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'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.

Findings: 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 personalized 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.

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1. Introduction

Benzodiazepine receptor agonists (BZRA), which encompass both benzodiazepines and Z-drugs, are commonly prescribed for anxiety, sedation, and sleep disorders. Nevertheless, both short and long-term use of this class of psychotropic medications can result in adverse effects, including physiological and psychological dependence, increased cognitive impairment, and elevated risks of injuries, such as falls, hip fractures, road accidents, and even suicide attempts or completions (Dodds, 2017; Lader, 1999, 2011). Furthermore, individuals who have been taking BZRA may experience significant challenges with withdrawal symptoms when attempting to discontinue these medications (Lader, 2014). During attempts to 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 destabilizing 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 cut-off 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

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et al., 2022b). While they play a short-term role in specific conditions, their use should be limited or discontinued after a short time (maximum one week for insomnia and four weeks for anxiety (Centre Belge d'Informations Pharmacothérapeutique, n.d.) in cases where they are unnecessary. