |
| | practitioners who over-prescribe, prescribe or delivered unsafely BZRA. | |
| 24 | Extend the patient inclusion criteria of the new reimbursement scheme for | IR |
| | 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 | IR |
| | 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 | NR |
| | process. | |
| 27 | Tailor residential addiction care programmes, specifically to BZRA | NR |
| | withdrawal. | |
| | | |

Table 4.3 List of the 27 recommandations

Among the recommendations, a level of consensus was established based on the technique developed by 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. In the first round, percentages were calculated based on the total number of participants (n=111). In the second round, percentages for the seven additional recommendations were calculated based on the number of participants in that round (n=62). As described in the method, the level of consensus was then calculated and classified using a 4-point scale of high, moderate, low and none (Table 4.4).

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'; 2, '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.

| Statement | Feasi | Feasibility | Support | port | Impor | Importance | Cond | Conditions |
|-----------|-----------|-------------|-----------|-----------|-----------|------------|-----------|------------|
| number | Level of | | Level of | | Level of | | Level of | |
| | consensus | Direction | consensus | Direction | consensus | Direction | consensus | Direction |
| Q1 | High | + | High | + | High | + | Moderate | + |
| Q2 | High | + | High | + | High | + | Moderate | + |
| Q3 | High | + | | + | High | + | High | + |
| Q4 | Moderate | + | High | + | High | + | Moderate | + |
| Q5 | High | + | High | + | Moderate | + | Moderate | + |
| Q6 | 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 | II |
| Q24 | Low | + | Moderate | + | High | + | None | |
| Q25 | Low | + | Moderate | + | High | + | None | |
| Q26 | Moderate | + | High | + | High | + | None | |
| Q27 | Low | + | Moderate | + | Low | + | None | |

Moderate level of consensus

No recommendation was assessed as having a moderate level of consensus for all four 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 nonstigmatising 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 four categories. Some more restrictive recommendations had three 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 (Table 4.4). 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.

Disparities in Perspectives Between Patients and Healthcare Professionals

The level of consensus varied between patients and healthcare professionals for several of the recommendations listed below and in Table 4.5. There is a jump from one level to another, skipping at least one intermediate stage. For many recommendations, patients did not reach a consensus level, which is noted as 'none,' whereas for professionals, the level is considered two categories higher (e.g., 'high' for professionals and 'none' for patients). This is the case for the following items: Feasibility: Q8; Support: Q8, Q14, Q21; Importance: Q1–Q4; Q6; Q8–Q9; Q15–Q18; Q21–Q22; Q24–Q26; Conditions: Q1–Q6; Q8–Q9; Q17; Q22. Additionally, some recommendations stand out. For instance, Recommendation 18 ("Establish and provide a list of healthcare providers specialized in tapering off

BZRA") shows a low level of consensus among professionals but a high level of consensus among patients regarding feasibility.

A different pattern emerged for Recommendation 20 ("Develop the 'benzo-buddy system"). While patients reached a moderate level of consensus regarding support and a low level of consensus regarding feasibility, healthcare professionals showed low or no consensus for both aspects.

| | | Feasibility | illity | | | Su | Support | | | Importance | ance | | | Con | Conditions | |
|-----------|---------------|-------------|-----------|-----------|---------------|-----------|-----------|-----------|---------------|------------|-----------|-----------|---------------|-----------|------------|-----------|
| Statement | Professionals | onals | Patients | nts | Professionals | | Patients | ıts | Professionals | nals | Patients | ents | Professionals | onals | Patients | ts |
| number | Level of | | Level of | | Level of | | Level of | | Level of | | Level of | | Level of | | Level of | |
| | consensus | Direction | consensus | Direction | consensus | Direction | consensus | Direction | consensus | Direction | consensus | Direction | consensus | Direction | consensus | Direction |
| 01 | High | + | Moderate | + | High | + | High | + | High | + | None | | High | + | None | |
| 02 | High | + | Moderate | + | High | + | | + | High | + | None | | Moderate | + | None | |
| 03 | High | + | High | + | | + | | + | | + | None | | High | + | None | |
| Q4 | High | + | Moderate | + | High | + | High | + | High | + | None | | Moderate | + | None | |
| 0,5 | High | + | High | + | High | + | High | + | Low | + | None | | Moderare | + | None | |
| Q6 | None | | None | | None | | None | | | + | None | | Moderate | + | None | |
| ۵7 | None | | None | | None | | None | | None | | None | | None | | None | |
| 08 | High | + | None | | High | + | None | | High | + | None | | Moderate | + | None | |
| 60 | High | + | High | + | | + | High | + | High | + | None | | Moderate | + | None | |
| Q10 | None | | None | | None | | None | | None | | None | | None | | None | |
| Q11 | None | | None | | None | | None | | Low | + | None | | None | | None | |
| Q12 | None | | None | | None | | None | | Low | + | None | | None | | None | |
| Q13 | Low | + | None | | Low | + | None | | None | | None | | Low | + | None | |
| Q14 | Low | + | None | | Moderate | + | None | | Low | + | None | | None | | None | |
| Q15 | Moderate | + | Low | + | High | + | High | + | Moderate | + | None | | None | | None | |
| Q16 | None | | None | | | + | None | | High | + | None | | Low | + | None | |
| Q17 | High | + | High | + | High | + | High | + | High | + | None | | High | + | None | |
| Q18 | Low | + | High | + | Moderate | + | High | + | Moderate | + | None | | None | | None | |
| 019 | Low | + | Moderate | + | Moderate | + | High | + | None | | None | | None | | None | |
| 020 | None | | Low | + | Low | + | Moderate | + | None | | None | | None | | None | |
| 021 | High | + | Moderate | + | High | + | None | + | Moderate | + | None | | Low | + | None | |
| Q22 | High | + | Moderate | + | High | + | High | + | High | + | None | | Moderate | + | None | |
| 023 | None | | None | + | None | | None | | None | | None | | None | | None | |
| 024 | Low | + | None | + | Moderate | + | Moderate | + | Moderate | + | None | | None | | None | |
| 0,25 | Moderate | + | Low | | High | + | Moderate | + | Moderate | + | None | | Low | + | None | |
| 026 | None | | None | + | None | | None | | High | + | None | | None | | None | |
| 027 | None | | None | + | None | | None | | Low | + | None | | None | | None | |

Table 4.5. Level of consensus and direction: divergence among professionals and patients

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 nonstigmatising 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.

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. However, 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.

The strong support for awareness-raising campaigns suggests that participants view these initiatives as both necessary and currently underutilized in Belgium. Internationally, public health campaigns have been deployed to address benzodiazepine dependence, yet few have been rigorously evaluated for their effectiveness. In Australia, for instance, a multi-strategic approach was implemented to reduce benzodiazepine use, combining media outreach (newspaper articles, radio commercials, posters) with targeted interventions. This has illustrated that sustainable reductions in BZRAs consumption are achievable

when awareness initiatives are integrated into broader, evidence-based strategies (Dollman et al., 2005).

Other initiatives, such as the "Choosing Wisely" campaign, have also emerged. Launched in the United States in 2012, the campaign was later adopted in Canada and several European countries (*Choosing Wisely (Australia*), n.d.; *Choosing Wisely (Canada*), n.d.; *Choosing Wisely (Italia*), n.d.; Levinson et al., 2015). Its primary objective was to reduce the use of low-value medical interventions. Within this framework, physicians and patients were encouraged to avoid prescribing benzodiazepines as a first-line treatment for insomnia in older adults. However, no formal evaluation has been conducted on its impact on benzodiazepine prescribing trends, leaving its effectiveness uncertain.

Research shows that well-designed public health initiatives can enhance medication adherence and awareness. However, to be effective across diverse populations, messages must be adapted, clearly formulated, and supported by adequate funding, research, and evaluation (Gupta et al., 2016; Huang et al., 2006; Ranjbar et al., 2017; Shen et al., 2006; Wakefield et al., 2010; Wen et al., 2007). 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, ensuring that they remain nonstigmatising 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 nonstigmatising language, emphasizing support and recovery rather than blame or judgment.

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 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, Habraken, Petrovic, 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, Habraken, Petrovic, 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, Habraken, Petrovic, 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 reinforce the need for specialised training programs for professionals on BZRA withdrawal. These proposals were widely endorsed for their feasibility, support and importance, reflecting strong participant 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 upto-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. The latter, in particular, received low consensus across multiple criteria, including feasibility, support, importance, and implementation conditions. However, when considering only the perspective of patients—the primary stakeholders of this recommendation—the level of consensus was moderate. This highlights the importance of further exploring such initiatives, as their innovative and original nature may lead them to be overlooked despite their potential impact.

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. Prioritising widely supported recommendations is advisable, as they are more feasible and broadly endorsed. Meanwhile, lower-consensus proposals may need further refinement to address concerns related to implementation. 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.

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. This discrepancy in participant numbers between the two phases represents a limitation of our study. Specifically, the evaluation of the final seven recommendations was conducted by only 62 participants, whereas the initial 20 recommendations were assessed by 111 participants. Although this shows a considerable drop out between round one and two, the minimum required number of participants for this type of multistakeholder Delphi study as set out by Manyara et al. (2024) was nonetheless reached (Manyara et al., 2024).

Conclusion

The diversity of recommendations and the levels of consensus underscore the complexity of addressing long-term BZRA use in Belgium. Nevertheless, a comprehensive approach combining education, raising awareness, and healthcare training, seems feasible and well supported. Key strategies include informing patients, training healthcare providers and fostering a supportive environment for withdrawal. Some recommendations received less consensus but stand out for

their originality and innovative nature. Notably, like the benzo-buddy system, these recommendations were more strongly supported by patients. Further research could disentangle this hesitancy of health-care providers. Peer support by patients with lived experience is already well established in mental and addiction care, yet still has to be further explored in care for tapering from prescription medication. Integrating multiple strategies is crucial. Applying implementation science framework, such as the behaviour change wheel and the theoretical domain framework, could help structure effective public health interventions and guide future policy development (Michie et al., 2005).

Ethics approval and consent to participate

Approval for this study was granted by the Ethics Committee (Hospital University Faculty Ethics Committee of Liège with approval number: 2021/121 and Ethics Committee of the Faculty of Political and Social Sciences of Ghent University with reference number: EC-2021-22). Before agreeing to participate in the e-study, the participants were provided with detailed information about the study and its objectives. They then provided voluntary and informed consent online. To maintain anonymity, all names and identifying information were omitted from the data.

Consent for publication

The participants who took part in the Policy Delphi were informed and agreed that the results would be published in a scientific journal.

Availability of data and materials

Anonymised datasets analysed as part of this study are available from the corresponding author on reasonable request.

Competing interests

The authors report that there are no competing interests to declare.

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Authors' contributions

PV conceived and designed the study, carried out the investigation and methodology, and drafted the original manuscript. BS contributed to the conceptualisation and investigation, carried out the methodology, supervised the work, acquired funding, and reviewed and edited the manuscript. JLB supervised the work, acquired funding, and reviewed and edited the manuscript. MC contributed to the conceptualisation and investigation, carried out the methodology, supervised the work, acquired funding, and reviewed and edited the manuscript.

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Additional File 4.1

Characteristics of professional participants

| | Interview | | Professional | | | |
|--------|-----------|--------|--------------|--------------------|-----------|----------|
| Code | date | Gender | background | Type of practice | Location | Region |
| RESP1 | 14-07-21 | Female | GP | Addiction care | Urban | Flanders |
| RESP2 | 20-09-21 | Male | GP | Addiction care | Urban | Flanders |
| | | | social | | | |
| RESP3 | 13-10-21 | Male | worker | Addiction care | Urban | Flanders |
| RESP4 | 20-10-21 | Male | GP | Addiction care | Urban | Flanders |
| RESP5 | 22-10-21 | Male | Psychiatrist | Addiction care | Urban | Flanders |
| RESP6 | 03-11-21 | Female | GP | Addiction care | Urban | Flanders |
| RESP7 | 04-11-21 | Female | GP | Addiction care | Urban | Flanders |
| RESP8 | 17-11-21 | Female | GP | Primary care | Urban | Flanders |
| RESP9 | 30-11-21 | Female | Psychiatrist | Addiction care | Urban | Flanders |
| | | | | | Urban/rur | |
| RESP10 | 09-12-21 | Female | GP | Primary care | al | Flanders |
| RESP11 | 29-12-21 | Female | Nurse | Mental health care | Urban | Flanders |
| | | | Psychologis | | | |
| RESP12 | 07-01-22 | Male | t | Mental health care | Urban | Flanders |
| RESP13 | 07-01-22 | Male | Psychiatrist | Mental health care | Urban | Flanders |
| RESP14 | 08-07-21 | Female | GP | Primary care | Rural | Wallonia |
| RESP15 | 05-08-21 | Male | GP | Primary care | Urban | Wallonia |
| | | | Psychologis | | | |
| RESP16 | 23-08-21 | Female | t | Addiction care | Urban | Brussels |
| RESP17 | 23-08-21 | Female | GP | Addiction care | Urban | Brussels |
| | | | Social | | | |
| RESP18 | 06-09-21 | Female | worker | Addiction care | Rural | Wallonia |
| RESP19 | 09-09-21 | Female | Nurse | Addiction care | Urban | Brussels |
| RESP20 | 10-09-21 | Male | Psychiatrist | Mental health care | Rural | Wallonia |
| RESP21 | 13-09-21 | Male | GP | Primary care | Urban | Brussels |
| | | | Psychologis | | | |
| RESP22 | 21-09-21 | Male | t | Addiction care | Rural | Wallonia |
| RESP23 | 22-09-21 | Male | Psychiatrist | Addiction care | Urban | Brussels |
| | | | Social | | | |
| RESP24 | 19-11-21 | Female | worker | Addiction care | Rural | Wallonia |

Characteristics of participating patients

| Code | Interview | Gender | Year of | Professional | Reason for | Region |
|--------|-----------|--------|---------|--------------|-------------|----------|
| | date | | birth | status | first | |
| | | | | | presciption | |
| RESP1 | 27-04-22 | М | 1980 | Working | Anxiety | Flanders |
| RESP2 | 22-07-22 | М | 1964 | Unemployed | Acute | |
| | | | | | psychosis | |
| | | | | | due to drug | |
| | | | | | abuse | Flanders |
| RESP3 | 29-07-22 | F | 1985 | On sick | Insomnia | |
| | | | | leave | | Flanders |
| RESP4 | 31-08-22 | М | 1989 | On sick | Anxiety | |
| | | | | leave | | Flanders |
| RESP5 | 02-09-22 | М | 1969 | Working | Stress | Flanders |
| RESP6 | 15-12-22 | F | 1971 | Unemployed | Insomnia | Flanders |
| RESP7 | 09-05-22 | F | 1948 | Retired | Anxiety | Wallonia |
| RESP8 | 25-05-22 | F | 1948 | Retired | Pain | Wallonia |
| RESP9 | 07-06-22 | F | 1969 | Working | Sleep | Wallonia |
| RESP10 | 23-06-22 | М | 1970 | Unemployed | Anxiety | Wallonia |
| RESP11 | 11-07-22 | F | 1970 | Working | Anxiety | Wallonia |
| RESP12 | 08-09-22 | М | 1949 | Retired | Sleep | Wallonia |
| RESP13 | 09-09-22 | F | 1961 | Reitred | Sleep | Wallonia |
| RESP14 | 14-09-22 | F | 1961 | Working | Sleep and | Wallonia |
| | | | | | anxiety | |
| RESP15 | 16-09-22 | F | 1971 | Working | Anxiety | Brussels |
| RESP16 | 21-09-22 | М | 1950 | Retired | Anxiety | Wallonia |
| RESP17 | 30-09-22 | F | 1986 | Working | Anxiety | Brussels |
| RESP18 | 05-10-22 | F | 1973 | Unemployed | Anxiety | Wallonia |
| RESP19 | 10-10-22 | F | 1976 | Working | Anxiety | Wallonia |

Additional File 4.2

Questionnaire policy Delphi - First round

Dear Sir/Madam,

The purpose of this survey is to establish policy recommendations on the management of sleeping pills and sedatives (benzodiazepines and Z-drugs) based on your experience as a professional in mental health care, addiction care, primary health care, pharmaceuticals or as a patient who has taken or is taking sleeping pills and sedatives. Based on interviews with professionals and patients, twenty recommendations emerged. In this questionnaire, we would like you to assess the feasibility and the extent to which you support these proposed recommendations. The order of recommendations in the survey follows the trajectory from primary prevention (when a person is not yet using) to tertiary prevention when a person is already using heavily. Completing the questionnaire will take you approximately 15 minutes. You will be contacted again to complete a second questionnaire at the end of April to further analyse these recommendations. You will be asked what conditions are necessary to make each recommendation feasible and how do you prioritise them.

Thank you for your collaboration and participation.

My participation is voluntary. I have the right to withdraw my consent at any time without giving a reason. * YES/NO

In order to meet the needs of this study, I consent to the collection and use of my data; * YES/NO

I authorise the consultation of my data to the persons collaborating in this research. * YES/NO

I give permission to reuse my data for further scientific research outside the scope of the current study.* YES/NO

After this study, I agree to be approached for further research. * YES/NO I wish to participate in this survey. * YES/NO

Your name *:

Your firstname *:

Your email address *:

What country do you live in? *

Please choose only one of the following:

Belgium / Luxembourg / Netherlands / France

In this study, are you responding as: *

Please choose only one of the following:

- A patient who has taken or is taking sleeping pills or sedatives
- A professional in mental health care, addiction care, primary care or pharmaceutical or a healthcare professional
- Both

What is your gender? *

Please choose only one of the following:

- Female
- Male
- Other

What is year of birth? *

Please enter a date:

<u>For professionals and responding as both:</u> What is your current profession? *

Please choose only one of the following:

- Psychiatrist
- General practionner
- Psychologist
- Pharmacist
- Nurse
- Social worker
- Health care professional
- Other

<u>For professionals and responding as both:</u> What is the postal code of your principal activity? *

For professionals and responding as both: How many years of experience do you have in your profession (for physicians: including years as physician assistant)?

Please write your answer here:

What is your postcode? *

Please write your answer here:

For patients: What is your occupation? *

For patients: Please choose only one of the following:

- Student
- Worker
- · On sick leave
- Unemployed
- Retired
- Other

<u>For patients</u>: Have you ever used sleeping sleeping pills or sedatives (benzodiazepines and Z-drugs) longer than 2-4 weeks? * Yes/No

For patients: Are you currently: *

- In the process of tapering-off one or more benzodiazepines and Z-drugs
- Completely tapered-off one or more benzodiazepines and Z-drugs
- Using one or more benzodiazepines and Z-drugs in the long term
- Other

Are you helping other patients to taper off benzodiazepines and Z-drugs? * Yes/No

How strongly do you agree or disagree with the following statements?* Please choose the appropriate response for each item:

| | Completely | Disagree | Neither agree | Agree | Completely |
|---|------------|----------|---------------|-------|------------|
| | agree | | nor disagree | | agree |
| In the current circumstances, it is feasible to implement an awareness | | | | | |
| raising campaign among the general public on tapering off benzodiazepines | | | | | |
| and Z-drugs. | | | | | |
| In the current circumstances, I would support the implementation of an | | | | | |
| awareness raising campaign among the general public on tapering off | | | | | |
| benzodiazepines and Z-drugs. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

| | Completely | Disagree | Neither agree | Agree | Completely |
|---|------------|----------|---------------|-------|------------|
| | agree | | nor disagree | | agree |
| I the current circumstances, it is feasible to implement an awareness raising | | | | | |
| campaign for patients on the challenges of withdrawing benzodiazepines | | | | | |
| and Z-drugs from multiple medications. | | | | | |
| I the current circumstances, I would support the implementation of an | | | | | |
| awareness raising campaign for patients on the challenges of withdrawing | | | | | |
| benzodiazepines and Z-drugs from multiple medications. | | | | | |

| | Completely | Disagree | Neither agree | Agree | Completely |
|--|------------|----------|---------------|-------|------------|
| | agree | | nor disagree | | agree |
| In the current circumstances, it is feasible to implement an awareness | | | | | |
| raising campaign for professionals on the challenges of withdrawing from | | | | | |
| multiple medications. | | | | | |
| In the current circumstances, I would support the implementation of an | | | | | |
| awareness raising campaign for professionals on the challenges of | | | | | |
| withdrawing from multiple medications. | | | | | |

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|---|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to implement an awareness raising campaign of the risks of benzodiazepines and Z-drugs in empathetic and non-stigmatising way. | | | | | |
| In the current circumstances, I would support an awareness raising campaign of the risks of benzodiazepines and Z-drugs in empathetic and non-stigmatising way. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|---|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to add warnings of the risk of | | | | | |
| dependance on the benzodiazepines and Z-drugs package. | | | | | |
| In the current circumstances, I would support the addition of warnings of the | | | | | |
| risk of dependance on the benzodiazepines and Z-drugs package. | | | | | |

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|---|------------------|----------|----------------------------------|-------|---------------------|
| In the current circumstances, it is feasible to increase the price per benzodiazepines and Z-drugs package. | | | | | |
| In the current circumstances, I would support increasing the price per benzodiazepines and Z-drugs package. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

| | Completely | Disagree | Neither | Agree | Completely |
|---|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to create smaller packages of | | | | | |
| benzodiazepines and Z-drugs is feasible. | | | | | |
| In the current circumstances, I would support the creation of smaller packages of | | | | | |
| benzodiazepines and Z-drugs. | | | | | |

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|--|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to provide information by the prescriber to the patient regarding the risks of dependency of benzodiazepines and Z-drugs at first use. | | | | | |
| In the current circumstances, I would support the provision of information by the prescriber to the patient regarding the risks of dependency of benzodiazepines and Z-drugs at first use. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|--|------------|----------|-----------------------|-------|------------|
| | agree | | agree nor disagree | | agree |
| In the current circumstances, it is feasible to encourage prescribers to add the | | | | | |
| indication for substance use disorders next to insomnia/anxiety to patient records | | | | | |
| when use exceeds guidelines. | | | | | |
| In the current circumstances, I would support the encouragement of prescribers | | | | | |
| to add the indication for substance use disorders next to insomnia/anxiety to | | | | | |
| patient records when use exceeds guidelines. | | | | | |

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|---|---------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to establish an agreement between the prescriber, the pharmacist and the patient to keep the same prescriber and pharmacist throughout treatment. | | | | | |
| In the current circumstances, I would support the establishment of an agreement between the prescriber, the pharmacist and the patient to keep the same prescriber and pharmacist throughout treatment. | | | | | |

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|--|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to create a shared policy position between professional groups in addiction care concerning the management of benzodiazepines and Z-drugs | | | | | |
| In the current circumstances, I would support the creation of a shared policy position between professional groups in addiction care concerning the management of benzodiazepines and Z-drugs. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|--|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to implement a training course on | | | | | |
| difficult tapering-off processes related to benzodiazepines and Z-drugs for | | | | | |
| professionals. | | | | | |
| In the current circumstances, I would support the implementation of a training | | | | | |
| course on difficult tapering-off processes related to benzodiazepines and Z- | | | | | |
| drugs for professionals. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|---|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to establish and providing a list of local | | | | | |
| healthcare providers trained in tapering off of benzodiazepines and Z-drugs for | | | | | |
| healthcare providers and patients. | | | | | |
| In the current circumstances, I would support the establishment and provision of | | | | | |
| a list of local healthcare providers trained in tapering off of benzodiazepines and | | | | | |
| Z-drugs for healthcare providers and patients. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|---|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to establish a support and advice line | | | | | |
| for people who want to taper off of benzodiazepines and Z-drugs. | | | | | |
| In the current circumstances, I would support the establishment of a support | | | | | |
| and advice line for people who want to taper off of benzodiazepines and Z- | | | | | |
| drugs. | | | | | |

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|--|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to develop a 'Benzo-buddy' system. | | | | | |
| In the current circumstances, I would support the development of a 'Benzo buddy' system. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|--|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to share patient testimonials about | | | | | |
| benzodiazepines and Z-drugs tapering-off. | | | | | |
| In the current circumstances, I would support the share of patient testimonials | | | | | |
| about benzodiazepines and Z-drugs tapering-off. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|--|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to develop culturally appropriate | | | | | |
| patient materials. | | | | | |
| In the current circumstances, I would support the development of culturally | | | | | |
| appropriate patient materials. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|---|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to create an ombudsperson for healthcare practitioners to report other practitioners who over-prescribe, prescribe or delivered unsafely. | | | | | |
| In the current circumstances, I would support the creation of an ombudsperson for healthcare practitioners to report other practitioners who over-prescribe, prescribe or delivered unsafely. | | | | | |

| | Completely | Disagree | Neither | Agree | Completely |
|---|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to extend the patient inclusion criteria | | | | | |
| of the new reimbursement scheme for the compounding of smaller doses of | | | | | |
| benzodiazepines and Z-drugs to residents living in nursing homes is feasible. | | | | | |
| In the current circumstances, I would support the extension of the patient | | | | | |
| inclusion criteria of the new reimbursement scheme for the compounding of | | | | | |
| smaller doses of benzodiazepines and Z-drugs to residents living in nursing | | | | | |
| homes. | | | | | |

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|--|---------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to extend the patient inclusion criteria of the new reimbursement scheme for the compounding of smaller doses of benzodiazepines and Z-drugs to patients who are taking more than one type of benzodiazepines or Z-drugs. | | | | | |
| In the current circumstances, I would support the extension of patient inclusion criteria of the new reimbursement scheme for the compounding of smaller doses of benzodiazepines and Z-drugs to patients who are taking more than one type of benzodiazepines or Z-drugs. | | | | | |

If you have any suggestions for additional recommendations, please indicate them here:

Please write your answer here:

Thank you for your participation to this study!

Additional File 4.3

Questionnaire policy Delphi - Second round

Dear Sir/Madam,

We would like to thank you for completing the first survey for the BENZOCARE study. We received a lot of valuable feedback on the different recommendations with regard to benzodiazepines and Z-drugs, as well as suggestions for new additional recommendations.

We now kindly invite you to participate in the second round of the online survey.

The purpose of this survey is threefold. We will first ask your opinion on the additional recommendations. We will then zoom in on rating all recommendations. Finally, we will ask you to prioritise and rank the recommendations that you deem most important and this per tier of prevention (primary, secondary and tertiary). Finally, we will ask you to provide information on the necessary conditions to implement a recommendation. The latter question is not mandatory, as we realise that for some recommendations this might be sector specific.

We would like to point out that we take on board all feedback in the previous round. For reasons of comparability we decided not to change the wording of certain recommendations in this phase, however, we will integrate the received feedback on this aspect in the final report.

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|---|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to provide higher remuneration for prescribers for long follow up consultations dedicated to benzodiazepines and Z-drugs. | | | | | |
| In the current circumstances, I would support the provision of higher remuneration for prescribers for long follow up consultations dedicated to benzodiazepines and Z-drugs. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|---|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| It is important to provide higher remuneration for prescribers for long follow up consultations dedicated to benzodiazepines and Z-drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible?

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|---|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to give access to other healthcare professionals related to the treatment of benzodiazepines and Z-drugs to the part of the medical file related to prescriptions. | | | | | |
| In the current circumstances, I would support giving access to other healthcare professionals related to the treatment of benzodiazepines and Z-drugs.to the part of the medical file related to prescriptions. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

How important do you think it is to implement this recommendation?

| | Unimportant | Slightly | Neither | Important | Very |
|---|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to give access to other | | | | | |
| healthcare professionals related to the treatment of benzodiazepines | | | | | |
| and Z-drugs to the part of the medical file related to prescriptions. | | | | | |

Are the conditions already met to make it feasible?

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|--|------------------|----------|----------------------------------|-------|---------------------|
| In the current circumstances, it is feasible to allow prescription/provision of | | | | | |
| benzodiazepines and Z-drugs per unit. | | | | | |
| In the current circumstances, I would support allowing prescription/provision of | | | | | |
| benzodiazepines and Z-drugs per unit. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly | Neither | Important | Very |
|---|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| I In the current circumstances, it is important to allow | | | | | |
| prescription/provision of benzodiazepines and Z-drugs per unit. | | | | | |
| | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible?

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|--|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to offer group therapy to non-hospitalised patients to support the tapering off process. | | | | | |
| In the current circumstances, I would support offering group therapy to non-hospitalised patients to support the tapering off process. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly | Neither | Important | Very |
|---|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to offer group therapy to | | | | | |
| non-hospitalised patients to support the tapering off process. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible?

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|---|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to undertake further research on the mechanisms surrounding the first prescription of benzodiazepines and Z-drugs. | | | | | |
| In the current circumstances, I would support undertaking further research on the mechanisms surrounding the first prescription of benzodiazepines and Z-drugs. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|--|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to undertake further research on | | | | | |
| the mechanisms surrounding the first prescription of benzodiazepines and Z- | | | | | |
| drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible?

| | Completely agree | Disagree | Neither agree nor disagree | Agree | Completely agree |
|--|------------------|----------|----------------------------------|-------|------------------|
| In the current circumstances, it is feasible to create an inter-professional communication channel at local level, between pharmacists and GPs to discuss common patients. | | | | | |
| In the current circumstances, I would support the creation an inter-professional communication channel at local level, between pharmacists and GPs to discuss common patients. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly | Neither | Important | Very |
|--|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to create an inter- | | | | | |
| professional communication channel at local level, between pharmacists | | | | | |
| and GPs to discuss common patients. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible?

Please write your answer here:

How strongly do you agree or disagree with the following statements?

| | Completely | Disagree | Neither | Agree | Completely |
|---|------------|----------|-----------|-------|------------|
| | agree | | agree nor | | agree |
| | | | disagree | | |
| In the current circumstances, it is feasible to tailor specific residential addiction | | | | | |
| programmes to benzodiazepines and Z-drugs. | | | | | |
| In the current circumstances, I would support tailoring specific residential | | | | | |
| addiction programmes to benzodiazepines and Z-drugs. | | | | | |

If you would like to elaborate on your responses, please do so here (optional):

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor | Important | Very Important |
|---|-------------|-----------------------|-----------------------|-----------|-------------------|
| | | | unimportant | | |
| In the current circumstances, it is important to tailor specific residential addiction programmes to benzodiazepines and Z-drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible?

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|--|-------------|-----------------------|---|-----------|-------------------|
| In the current circumstances, it is important to implement an awareness raising campaign among the general public on tapering off benzodiazepines and Z-drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly | Neither | Important | Very |
|--|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to Implement an | | | | | |
| awareness raising campaign for patients on the challenges of | | | | | |
| withdrawing benzodiazepines and Z-drugs from multiple medications. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly | Neither | Important | Very |
|--|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| | | | | | |
| In the current circumstances, it is important to implement an awareness | | | | | |
| raising campaign for professionals on the challenges of withdrawing from | | | | | |
| multiple medications. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|--|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to implement an awareness raising campaign of the risks of benzodiazepines and Z-drugs in empathetic and non-stigmatising way. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|---|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to add warnings of the risk of dependence on the benzodiazepines and Z-drugs package. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|---|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to increase the price per | | | | | |
| benzodiazepines and Z-drugs package. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|--|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to create smaller packages | | | | | |
| of benzodiazepines and Z-drugs | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|--|-------------|-----------------------|---|-----------|-------------------|
| In the current circumstances, it is important to provide information | | | | | |
| by the prescriber to the patient regarding the risks of dependency | | | | | |
| of benzodiazepines and Z-drugs at first use. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|---|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to encourage prescribers to add the indication for substance use disorders next to insomnia/anxiety to patient records when use exceeds guidelines. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly | Neither | Important | Very |
|--|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to establish an | | | | | |
| agreement between the prescriber, the pharmacist and the patient | | | | | |
| to keep the same prescriber and pharmacist throughout treatment. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|--|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to create a shared policy position between different professionals' groups in addiction care concerning the management of benzodiazepines and Z-drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly | Neither | Important | Very |
|---|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to Tailor residential | | | | | |
| addiction care programmes, specifically to benzodiazepines and Z- | | | | | |
| drugs withdrawal. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly | Neither | Important | Very |
|--|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to establish and providing | | | | | |
| a list of healthcare providers specialised in tapering off of | | | | | |
| benzodiazepines and Z-drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|---|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to establish a support and advice line for people who want to taper off of benzodiazepines and Z-drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly | Neither | Important | Very |
|--|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to develop a 'Benzo-buddy' system. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|---|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to share patient testimonials about benzodiazepines and Z-drugs tapering-off. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|--|-------------|-----------------------|---|-----------|-------------------|
| In the current circumstances, it is important to develop culturally appropriate patient materials. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible?

Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly important | Neither important nor unimportant | Important | Very Important |
|---|-------------|-----------------------|-----------------------------------|-----------|-------------------|
| In the current circumstances, it is important to create an ombudsperson for healthcare practitioners to report other practitioners who over-prescribe, prescribe or delivered unsafely benzodiazepines and Z-drugs. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| | Unimportant | Slightly | Neither | Important | Very |
|--|-------------|-----------|---------------|-----------|-----------|
| | | important | important nor | | Important |
| | | | unimportant | | |
| In the current circumstances, it is important to extend the patient inclusion criteria of the new reimbursement scheme for the compounding of smaller doses of benzodiazepines and Z-drugs to residents living in nursing homes. | | | | | |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

How important do you think it is to implement this recommendation? *

| Unimportant | Slightly | Neither | Important | Very |
|-------------|-----------|---------------|-------------|-------------|
| | important | important nor | | Important |
| | | unimportant | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | unimportant | unimportant |

Are the conditions already met to make it feasible? *

Choose one of the following answers. Please choose only one of the following: Yes/ No / I don't know

[If no] What are the necessary conditions to make it feasible? Please write your answer here:

In the current circumstances, which are the three most important recommendations to implement in the primary prevention?

Select 3 and order them with the most important first: All your answers must be different and you must rank in order.

Please select 3 answers

[List of recommendations]

In the current circumstances, which are the three most important recommendations to implement in the secondary prevention?

Select 3 and order them with the most important first: All your answers must be different and you must rank in order.

Please select 3 answers

[List of recommendations]

In the current circumstances, which are the three most important recommendations to implement in the tertiary prevention?

Select 3 and order them with the most important first: All your answers must be different and you must rank in order.

Please select 3 answers

[List of recommendations]

Chapter 5

Development of a tool for the first prescription of Benzodiazepines receptor agonists: Co-conception and acceptability study

Van Ngoc, P., Khalifé, P., Bragard, I., Belche, J.L., & Scholtes, B. Development of a tool for the first prescription of Benzodiazepines receptor agonists: Coconception and acceptability study [to be submitted]

Abstract

Introduction: Anxiety and insomnia are common conditions often managed with benzodiazepine receptor agonists (BZRA) in primary care, despite guidelines discouraging their first-line use due to risks of dependence and side effects. Preventing initial BZRA prescriptions has received less attention than deprescribing efforts. This study aimed to co-develop and evaluate the acceptability of a patient education leaflet to support communication about BZRA risks during initial prescriptions.

Methods: The co-development process followed a user-centered design (UCD) framework across three phases: understanding user needs through interviews and material analysis, iteratively developing the leaflet with feedback from professionals and patients, and assessing retrospective acceptability via semi-structured interviews. Thirty participants (19 healthcare professionals and 11 patients) contributed across all phases. Interviews revealed diverse perspectives on BZRA use, which guided iterative improvements to the leaflet.

Results: The final leaflet emphasizes concise, clear information, the promotion of alternative treatments, and encourages shared decision-making. It aligns with Belgian policy recommendations and aims to increase health literacy among patients. Feedback highlighted the importance of providing patients with accessible, actionable advice on BZRA and alternative therapies, fostering informed decision-making and long-term health management.

Conclusion: Overall, the tool demonstrated potential to improve patient understanding and support healthier, more informed decisions regarding BZRA use in primary care.

Introduction

Anxiety and insomnia are common conditions that impact individuals' well-being and are generally treated in primary care settings (Ansseau et al., 2004; Kroenke et al., 2007; Olfson, 2000; Perlis et al., 2022). These conditions can disrupt daily functioning, reduce quality of life, and often lead patients to seek medical support for symptom relief (Mendlowicz & Stein, 2000; Perlis et al., 2022). To treat sleep disorders and anxiety, benzodiazepine receptor agonists (BZRA) can be prescribed. However, they are not recommended as a first-line treatment due to their side effects and the challenges associated with withdrawal (Brandt et al., 2024; Centre belge d'information pharmacothérapeutique, n.d.; Lader, 2011, 2014). As a result, guidelines advise against using these drugs as an initial intervention and recommend limiting their use to a maximum of 2 to 4 weeks (Brandt et al., 2024). Nevertheless, long-term BZRA use remains a significant global public health concern, particularly in Belgium (Ma et al., 2023). Factors such as social or financial disadvantage, concurrent opioid or psychotropic use, and frequent healthcare utilisation further increase the likelihood of prolonged BZRA use (Brandt et al., 2021).

Correspondingly, BZRA are positioned at the highest, most complex level of intervention option within the Comprehensive Personalised Care Model (NHS England, n.d.-a) (Figure 5.1). This model advocates for a stepwise, personcentered approach, starting with low-complexity, accessible interventions tailored to individual needs, and only progressing to more intensive, pharmacological treatments when simpler, non-pharmacological strategies have proven insufficient (NHS England, n.d.-b, n.d.-a).

Comprehensive Personalised Care Model





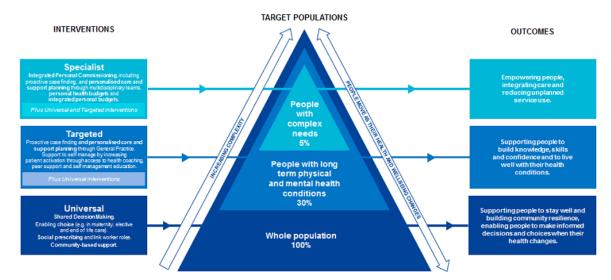


Figure 5.1. Comprehensive Personalised Care Model (NHS England, n.d.-a)

However, despite their classification as a last-resort treatment, reducing BZRA prescriptions in clinical practice remains challenging. Indeed, general practitioners (GPs) face several challenges when trying to avoid prescribing BZRA. These challenges include time constraints, a perceived lack of alternative actions to implement, insufficiently precise knowledge among healthcare professionals, and a lack of clarity regarding prescription practice (Anthierens, Habraken, Petrovic, et al., 2007; Mokhar et al., 2019; Opondo et al., 2012). From the patient's perspective, a study shows that patients often seek "something" from their doctor when they feel distressed and need help, which can lead GPs to prescribe a BZRA more quickly (Sirdifield et al., 2017). These factors, combined with beliefs about low side effects and dependence risks, lead GPs to continue prescribing BZRA (Anthierens, Habraken, Petrovic, et al., 2007).

Considerable attention has been given to deprescribing BZRA among long-term users and numerous tools are available to aid physicians, pharmacists and patients to discuss this issue (Chan et al., 2023; Reeve, 2020; Thompson & Reeve, 2022). To our knowledge, the prevention of initial prescriptions in primary care has received comparatively less focus (Anthierens, Habraken, Petrovic, et al., 2007; Brandt et al., 2021), despite nearly 1 in 20 patients becoming long-term users ≥180 days after an initial prescription (Brandt et al., 2021).

To promote the appropriate prescription and use of BZRA, it is important to reinforce prevention and to inform patients with educational strategies. Patients need to be actively involved in the care process and provided with all necessary information to make informed decisions about their treatment. This includes detailed explanations of treatment options, their benefits and risks, and support in clarifying their values regarding the outcomes. Decision aids that offer this level of guidance are more effective than standard patient education leaflets (Légaré & Witteman, 2013; Mokhar et al., 2019). Therefore, the aim of this study was to codevelop patient resources that could be used in general practice at the time of first prescription and in community pharmacies at the time of first dispensing. The leaflet was then evaluated in terms of retrospective acceptability for users. The study posed the following research questions:

- How can the professional patient communication around the risks of BZRA be improved?
- What form of patient resources could be developed to support this communication?
- What should the patient resources include?
- What is the retrospective acceptability of the resource developed?

Materials and methods

Co-development process

The co-development process followed the user-centred design (UCD) framework (Witteman et al., 2021) to develop health tools. This framework is iterative and cyclical, allowing for the creation of a tool that best meets the needs and preferences of future users. It includes three key components: (1) understanding users; (2) developing/refining the prototype; (3) observing users. In the third phase, a retrospective acceptability study was conducted with future users to gather their feedback regarding the use of this brochure (figure 5.2) using the theoretical framework of acceptability developed by Sekhon et al. 2017 (Sekhon et al., 2017).

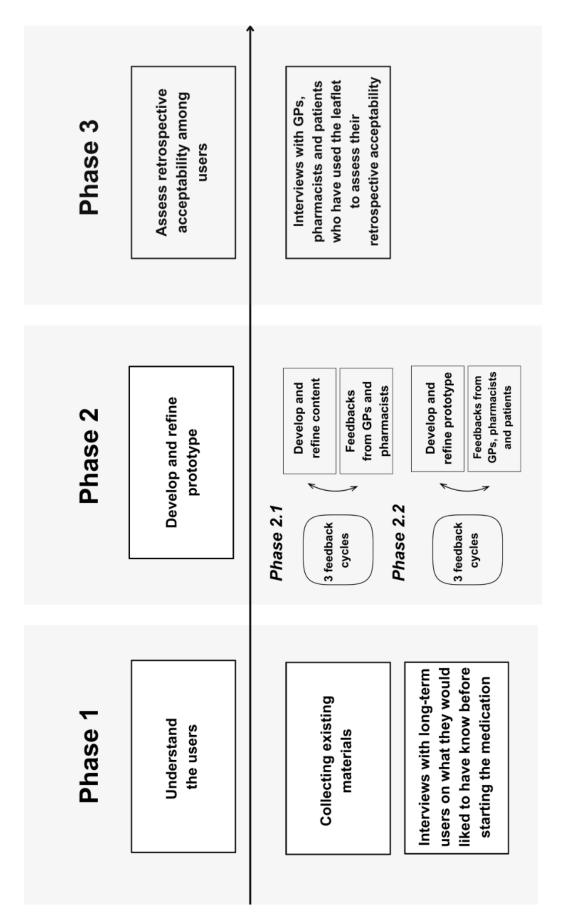


Figure 5. 2. Co-development methodology following user-centred design

framework

Phase 1: Understanding the user

In the first step, existing materials in the domain of insomnia and anxiety and the avoidance of prescribing BZRA were collected and analysed. Additionally, semi-structured interviews were conducted with long-term users (≥ 6 months) to explore what information they would have liked to have received upon their first BZRA prescription. The interview guide is in Additional File 5.1. The interviews were conducted by the first author (PV, female, PhD student and psychologist by training). The semi-structured interviews took place one-on-one at the location most convenient for the participant or by video conference.

Phase 2.1: Content development

Following the conclusions of Phase 1, it was decided that the most appropriate type of patient resource to develop would be a leaflet. An initial prototype of the content to be included was developed based on international literature, guidelines, and existing patient resources. The document was designed to empower and motivate readers while maintaining an empathetic and sensitive tone. Feedback regarding the content of the leaflet was received from healthcare professionals through comments made directly in the document, evaluating its quality, readability, and use of empathetic and motivational language. This process of prototype development and evaluation was repeated three times to refine the leaflet content. Subsequently, the content was reviewed by a communication expert to improve sentence construction and ensure the document was as readable as possible.

Phase 2.2 Co-develop and refine the prototype

Once the content had been finalised it was transferred to a graphic designer who formatted the leaflet into an easily printable A4 size. Feedback was received from GPs, pharmacists, and patients regarding the layout of the leaflet. Participants were asked to read the brochure aloud and provide comments on its layout, content, illustrations, font, and font size. The think-aloud method was used to encourage participants to verbalize everything they were thinking (Eccles & Arsal, 2017). This development process was repeated three times to adapt the leaflet

based on the feedback provided by the participants. The interview guide is in Additional File 5.2. The interviews were conducted by the first author (PV, female, PhD student and psychologist by training) and the last author (BS, female, Public health postdoc researcher). The interviews took place one-on-one at the location most convenient for the participant or by video conference.

Phase 3: Retrospective acceptability

The final phase of the process focused on the acceptability of the final version of the leaflet. This phase took the form of a pilot study conducted in pharmacies and GP practices. It focused on the experiences of a sample of GPs, pharmacists and patients. Retrospective acceptability (Sekhon et al., 2017) was assessed in the final phase of the project using semi-structured interviews with participants in the pilot study based on the model of acceptability. The think-aloud method was also used (Eccles & Arsal, 2017). The interview guide is in Additional File 5.3. The interviews were conducted by the first author (PV, female, PhD student and psychologist by training) and the second author (PK, male, trainee GP).

Recruitment

Throughout all phases, participants, including both healthcare professionals and patients, were recruited through primary care networks, as well as via our professional network, and through various channels such as newsletters, website announcements, flyers, and invitation emails.

In Phase 1, patients with long-term BZRA use who had stabilized, reduced, or discontinued their use were recruited to provide feedback on the information they would like to have at the time of their initial prescription.

For Phase 2, a decision was made to avoid the repeated involvement of the same participants within this phase in order to maximize the diversity of feedback regarding the leaflet. More specifically, in Phases 2.1 and 2.2, healthcare professionals were recruited with particular attention to ensuring diversity in geographic location, gender, and professional roles. Furthermore, in Phase 2.1, patients with no prior experience with BZRA were recruited to gather feedback on

the draft leaflet. The inclusion of patients without previous exposure to BZRA was intended to capture insights from individuals who might be potential recipients of the leaflet in real-world clinical settings.

Subsequently, in Phase 2.3, recruitment was conducted through professionals' networks using flyers, emails, or phone calls sent to GPs and pharmacists. During this phase, patients were invited to participate by their GP during a consultation in which the leaflet was discussed. This recruitment method was chosen to ensure that participants had the opportunity to review the leaflet in a context that closely resembled its intended clinical use.

Data analysis

Meetings between researchers were held periodically to discuss how the data collection was progressing. Then, an inductive thematic analysis was conducted with Nvivo 14 for phase 1 and 2 to identify recurring themes from each interview. Several discussions were organized during the data analysis to enrich the process using an iterative approach. In the third phase, the interviews were analysed using a deductive thematic analysis based on the Theoritical Framework of Acceptability developed by Sekhon et al. 2017 with Nvivo 14 (Sekhon et al., 2017). For phase 3, the retrospective acceptability of the leaflet was assessed by GPs, pharmacists, and patients who had used it, through semi-structured interviews.

Ethical considerations

All participants who contributed to this study signed a consent form before the interview. These interviews were audio-recorded and transcribed. Then, all identifiable information was removed from the transcriptions.

Participants were informed on the goal of the study and gave their written informed consent. The Ethics Committee (Comité d'Éthique Hospitalo-Facultaire Universitaire de Liège) has given their agreement for the study with the approval number: 2023-61 (for phase 1 and 2) and 2024-50 (for phase 3).

Results

Participants

In total, 30 participants shared their perspectives over the three phases of the study. Among them, 19 healthcare professionals were involved (table 5.1), primarily general practitioners and pharmacists as well as one neurologist and one public health professional provided feedback on the brochure content across the three phases.

| ID | Phase | Gender | Profession | |
|-----------------|-----------|--------|----------------------------|--|
| Professional 1 | Phase 2.1 | Male | Pharmacist | |
| Professional 2 | Phase 2.1 | Male | GP | |
| Professional 3 | Phase 2.1 | Male | Neurologist | |
| Professional 4 | Phase 2.1 | Female | GP | |
| Professional 5 | Phase 2.1 | Male | GP | |
| Professional 6 | Phase 2.1 | Female | Public health professional | |
| Professional 7 | Phase 2.1 | Female | Pharmacist | |
| Professional 8 | Phase 2.1 | Female | Pharmacist | |
| Professional 9 | Phase 2.1 | Female | Pharmacist | |
| Professional 10 | Phase 2.2 | Female | GP | |
| Professional 11 | Phase 2.2 | Female | Pharmacist | |
| Professional 12 | Phase 3 | Male | GP | |
| Professional 13 | Phase 3 | Female | GP | |
| Professional 14 | Phase 3 | Male | GP | |
| Professional 15 | Phase 3 | Male | GP | |
| Professional 16 | Phase 3 | Male | GP | |
| Professional 17 | Phase 3 | Female | Pharmacist | |
| Professional 18 | Phase 3 | Female | Pharmacist | |
| Professional 19 | Phase 3 | Female | Pharmacist | |

Table 5.1 Characteristics of participating health care professionals

Additionally, 11 patients participated (table 5.2), including those from Phase 1, who were long-term users of BZRA and had since stabilised, reduced, or tapered their dosage.

| | | | Previous BZRA use |
|------------|-----------|--------|-------------------|
| ID | Phase | Gender | / No previous use |
| Patient 1 | Phase 1 | Female | Previous BZRA use |
| Patient 2 | Phase 1 | Female | Previous BZRA use |
| Patient 3 | Phase 1 | Male | Previous BZRA use |
| Patient 4 | Phase 1 | Female | Previous BZRA use |
| Patient 5 | Phase 1 | Male | Previous BZRA use |
| Patient 6 | Phase 2.2 | Male | No previous use |
| Patient 7 | Phase 2.2 | Male | No previous use |
| Patient 8 | Phase 2.2 | Male | No previous use |
| Patient 9 | Phase 3 | Female | No previous use |
| Patient 10 | Phase 3 | Female | No previous use |
| Patient 11 | Phase 3 | Male | No previous use |

Table 5.2 Characteristics of participating patients

Phase 1

First, the collection and evaluation of existing Belgian patient resources regarding the first prescription of BZRA revealed several insights. While existing brochures provide useful information for patients and can serve as tools for healthcare professionals involved in deprescribing, they do not specifically address the initial prescription of BZRA.

The resources identified were primarily developed by the Federal Public Service (FPS) as part of the awareness campaign entitled "Sleeping pills and tranquilizers, consider other solutions first". As part of this campaign, brochures were produced for medical practices, waiting rooms, and pharmacies (Service Public Fédéral, 2018). These materials included tools designed for GPs, pharmacists, and patients.

However, the development process for these tools was not clearly documented, and it remains unclear whether patients were involved in the co-development of these resources. While the font used in the brochures was easy to read, the text was dense and the font size relatively small which may affect readability.

Other brochures were also identified, but their content tends to focus either on sleep-related issues or medications more broadly. Examples include the brochure "A Medicine Is Not a Candy" from the Agence Fédérale des Médicaments et des Produits de Santé (AFMPS), which addresses various substances, including BZRA, as well as materials from different mutual insurance organizations, such as "A Good Night's Sleep" (ML MUTPLUS, n.d.) which provide practical advice on sleep hygiene.

Although these brochures offer valuable information for patients and can serve as tools for deprescribing physicians and pharmacists, they do not specifically target the context of the initial prescription of BZRA.

Secondly, in the semi-structured interviews with patients who have used BZRA for long-term use, inductive thematic analysis revealed several key insights. Patients reported insufficient information at the time of prescription and reported only vague recollections of the explanations provided. They expressed a preference for concise informational leaflets and emphasized the value of interactive discussions and active listening from the prescribing physicians.

'Not much. He had told me, I'll prescribe this for you, it's not too strong and this, this will help you.' (Patient 3)

Additionally, patients underscored the need for clear explanations regarding the practical mechanisms of BZRA, potential side effects, and the risks of dependency. They also highlighted the importance of presenting alternative treatment options to BZRA.

'It would be good to indicate how long it takes to become dependent, the fact that it's very important to take it on an irregular and completely anecdotal basis. What consequences taking drugs can have on the brain, on the body...'.

(Patient 4)

Moreover, patients also expressed a preference for having this resource in the form of a brochure that is short and easy to read.

Phase 2

The second phase of the study was divided into two stages: content development and prototype design. The first stage focused on developing and refining the content of the leaflet. Based on the findings from Phase 1, a brochure with four distinct sections was created. The first section provides an introduction, aiming to normalize and reassure patients without trivializing the use of BZRAs. The second section, presented as a double-page spread, outlines alternative strategies for managing insomnia and anxiety. The third section offers clear, accessible information about BZRAs, including potential short- and long-term side effects, which were listed in bullet points to facilitate reading. Finally, the last section includes a space designed to encourage interaction between the healthcare professional and the patient.

To enhance readability, key pieces of information were highlighted with phrases such as "good news" or "solutions for finding calm". The text layout was adjusted to create a natural reading flow, while sentence structures were simplified by eliminating negations and using conversational language. The design of the double-page spread was carefully organized to ensure the information was well-spaced and visually accessible.

In terms of visual presentation, most participants appreciated the soft, calming style of the illustrations, as well as the colour scheme and typography. The handwrittenstyle font was well-received, as it captured attention and made the content feel more approachable. However, some participants noted that cursive writing might reduce readability for certain readers. Since the majority of participants found the cursive text appealing, it was retained in the final version.

The final leaflet can be found in Additional File 5.4.

Phase 3

In phase three the seven components of acceptability were used to structure the analysis, the results are presented below.

1. Affective attitude

The emotional attitude is defined by Sekhon et al. (2017) as "how an individual feels about taking part in an intervention" emerged from data (Sekhon et al., 2017). Participants expressed overall satisfaction, particularly with its structure and aesthetic. 'It's initiatives like these that will get us through.' (Professional 12, GP) Some described positive emotional reactions, referring to it as soothing, engaging, and enjoyable. 'It's pleasant and makes you want to read it.' (Patient 11). Some participants mentioned perceiving the approach as non-judgmental and encouraging, emphasizing that importance of indicating that changing behaviour is not something that happens overnight. However, a GP cautioned about the potential for misinterpreting certain advice. Indeed, they explained that stating it takes two months to change a behaviour might reassure some patients but could discourage others who do not succeed within that timeframe.

2. Burden

The third theme is burden, which Sekhon et al. (2017) defines as "the perceived amount of effort that is required to participate in the intervention" (Sekhon et al., 2017). Within this theme, participants explained that they found the brochure to be well-spaced, not overloaded with information, and non-constraining due to its concise format. However, some noted that certain parts of the brochure, particularly the bottom of the last page, duplicated what the doctor would already record in the medical file (though it is important to mention that this would likely not be visible to patients).

'Yes, because I'm already writing it down in the file and I have to write the prescription, etc. So all this information, some of it, if I have to rewrite it here, it's duplication and I find double entries a bit complicated.' (Professional 14, GP)

Some GPs mentioned that they didn't have enough time to use the leaflet during the consultation, as discussions about medications often took place at the end of the visit, which left them constrained to simply give the brochure to the patient without further explanation. A pharmacist also explained that he leaves the leaflet on the pharmacy counter for patients to pick up.

3. Ethicality

According to Sekhon et al. 2017 (Sekhon et al., 2017), **ethicality** refers to the extent to which a healthcare intervention aligns with an individual's personal values and moral beliefs. It captures whether participants perceive the intervention as morally acceptable or consistent with their ethical standards. However, in the context of this study, participants did not express any concerns regarding the ethicality of the informational leaflet provided. No feedback indicated that the content or delivery of the leaflet posed any ethical issues.

4. Intervention coherence

The fourth theme focuses on the coherence of the intervention, defined by Sekhon et al. (2017) (Sekhon et al., 2017) as the individual's understanding of the intervention's logic and objectives. Some participants used the brochure, which was intended for first-time prescriptions, in various ways: some during consultations, others left it on the counter in the pharmacy, or handed it to patients without explanation. This suggests a lack of clarity regarding its intended purpose and use.

Participants also suggested broadening the brochure's target audience to include patients already taking BZRA or those with anxiety and insomnia without medication. This reflects a perceived misalignment between the brochure's purpose and its potential wider applicability. Healthcare professionals and pharmacists view the brochure as a complementary communication tool, supporting both pharmacological and non-pharmacological approaches to managing anxiety and insomnia. For patients, it encourages avoiding medication use.

'So, it's a truly complementary tool that addresses our concerns and what we observe.' (Professional 14, GP)"

5. Opportunity costs

According to Sekhon et al. (2017) (Sekhon et al., 2017), opportunity costs represent the benefits, values, or resources that participants forgo in order to engage in a healthcare intervention. This includes the time, effort, or income they might sacrifice to attend consultations or adhere to treatment. In this context, few participants highlighted how the pressure to stay on schedule for appointments and avoid delays for others illustrates the compromises involved. One participant remarked:

'It's already a consultation that takes a lot of time, and I think, 'Oh no, I'm going to fall behind,' and then there's the pressure of the next person waiting.' (Professional 14, GP)

6. Perceived efficacy

The fifth theme focuses on perceived effectiveness, defined by Sekhon et al. (2017) (Sekhon et al., 2017) as the extent to which an individual believes the intervention will achieve the desired objectives. In this theme, participants explained that the scientific and academic nature of the brochure adds value and increases interest. Some professionals considered continuing to use the brochure in their practice. For patients, the thick paper of the brochure was seen as a value-added feature, and it served as both a reminder and a source of additional information during and after consultations. The section completed by the doctor, especially with medication details and the date of the next appointment, reassured patients. Writing in the brochure reinforced its value, making it feel like a prescription or a contract.

'Now, to put it simply, the brochure is next to me, on my nightstand, on my bedside table. So, if only to recall certain tips sometimes. For me, it's a brochure that I now use daily.'

(Patient 11)

7. Self-efficacy

Self-efficacy, as defined by Sekhon et al. (2017) (21), refers to "the participant's confidence that they can perform the behaviour(s) required to participate in the intervention." General practitioners and pharmacists expressed a sense of confidence and security when using the brochure as part of their care approach.

'So, I think it's also a kind of safety for us to have this brochure, knowing that the patient left with it. If I happen to forget to mention something, I know they'll be able to read it and find the information' (Professional 15, GP)

In contrast, patients indicated that while reading the brochure, they doubted their ability to implement all the advice provided. In such cases, patients explained that these challenges applied to them specifically but likely not to others, as the applicability depended on individual circumstances.

'Well, of course, this is just my case. Exposing myself directly to daylight is almost impossible for me, given my situation. As I mentioned before, being self-employed, it's nearly impossible because I'm already outside at 4:30 in the morning. So, for me personally, it's already more complicated.' (Patient 11)

Discussion

This paper described the co-development of patient resources for the initial prescription of BZRA, intended for use in GP consultations and pharmacies. The process of development was divided into three phases, following the UCD framework: an initial phase of understanding user needs through the review of existing resources and research and gathering patient input; a subsequent phase of co-creation and refinement of the content and form with healthcare professionals and patients; and finally, an evaluation of the retrospective acceptability from the point of view of patients and professionals.

The leaflet developed emphasizes simplicity, alternative non-pharmacological approaches, and actionable advice, which improved engagement and acceptability. Feedback highlighted its value in offering clear alternatives to BZRA,

though time constraints and the clarity of its purpose were noted as challenges. The leaflet supports primary prevention of BZRA use by providing complete information on risks and alternatives at the first prescription, aligning with one of the Belgian policy recommendations from the policy Delphi study, which advocates for informing patients about the risks of dependency at the first prescription (Van Ngoc et al., n.d.).

Studies show that patients often feel they lack sufficient information about BZRA before being prescribed them (Anthierens, Habraken, Petrovic, et al., 2007; Van Ngoc et al., 2023). While benzodiazepines were initially considered safer alternatives to barbiturates in the 1960s, our understanding has evolved (López-Muñoz et al., 2011; Sirdifield et al., 2013), and current evidence highlights the risks of long-term use (Lader, 2011, 2014). Given this historical perception of their safety, it is crucial to (re)explain what BZRA are, how they work, and the potential risks involved.

The value of the Comprehensive Personalised Care Model (NHS England, n.d.-a) lies in its ability to clearly illustrate the appropriate sequencing of interventions for patients with insomnia or anxiety. It demonstrates that providing educational resources, like the leaflet developed in our study, should be the first step for all patients. This initial step ensures that individuals receive practical, accessible information about their condition, along with guidance on evidence-based, non-pharmacological strategies.

Despite this structured approach, many still perceive BZRA as a first-line solution, often turning to these medications before considering psychological support or behavioural interventions. This misconception underscores the importance of reinforcing the role of sleep hygiene, lifestyle measure early in the care process. Yet, research supports the value of sleep hygiene education in improving sleep quality, though it is less effective than more structured therapies such as Cognitive Behavioural Therapy for Insomnia (CBT-I) or mindfulness-based therapy (Chung et al., 2018). Notably, CBT-I was also included in the leaflet, as it is the recommended first-line treatment for insomnia and anxiety. Evidence indicates that while both CBT-I and pharmacological treatments can yield short-term benefits (Perlis et al., 2022), CBT-I stands out for its long-term effectiveness, with

improvements that can last for years after treatment concludes (Beaulieu-Bonneau et al., 2017; Castronovo et al., 2018).

By promoting these strategies as standard practice and providing clear, engaging educational resources, the objective is to shift perceptions and encourage a more appropriate, stepwise approach to care. The leaflet was specifically developed with these principles in mind, equipping patients with the knowledge and tools necessary to explore their options and actively participate in their treatment journey.

Empowering patients in this manner not only addresses their immediate concerns but also contributes to the broader objective of fostering sustainable, long-term improvements in sleep and mental health. Particular attention was given to the clarity of the language used, ensuring accessibility through the use of short, straightforward sentences, avoiding negations, and minimizing any potential for feelings of guilt. It is essential to tailor patient information in brochures to be concise, well-organized, readability and easy to read. Additionally, visuals can be a valuable tool in capturing attention, prompting questions, and enhancing patients' understanding of written information (Van Beusekom et al., 2016).

Some healthcare professionals perceived the leaflet as an additional workload, with certain pharmacists leaving it on the counter rather than engaging with patients in a more interactive manner. Similarly, some general practitioners handed the leaflet to patients only at the end of the consultation, limiting its potential for patient education. At the same time, the role of community pharmacists has been evolving over the past several years, with increasing involvement in patient care and the adoption of a more proactive, with an approach that can contribute to the safe, effective, and efficient use of medications (Mossialos et al., 2015). Pharmacists can play a critical role in the identification and management of drugrelated problems, thereby contributing to the optimisation of pharmacotherapy. When it comes to GPs, many report a lack of time for preventive care and in-depth discussions (Yarnall et al., 2003). Nevertheless, investing time during the initial prescription phase can yield long-term benefits and save time for future consultations/ delivery. The leaflet was developed in response to data from

professionals concerning challenges they face transmitting complex information such as sleep hygiene advice. It is also important to insist that, supporting patients to fully understand their options and the risks involved may be time consuming but a quick intervention (such as a prescription for BZRA) that goes against evidence-based guidelines is not ethically appropriate.

While the leaflet has shown promise in its current form, further research is needed to evaluate its effectiveness in a larger and more diverse patient population, on patient outcomes, BZRA prescriptions, patients' understanding of BZRA, engagement, and their ability to make more informed decisions. In particular, there may be a need to develop a version with only illustrations, especially for patients with low health literacy or limited proficiency in French. Such a visual-only leaflet could help overcome language barriers and improve accessibility for those who struggle with written text. This adapted version could incorporate illustrations, images, or visual aids to enhance comprehension. Tools such as the Flesch Reading Ease Score (Farr et al., 1951) could also be utilized to assess the readability and accessibility of the content.

Limitations

First, the sample size was relatively small, which may limit the generalizability of the findings to broader populations. The evaluation focused on retrospective acceptability rather than clinical outcomes, making it difficult to determine the leaflet's real-world effectiveness in reducing BZRA prescriptions.

Lastly, the leaflet was developed in French, which may pose accessibility challenges for individuals with low health literacy or limited language proficiency. Future studies should assess its effectiveness in clinical practice and explore adaptations for diverse populations.

Conclusion

This study successfully co-developed a tool to support the initial prescription of BZRA, integrating patient and healthcare professional feedback to create a clear and interactive leaflet. This tool, aligned with the principles of the Comprehensive

Personalized Care Model, offers patients essential information on both BZRA and alternative approaches, empowering them to make informed decisions. While some challenges remain, the positive feedback on its engagement and acceptability highlights its potential in promoting shared decision-making and improving health literacy concerning first BZRA prescription.

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Author's contributions

PV carried out the investigation, data collection and methodology and drafted the original manuscript. PK contributed to the conceptualisation of the phase 3 and reviewed and edited the manuscript. IB reviewed and edited the manuscript. JLB reviewed and edited the manuscript. BS conceived and designed the study, carried out the investigation and methodology supervised the work, acquired funding, and reviewed and edited the manuscript.

Additional File 5.1

Guide d'entretien

- Quand avez-vous reçu votre premier somnifère/calmant ?
- 2. Dans quel contexte avez-vous reçu votre premier somnifère/calmant?
- 3. Quel professionnel vous a prescrit votre premier somnifère/calmant?
 - a. Psychiatre?
 - b. Médecin généraliste?
 - c. Autres?
- 4. Si vous n'avez pas reçu le somnifère/calmant via un médecin, comment avez-vous reçu votre première somnifère/calmant?
- 5. Quelles informations avez-vous reçues lors de votre première prescription de votre somnifère/calmant?
 - a. Pensez-vous avoir reçu suffisamment d'informations lors de votre première prescription ?
 - i. Si non, quelles informations auriez-vous voulu recevoir à ce moment-là?
 - ii. Qu'attendiez-vous comme informations à ce moment-là?
- 6. Quelles informations avez-vous reçues lorsque vous avez reçus votre premier somnifère/calmant ?
 - a. Pensez-vous avoir reçu suffisamment d'informations lorsque vous avez reçu votre premier somnifère/calmant ?
 - Si non, quelles informations auriez-vous voulu recevoir à ce moment-là?
 - ii. Qu'attendiez-vous comme informations à ce moment-là?
- 7. Comment cette première prescription a été suivie par le prescripteur ?
 - a. Pensez-vous avoir été bien suivi pour cette première prescription ?
 - b. Comment auriez-vous voulu être suivi ?
- 8. Avez-vous reçu un dispositif d'informations pour les patients tels que des brochures, des vidéos, un site web, lors de votre première prescription ?
- 9. A ce moment-là, étiez-vous disposé-e à recevoir des informations sur la molécule?
- 10. Selon vous, de quelles informations les patients qui prennent pour la première fois des somnifères/calmants ont-ils besoin ?

11. Sous quelle forme (brochure, site web, dépliant, etc.) pensez-vous que les patients qui prennent des somnifères ou des calmants pour la première fois aimeraient recevoir l'information ?

Additional File 5.2

Guide d'entretien

THINK ALOUD:

La méthodologie "think aloud" consiste à demander aux participants de verbaliser leurs pensées tout en explorant une brochure de santé, permettant ainsi d'évaluer son acceptabilité et son utilisabilité. Les participants partagent leurs impressions à voix haute, avec des relances du chercheur en cas d'interruption. Les entretiens, enregistrés et transcrits, sont ensuite renvoyés aux participants pour validation.

APPROFONDISSEMENT:

Pouvez-vous m'en dire plus sur « »

RELANCE:

- Continuer à penser à haute voix.
- Que pensez-vous de cette partie?
- Est-ce que les informations sont claires?
- A quoi cela vous fait-il penser?

1. Attraction

- Quelles sont vos impressions générales?
- Lorsque vous regardez la brochure, est-ce que cela vous donne l'envie de la lire?
- Si ce n'est pas le cas, pourriez-vous nous dire pourquoi?
- Qu'est-ce qui attire votre regard?
- Que pensez-vous de la mise en page?
- Qu'est-ce que l'image, le dessin vous raconte?
- Que pensez-vous des images/dessins de la brochure?
- Que pensez-vous des couleurs?

- Est-ce qu'une image/dessin devrait être ajouté/supprimé?
- Que pensez-vous du format de la brochure ?
- Que pensez-vous de la police?
- Que pensez-vous de la taille des caractères?

2. Contenu de la brochure

- Que pensez-vous du contenu de la brochure?
- A qui s'adresse ce dépliant selon vous ?
- Que comprenez-vous de la brochure?
- Qu'apprenez-vous après avoir lu la brochure ?
- Que pensez-vous du ton employé dans la brochure ?

4. Point de vue global

- D'un point de vue global, quelle est votre opinion par rapport à la brochure?
- Qu'est-ce qui manque dans la brochure?
- Comment amélioreriez-vous la brochure?
- Qu'apporte ce dépliant ? Qu'est-ce qui vous semblait le plus intéressant dans ce dépliant ?
- La démarche du dépliant est-elle intéressante pour vous ? L'utiliseriezvous dans votre pratique / vie quotidienne ?
- Que faut-il améliorer ? Comment ? / Que changeriez-vous dans le dépliant ?
- Quelles sont les autres informations que vous aimeriez recevoir ?
- Avez-vous autre chose à ajouter sur le sujet ?

Additional File 5.3

Topic guide for patients:

- Dans quelles circonstances vous a-t-on introduit ce dépliant ?
- Qui vous l'a donné ?
- Quelles informations vous a-t-on donné?
- Parlez de votre « insomnie / anxiété », comment impact-elle votre vie ?

THINK ALOUD:

La méthodologie "think aloud" consiste à demander aux participants de verbaliser leurs pensées tout en explorant une brochure de santé, permettant ainsi d'évaluer son acceptabilité et son utilisabilité. Précédé d'un entretien semi-structuré, cet exercice se déroule en face à face ou via vidéoconférence. Les participants partagent leurs impressions à voix haute, avec des relances du chercheur en cas d'interruption. Les entretiens, enregistrés et transcrits, sont ensuite renvoyés aux participants pour validation.

APPROFONDISSEMENT:

Pouvez-vous m'en dire plus sur «»

RELANCE:

- Continuer à penser à haute voix.
- Que pensez-vous de cette partie?
- Est-ce que cela vous est arrivé ou est arrivé à quelqu'un que vous connaissez
 ?
- Est-ce que les informations sont claires?
- A quoi cela vous fait-il penser?

FIN:

- Quels sont vos impressions générales ?
- A qui s'adresse ce dépliant selon vous?

- Qu'apporte ce dépliant ? Qu'est-ce qui vous semblait le plus intéressant dans ce dépliant ?
- La démarche du dépliant est-elle intéressante pour vous ? L'utiliseriez-vous dans votre vie quotidienne ?
- Que faut-il améliorer ? Comment ?
- Que changeriez-vous dans le dépliant?
- Quelles sont les autres informations que vous aimeriez recevoir ?
- Avez-vous autre chose à rajouter sur le sujet ?

Topic guide for professionals:

- Comment la prise en charge de l'anxiété et de l'insomnie impact votre pratique ?
- Quelle est votre opinion concernant les benzodiazépines et les Z-drugs?
- Quelle est votre expérience avec les somnifères ?
- Depuis combien de temps utilisez-vous le dépliant ?
- Comment vous en servez-vous?
- Le dépliant a-t-il changé quelque chose dans votre pratique professionnel ou vie personnelle ?

THINK ALOUD:

La méthodologie "think aloud" consiste à demander aux participants de verbaliser leurs pensées tout en explorant une brochure de santé, permettant ainsi d'évaluer son acceptabilité et son utilisabilité. Précédé d'un entretien semi-structuré, cet exercice se déroule en face à face ou via vidéoconférence. Les participants partagent leurs impressions à voix haute, avec des relances du chercheur en cas d'interruption. Les entretiens, enregistrés et transcrits, sont ensuite renvoyés aux participants pour validation.

APPROFONDISSEMENT:

Pouvez-vous m'en dire plus sur « »

RELANCE:

- Continuer à penser à haute voix.
- Que pensez-vous de cette partie?
- Est-ce que cela vous est arrivé ou est arrivé à quelqu'un que vous connaissez
 ?
- Est-ce que les informations sont claires?
- A quoi cela vous fait-il penser?

FIN:

- Quels sont vos impressions générales?
- A qui s'adresse ce dépliant selon vous ?
- Qu'apporte ce dépliant ? Qu'est-ce qui vous semblait le plus intéressant dans ce dépliant ?
- La démarche du dépliant est-elle intéressante pour vous ? L'utiliseriez-vous dans votre pratique / vie quotidienne ?
- Que faut-il améliorer ? Comment ? / Que changeriez-vous dans le dépliant ?
- Quelles sont les autres informations que vous aimeriez recevoir ?
- Avez-vous autre chose à rajouter sur le sujet ?

Additional File 5.4

Votre médecin pourrait vous proposer un traitement médicamenteux de courte durée

Important à savoir: Les benzodiazépines (somnifères et calmants) se lient à certains récepteurs du cerveau et réduisent son activité. Prises sur une courte durée, elles peuvent améliorer les symptômes. Mais, sur une longue durée, elles peuvent les renforcer.

Effets possibles à court et long-terme :

- Aggravation de l'insomnie

Difficultés d'arrêt

- Tolérance et dépendance (votre dose prévue finit par ne plus avoir d'effet) et de l'angoisse
- Vertiges et chutes Somnolence
- Accidents de la route
- Problèmes de mémoire et de concentration

- → Tentez d'abord les actions de la page précédente.
- **que vous prenez** pour vérifier les interactions avec d'autres médicaments → Listez avec votre médecin et votre pharmacien.ne les médicaments et les contre-indications
 - → Prenez la plus petite dose efficace.
- 2 semaines pour l'anxièté) et ne recommencez pas sans un avis médical → Limitez la durée du traitement (maximum 1 semaine pour l'insomnie /

de prendre un traitement médicamenteux Si vous décidez avec votre médecin

Suivez attentivement les conseils de votre médecin et de votre pharmacien ne concernant la prise, la durée, l'arrêt de ces médicaments et les précautions particulières (consommation d'alcool, grossesse...)

Date de démarrage du traitement :

Date de fin :

Nom du médicament :

Dose (mg):

Prochain rendez-vous chez le médecin : Combien de comprimés par jour : Pendant combien de jours :

Une initiative du Département de Médecine Générale de l'ULiège Financé par la Fondation Roi Baudeuin

Fondation Rol Baudouin Département de Nédecine Générale

Une initiative du Départem

Vous ressentez du stress ou de l'anxiété? Vous dormez difficilement?

Cette situation peut se produire à des moments de vie et cela peut fort vous impacter.

lo from nowelle ex anil exist ples solutions,

Voici quelques conseils pour vous guider...

Comment retrouver le calme lorsque vous ressentez de l'angoisse? Que faire la journée pour mieux dormir la nuit?

Voici une série d'actions naturelles, efficaces et accessibles à mettre en place avant de prendre des somnifères ou des calmants :

Mangez tôt dans la soirée

pour que votre cerveau se réveille. par vous exposer directement dans l'heure après votre lever à la Cumière du jour Commencez la journée

Au réveil, Adrez la chambre au minimum 15 minutes pour assainir l'air.

your au minimum 30 Pratiquez une actuité Promenade, vélo, nage, étirements, danse ... Uminutes par jour:

en econtont votre appétit * un espace calme et sombre Aménagez-vous un expact sagréalle pour dormir: * température de 18-19°C pour faciliter la digestion

(bouchons d'oreille et masque si besoin) matelas et oreiller confortables.

× Réduisez un maximum les stimulants: le café, le tabac, l'alcool, les boissons sucrées et énergisantes comme les colas.

vous tracasse et réessayez de dormir activité colme, écrivez ce qui

dans les 20 à 30 minutes ou si

Si vous ne vous endormez pas

la nuit : sortez du lit, faites une

vous vous réveillez pendant

dès que vous ressentez de la fatigue.

cerveau en alerte.

couchez-vous à une heure Faites de votre coucher un riituel agriable

régulière pour que votre corps

soit préparé au sommeil.

en période de stress et pour améliorer contrôler votre rythme cardiaque et la méditation pour mieux Pratiquez la Me Koxotton la qualité de votre sommeil.

> pour vous aider à comprendue par un.e thérapeute spécialisé.e* les cours, et mettre en place Suivez un accompagnement dans le sommeil et l'anxiété dormez au maximum 20 minutes encore besoin de repos la nuit. pour que votre corps ait

Si vous aimez les Auestro,

Parlez-en à votre médecin. des solutions concrètes.

de vos écrans. Elle perturbe la production dans la chambre : diminuez la luminosité de l'hormone du sommeil et garde votre Évitez les écrans et smartphones

par exemple; une thérapie cognitivo-comportementale

Changer ses habitudes ne se fait pas du jour au lendemain. En moyenne, il faut 2 mois pour adopter un nouveau comportement. Gardez espoir, même si vous ne constatez pas d'effet positif dès les premiers jours.

Chapter 6

Discussion and Conclusion

Summary

This thesis explores the complexities surrounding the use of benzodiazepines and Z-drugs, from prescribing practices to long-term use and withdrawal. It begins by examining their widespread use, highlighting the risks associated with prolonged use and the challenges in deprescribing. The analysis starts with the perspectives of Belgian healthcare professionals, revealing the tensions they face in balancing guidelines, professional practices, and patient needs. Diverging approaches, such as prioritising total abstinence versus harm reduction, combined with limited patient involvement, point to the need for shared decision-making and a goal-oriented care model to improve deprescribing outcomes.

The patient perspective further underscores these challenges. Long-term users often struggle with withdrawal, face poor communication with healthcare providers, and are not involved by healthcare professionals in decisions about their care. These findings highlight the importance of personalised, slow, gradual tapering strategies and greater patient engagement to support successful deprescribing.

Prevention also plays a crucial role in addressing long-term benzodiazepines and Z-drugs use. A policy Delphi study identified 27 recommendations, emphasizing the importance of awareness campaigns, patient education, and professional training. The consensus underscores the need for multilevel, non-stigmatising strategies to improve both prescribing and deprescribing practices.

Finally, the development of a leaflet offers a practical tool to support safer prescribing. Co-designed with input from patients and healthcare professionals, the leaflet provides clear information about risks, alternatives, and encourages alternative treatments. While positively received, some challenges, such as time constraints during consultations, remain. Nonetheless, this initiative represents a step towards promoting informed patient choices and strengthening primary prevention efforts.

Together, these insights emphasise the need for a more integrated, patient-centred approach to benzodiazepines and Z-drugs prescribing and deprescribing, fostering better communication, shared decision-making, and ultimately safer use of these medications.

The complexity of (de)prescribing

The act of prescribing medication is far more complex than one might assume. As van der Geert (1996) highlighted, it is a social act where prescribers demonstrate attentiveness and concern for the complaints presented by the patient. Since it is culturally expected that a physician prescribes as part of medical practice, failing to do so contradicts these expectations, even when biomedical considerations suggest otherwise (van der Geest et al., 1996). These dynamics remain relevant today. More recent research has emphasized that prescribing is not merely a technical act guided by clinical guidelines, but is shaped by institutional constraints, power relations, and affective dynamics within the consultation (A. K. J. Smith, 2025). Prescribing is embedded in a complex, where the act itself may serve to validate patient concerns or conclude an encounter, regardless of clinical necessity.

Rinaldi et al. (2025) studied how physicians' decisions are routinely influenced by patients' requests or perceived expectations, even when these are not explicitly verbalized. This systematic review reveals that physicians often anticipate demand based on subtle cues, leading them to prescribe in ways that are as much about managing the clinical relationship as about treating a biomedical condition (Rinaldi et al., 2025).

Furthemore, prescribing also carries emotional and moral weight that influences clinical decision-making. In the case of benzodiazepines and Z-drugs, prescribers may feel pressured to give a prescription under various circumstances. An analysis by Ceuterick et al. (2023), based on the same sample used in **Chapter 2** but focusing exclusively on prescribers, describes prescribing practices as existing along a continuum shaped by three key factors: (a) prescribers' views on the necessity of prescribing and their risk negotiations, (b) the power dynamics between the healthcare provider and the patient, and (c) the rhetorical strategies used to justify the decision. These prescribing practices fall into four main approaches: (1) No prescribing, where doctors strictly avoid benzodiazepines and Z-drugs use; (2) Controlled prescribing, which limits use under strict conditions; (3) Compassionate prescribing, which prioritises patient well-being and comfort; (4)

Reluctant prescribing, where physicians feel pressured into issuing prescriptions despite their reservations (Ceuterick et al., 2023).

These different prescribing approaches influence not only the doctor-patient relationship but also the overall quality of care. In particular, compassionate and reluctant prescribing, while often motivated by empathy or external pressures, can contribute to the prolonged prescription of benzodiazepines and Z-drugs, even when the risks outweigh the benefits. This issue is particularly concerning in cases of insomnia or mild anxiety, where clinical guidelines recommend non-pharmacological alternatives such as cognitive behavioural therapy (CBT) (Belleville et al., 2011; Carpenter et al., 2018; Jernelöv et al., 2022). However, well-established prescribing habits, time constraints during consultations, and a perceived lack of alternatives often lead prescribers to continue these treatments despite increasing evidence of their long-term ineffectiveness (Anthierens, Habraken, Petrovic, et al., 2007; Cook, Marshall, et al., 2007; Sirdifield et al., 2013).

Additionally, studies further indicate that some physicians frame benzodiazepine and Z-drugs prescribing as an act of empathy, considering it the "lesser evil" compared to alternative interventions or patient dissatisfaction (Anthierens, Habraken, Habraken, et al., 2007). This perspective aligns closely with compassionate and reluctant prescribing, highlighting the difficulty of balancing clinical responsibility with patient expectations. Ultimately, prescribing is not just a biomedical decision but also a social and moral one, shaped by a complex interplay of medical, cultural, and emotional considerations. Indeed, the increasing medicalisation of psychosocial issues aligns with primary care physicians' tendencies to underestimate the potential risks of long-term prescribed psychotropic drug use (Conrad & Barker, 2010).

This complexity extends beyond prescribing to deprescribing, particularly in cases of long-term benzodiazepine and Z-drugs use. **Chapter 2** of this thesis explores how healthcare professionals manage cases of long-term users of benzodiazepines and Z-drugs, revealing that many prescribers feel "trapped" by patients' prolonged use. They often hesitate to initiate discussions about discontinuation for fear of damaging the therapeutic relationship.

An additional layer of complexity arises from the influence of institutional (de)prescription culture, which shapes the prescribing and deprescribing practices of healthcare professionals. Within each institution, professionals operate under a specific set of norms, routines, and implicit expectations that reflect the organisation's values. These institutional norms often stem from a normative approach, which provides guidelines or directives on what should be done in clinical practice, based on evidence and professional standards.

However, institutional culture can either facilitate or hinder adherence to these norms. For instance, a culture grounded in total abstinence principles may promote the systematic total deprescription of benzodiazepines and Z-drugs, sometimes without fully considering individual patient preferences or clinical context. This tension between standardised institutional practices and patient-centered care is a highlighted in **Chapter 2**. It illustrates how healthcare professionals must often navigate between normative expectations and the realities of clinical relationships within the institutional framework in which they work.

In this context, the training and education of healthcare professionals play a crucial role. Encouraging a shift towards a patient-centered model of care, one that is grounded in listening to the patient's goals, values, and lived experiences, can help professionals move beyond the limitations of institutional norms or prescriptive habits. Education that emphasizes patient-centred approach can help clinicians to better align clinical decisions with what truly matters to the patient. Rather than viewing deprescribing as a standardized protocol to enforce, it becomes a collaborative process rooted in empathy and respect.

Towards a Paradigm Shift in Benzodiazepine Management

By incorporating insights from both prescribers (**Chapter 2**) and patients (**Chapter 3**), this thesis makes an important contribution to the literature on benzodiazepines and Z-drugs management.

Prescribing and deprescribing decisions are often driven by cultural expectations, professional norms and institutional culture, yet they frequently miss the most critical question:

"What matters to the patient?"

Instead of rigidly following biomedical guidelines or focusing solely on symptom management, a goal-oriented care (GOC) approach shifts the narrative. It places patients' values, needs, and personal goals at the heart of the conversation (Boeckxstaens et al., 2020; Boeykens et al., 2022; Reuben & Tinetti, 2012). As Boeykens et al. (2022) highlight, this isn't a one-time discussion. It's a dynamic, ongoing process of goal elicitation, goal setting, and goal evaluation (Figure 6.1). By shifting the focus from disease control to individualised care, the GOC approach fosters greater alignment between clinical best practices and patient-centred outcomes.

This reinforces the importance of patient-centred decision-making, which research shows not only improves patient satisfaction and patient adherence but also leads to better health outcomes (Boeykens et al., 2022; Robinson et al., 2008; Stewart et al., 2000; Weiner et al., 2013). Especially in sensitive areas like benzodiazepines and Z-drugs withdrawal, where trust and collaboration are vital, engaging patients in open discussions about their fears, expectations, and goals can significantly enhance success.

Yet, despite its clear benefits, the GOC approach isn't without challenges. It demands a fundamental shift from focusing on disease-specific targets to prioritising patient-centred care (Im et al., 2019, 2023). This requires balancing clinical guidelines with individual patient preferences, which can be complex when these priorities conflict (Boeckxstaens et al., 2020; Boeykens et al., 2022). At the same time, both patients and providers may be unprepared for effective goal-setting. Patients often struggle to define or express meaningful goals, while providers may lack the skills to facilitate these discussions, making it difficult to create care plans that truly reflect what matters most to the patient (Boeckxstaens et al., 2020; Boeykens et al., 2022).

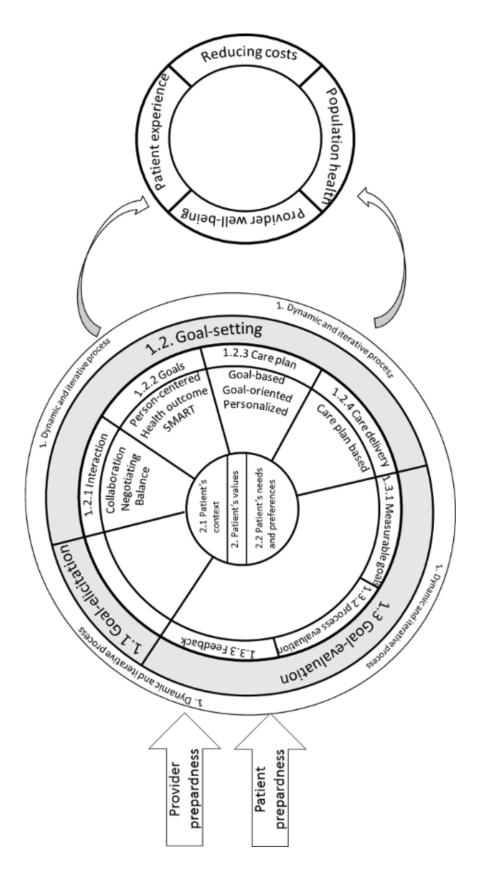


Figure 6.1 Schematic representation of the antecedents, attributes and consequences © 2022 Boeykens et al

The Patient's Voice in Prescribing and Deprescribing Decisions

A crucial element of this approach is ensuring that the patient's voice is heard throughout the decision-making process, placing the patient back at the centre of care. **Chapter 3** of this thesis explores patients' perspectives on prescribing and deprescribing. In this chapter, some patients reported feeling uninformed about the risks of prolonged use, often trusting their healthcare providers blindly without being actively involved in their treatment trajectory.

Research has shown that many patients feel dissatisfied with their consultations with GPs, citing a lack of sufficient support and information guidance, and shared decision-making (Mokhar et al., 2019). Many assume that the responsibility for prescribing lies entirely with their GP, expecting that if discontinuing benzodiazepines and Z-drugs were in their best interest, their doctor would proactively recommend it. When this recommendation was not made, they interpreted it as implicit validation of continued use (Anthierens, Habraken, Petrovic, et al., 2007; Sirdifield et al., 2017).

On the other hand, while some studies suggest that patients are often reluctant to discontinue benzodiazepines (Cook, Biyanova, et al., 2007; Hawkins et al., 2021; Komagamine et al., 2018), a recent survey conducted across 14 countries revealed that psychotropic medications rank among the ten most frequently mentioned drugs that patients aged 65 and older, who are on five or more medications, would consider deprescribing (Vidonscky Lüthold et al., 2025). This highlights the importance of transparent communication between the provider and the patient, as well as the need for a strong therapeutic alliance (Amberg, 2020; Carrie M. Silvernail & Wright, 2022; Hawkins et al., 2021; Sirdifield et al., 2017). Furthermore, qualitative evidence suggests that patients who experience withdrawal symptoms from psychotropic medications often feel dismissed or misdiagnosed, further underscoring the need for clinicians to be better informed and to foster open, validating communication (Guy et al., 2020).

This chapter highlights a disconnect between professional deprescribing strategies and patient readiness, emphasising the need for personalised, flexible withdrawal plans. While official guidelines propose structured deprescribing pathways,

patients in this study expressed that successful tapering depended on individualised pacing and emotional readiness.

Furthermore, recent research shows that patients who use benzodiazepines and Z-drugs often face forms of moral judgment and stigma in online discussions. Some are portrayed as non-compliant or less responsible when they continue using these medications, which may discourage them from seeking help or expressing ambivalence about stopping. This underscores the need to promote patient-centred care that avoids moralising framings and instead acknowledges the complexity of long-term use and the emotional contexts surrounding it.

Integrated care

The management of benzodiazepines and Z-drugs is a complex process influenced by patient and healthcare professional preferences and expectations, prescribing culture, and the broader healthcare system (Conklin et al., 2019; Farrell et al., 2015; McCarthy et al., 2022a). Given these complexities, an integrated and patient-centred approach is essential to ensure safe prescribing and deprescribing practices.

A significant obstacle to the safe management of benzodiazepines and Z-drugs is the fragmentation of care. Poor coordination among healthcare providers often leads to inappropriate prescriptions and medication overlaps (Prior et al., 2023). A 2016 study revealed that a significant number of patients prescribed benzodiazepines by psychiatrists were also receiving other prescriptions from different healthcare providers, underscoring the need for coordinated care to prevent medication overlaps (Ong et al., 2016). This fragmentation underscores the urgent need for coordinated care that ensures consistency across providers and promotes safe prescribing and deprescribing practices. It also highlights the importance of bridging the gap between specialists, such as psychiatrists or geriatricians, and primary care professionals to create a cohesive treatment plan.

To address the challenges posed by fragmented care, transparent communication, shared care plans, and ongoing patient monitoring are key to ensuring effective treatment (Naylor et al., 2011). A collaborative model involving GPs, psychiatrists, psychologists, social workers, nurses, and pharmacists, while actively involving patients and their support networks, can significantly enhance the likelihood of

successful outcomes in both prescribing and deprescribing processes (Katon et al., 2010; McCarthy et al., 2022b).

Primary care professionals play a pivotal role in benzodiazepine and Z-drug prescribing. A recent Belgian cohort study (Drieskens et al., 2024) found that 81% of benzodiazepine and Z-drug prescriptions were issued by GPs, compared to 12% by psychiatrists, with 6.8% involving prescriptions from both specialties. This places GPs at the frontline, giving them a key opportunity to influence prescribing practices and implement and coordinate risk-reduction strategies.

However, GPs often report lacking the time and resources necessary to manage benzodiazepine and Z-drugs prescriptions effectively, particularly when it comes to addressing the complexities of long-term use and deprescribing (Sirdifield et al., 2013). Conversely, many pharmacists feel they lack the legitimacy, skills, and confidence to assume a role that falls outside their traditional mandate (Bryant et al., 2010). To address these challenges, innovative models of care have been explored such as a team-based model with GPs and pharmacists (Furbish et al., 2017). Studies have shown that including pharmacists in deprescribing efforts significantly improves benzodiazepine discontinuation rates (Ashkanani et al., 2023).

Furthermore, pharmacists also play a critical role in reviewing medication regimens (Hernández-Prats et al., 2022) and identifying potentially harmful or unnecessary drugs (Balsom et al., 2020; Kua et al., 2021). Beyond deprescribing, they can educate patients on the risks of long-term benzodiazepine and Z-drugs use, offer guidance on non-pharmacological alternatives like sleep hygiene, and use motivational interviewing to support gradual dose tapering when necessary. In Belgium, the evolving role of pharmacists as primary care provider has reinforced their involvement in the management of long-term benzodiazepines and Z-drugs use. With increased responsibilities in patient counseling and medication management, pharmacists are now positioned to intervene more proactively during the dispensing process. They can identify patterns of chronic benzodiazepine use, flag potentially inappropriate prescriptions, and initiate conversations with patients. This shift aligns with national health priorities aiming to reduce psychotropic

overuse and highlights pharmacists' growing contribution to safe and rational medication use.

While optimising existing prescriptions is crucial, preventing unnecessary initiation remains equally important. As emphasised in the policy recommendations from **Chapter 4** of this thesis, avoiding the initial prescription of benzodiazepines and Z-drugs is critical to primary prevention efforts. Consequently, **Chapter 5** of this thesis explores the co-development of a decision-support tool designed to assist GPs and pharmacists in guiding first-time benzodiazepine prescriptions. This tool, developed in collaboration with healthcare professionals and patients, aims to facilitate structured discussions on risks, promote non-pharmacological alternatives, and encourage shared decision-making.

Adopting a multi-level approach

Prevention of long-term benzodiazepine and Z-drugs use requires a multidimensional approach. Rather than viewing it through a singular lens, it is essential to recognise that interventions at different levels of intervention, ranging from public health awareness to clinical practice changes, can each play a role in reducing long-term use. Addressing this challenge effectively necessitates a holistic and global perspective, integrating multiple complementary strategies.

The findings from this thesis in **Chapter 4** – the policy Delphi, demonstrate that benzodiazepines and Z-drugs management can be tackled through various entry points. This includes preventing initial prescriptions, preventing a first prescription from developing into long-term use, and addressing long-term use and dependence. Each of these entry points corresponds to the primary, secondary, and tertiary prevention strategies, which are already being implemented in Belgium to varying degrees. However, the effectiveness of these interventions depends not only on their individual impact but also on their coordination within the broader healthcare system.

Belgium presents a unique and complex policy landscape, as healthcare competencies are divided across federal, regional, and local levels. This decentralised structure means that the implementation of benzodiazepine-related

interventions must be strategically coordinated across different governing bodies to ensure effectiveness.

To discuss this, a stakeholder event was organised at the conclusion of the BENZOCARE research project, bringing together key stakeholders from various sectors, including health policymakers, healthcare professionals and researchers. Their collective expertise and insights contributed to the development of a structured framework, outlining which stakeholder is best positioned to oversee and implement each policy recommendation.

Table 6.1 shows each recommendation is mapped to the relevant stakeholders within the system. By aligning policy interventions with the appropriate level of governance, this framework aims to maximise the feasibility, sustainability, and impact of benzodiazepine and Z-drugs management strategies in Belgium in the future.

| | AFMPS FAGG APB | AVIQ | BCFI | Besho | CMP / Doi | Domus Medica FAGW | w Feda | FNRS | FPS | GLEN FWO LOK | GLEM Herstela LOK cademie | tela INAMI mie RIZIV | InfoSanté //Gezonheid //I en // wetenschap | d IPSA | KCE | King Baudouin Fondation LUSS | | Mental Health Sector Ophaco | Ordre des o médecin | Réseau s Santé Wallon | SSMG | SSPF VAD | Zones de première ligne / Eerstelijnsz ones | Comment | |
|--|-------------------|------|------|-------|-----------|----------------------|--------|----------|-----|-----------------|------------------------------|-------------------------|---|---------|-----|------------------------------------|---|-----------------------------------|------------------------|-----------------------------|------|----------|---|---|----------------------------|
| Implementing an awareness raising campaign among the general public on tapering off benzodiazepines and Z-drugs. | | | | | | | | | | | | | | | | | | | | | | | | | |
| Implementing an awareness raising campaign for patients on the challenges of withdrawing from multiple medications | | | | | | | | | | | | | | | | | | | | | | | | | |
| Implementing an awareness raising campaign for professionals on the challenges of withdrawing from multiple medications | | | | | | | | | | | | | | | | | | | | | | | | | |
| Implementing an awareness raising campaign of the risks of benzodiazepines and Z-drugs in empathetic and nonstigmatising way | | | | | | | | | | | | | | | | | | | | | | | | | |
| Adding warnings of the risk of dependence on the benzodiazepines and Z-drugs package | | | | | | | | | | | | | | | | | | | | | | | | For reasons of uniformity, this should be regulated at European level | ty, this curopean |
| Undertake further research on the mechanisms surrounding the first prescription of benzodiazepines and Z-drugs | | | | | | | | | | | | | | | | | | | | | | | | | |
| Create smaller packages of benzodiazepines and Z-drugs | | | | | | | | | | | | | | | | | | | | | | | | AFMPS/FAGG cannot oblige marketing authorisation holders to commercialise small pack sizes. | olige n holders pack |
| Provide information by the prescriber and provider to the patient regarding the risks of dependency of benzodiazepines and Z-drugs at first use | | | | | | | | | | | | | | | | | | | | | | | | | |
| Give access to other benzodiazepines and Z-drugs prescribers/providers to the part of the medical file related to prescriptions | | | | | | | | | | | | | | | | | | | | | | | | | |
| Allow the carer to dispense one or two doses of benzodiazepines and Z-drugs at the same time to provide correct (minimal) dose | | | | | | | | | | | | | | | | | | | | | | | | | |
| Encourage prescribers to add the indication for substance use disorders next to insomnia/anxiety to patient records when use exceeds guidelines | | | | | | | | | | | | | | | | | | | | | | | | | |
| Establish an agreement between the prescriber, the pharmacist and the patient to keep the same prescriber and pharmacist throughout treatment. | | | | | | | | | | | | | | | | | | | | | | | | | |
| Creating a shared policy position between different professionals groups in addiction care concerning the management of benzodiazepines and Z-drugs. | | | | | | | | | | | | | | | | | | | | | | | | | |
| Greate an inter-professional communication channel at local level, between pharmacists and GPs to discuss common patients | | | | | | | | | | | | | | | | | | | | | | | | | |
| Implement a training course on difficult tapering-off processes related to benzodiazepines and Z-drugs for professionals. | | | | | | | | | | | | | | | | | | | | | | | | | |
| Establish and provide a list of healthcare providers specialised in tapering off of benzodiazepines and Z-drugs | | | | | | | | | | | | | | | | | | | | | | | | | |
| Establish a support and advice line for people who want to taper off of benzodiazepines and Z-drugs. | | | | | | | | | | | | | | | | | | | | | | | | | |
| Develop a 'Benzo-buddy' (peer support) system. | | | | | 1 | \dashv | | \dashv | | + | | | _ | - | | | | | | | | | | | |
| Share patient testimonials about benzoulazepines and z- drugs tapering off. | | _ | | | | + | | \perp | | | | | | | | | | | | | | | | | |
| Develop culturally appropriate patient materials. | | _ | | | + | + | + | + | # | + | + | | | \perp | 1 | | + | + | | | 1 | + | | | |
| Extend the patient inclusion criteria of the new reinbursement scheme for the compounding of smaller doses of benzodiazepines and Z-drugs to residents living in nursing homes. | | | | | | | | | | | | | | | | | | | | | | | | | |
| Extend the patient inclusion criteria of the new reimbursement scheme for the compounding of smaller doses of benzodiazepines and Z-drugs to patients who are taking more than one | | | | | | | | | | | | | | | | | | | | | | | | | |

Limitations

While this work provides a comprehensive and in-depth exploration of benzodiazepine and Z-drugs prescribing and deprescribing practices, it is not without limitations. Across the different chapters, several methodological and contextual constraints should be acknowledged.

In **Chapter 2**, although the study offered meaningful insights into how professionals manage long-term benzodiazepines and Z-drugs use, it was not specifically focused on goal-oriented care, which may have limited the depth of analysis on this particular approach. The inclusion of participants from various professional backgrounds brought valuable diversity but reduced representativeness within each group. The over-representation of professionals in addiction care provided valuable insights from mental health care providers specialized in addiction, but reduced representativeness within primary care sector. Interpretation bias may also have occurred due to translations between Dutch and French.

In **Chapter 3**, exploring patients' lived experiences, may have been subject to recruitment bias, as participants were more engaged than the other patients that were not motivated to explain their lived experience. The use of Interpretative Phenomenological Analysis enriched the depth of the data but carries an inherent level of subjectivity.

In **Chapter 4**, the Policy Delphi process faced an imbalance between healthcare professionals and patients, potentially weakening the visibility of patient perspectives in the consensus results. A dropout rate may have affected the continuity and diversity of views across rounds, and the categorization of recommendations by the research team involved a degree of subjectivity, as some could arguably fall into multiple prevention levels.

In **Chapter 5**, this study involved a small sample size, limiting generalizability, and the evaluation focused on perceived acceptability rather than measurable clinical outcomes. The leaflet was developed only in French, which may reduce

accessibility for individuals with limited health literacy or different language backgrounds.

One key overarching limitation is the absence of complementary quantitative studies, which could have further enriched the findings and broadened the understanding of the phenomena observed. While the qualitative approaches used throughout the research provide detailed and nuanced perspectives, integrating quantitative data would have offered a broader context and potentially strengthened the conclusions.

Additionally, the focus on the Belgian healthcare system may limit the transferability of certain recommendations to other countries with different healthcare structures and policies.

Finally, although the deprescribing leaflet was well received by participants, its development and testing were conducted on a limited scale. Further large-scale evaluations are needed to determine its short- and long-term effectiveness in changing prescribing practices and improving patient outcomes.

Perspectives

This thesis provides an exploration of diverse perspectives on benzodiazepines and Z-drugs prescribing and deprescribing practices, as well as policy and intervention strategies. Nevertheless, several areas require further exploration to enhance implementation and ensure long-term impact.

One of the challenges is evaluating tools that have demonstrated potential, such as the decision-support tool co-developed in **Chapter 5**. Future research should focus on assessing its real-world effectiveness by evaluating how it influences prescribing behaviours over time and whether its integration into patient records could enhance usability in routine primary care settings. Additionally, training programs for healthcare professionals - particularly for GPs and pharmacists - should be further developed to strengthen their capacity to engage in shared decision-making with patients. Training programs for healthcare professionals, particularly GPs and pharmacists, should be further strengthened to support their engagement in shared decision-making with patients. These programs could be

integrated both into general practice specialization curricula and continuing professional development, in order to raise awareness among GPs about the management of long-term users of benzodiazepines and Z-drugs. Several key themes could be addressed, including the value of a goal-oriented care approach, the stigma that may affect both patients and healthcare providers, the benefits of a slow and gradual tapering process, and the importance of interdisciplinary collaboration in patient management. Additionally, involving patient partners in training initiatives could help to highlight real-life experiences and foster a more collaborative and empathetic approach to care.

At the policy level, the findings from the Policy Delphi study in **Chapter 4** highlight that while many recommendations received broad support, some more innovative measures were met with scepticism due to concerns over feasibility. Future efforts should focus on piloting and refining these innovative strategies, ensuring they can be adapted within Belgium's healthcare system. Stronger federal, regional, and local coordination mechanisms will also be necessary to align policy efforts and prevent fragmentation of benzodiazepine reduction strategies.

Conclusion

The issue of long-term benzodiazepine and Z-drugs use is deeply rooted in cultural, clinical, and systemic factors, making it a multifaceted public health challenge. This thesis has demonstrated that addressing this issue requires an integrated, multi-level strategy that combines evidence-based clinical practices, structured policy interventions, and patient-centred care models.

By incorporating insights from healthcare professionals (**Chapter 2**), patients (**Chapter 3**), policy recommendations (**Chapter 4**), and co-development patient tool (**Chapter 5**), this work contributes to the scientific and policy discourse on benzodiazepine management. The proposed goal-oriented care model, combined with primary prevention strategies, interprofessional collaboration, and decision-support tools, presents a path forward to reducing benzodiazepine dependence while maintaining high-quality patient care.

Faced with the complexity of long term BZRAs use, a comprehensive and personalised care model is essential. Such a model should not only focus on pharmacological aspects but also on psychosocial factors, enabling patients and providers to co-create care plans that prioritize both safety and patient autonomy. Moving forward, continued collaboration between policymakers, healthcare providers, and patients will be essential in shaping more sustainable, patient-centred solutions that not only prevent inappropriate benzodiazepine use but also support those seeking to discontinue these medications safely and effectively.

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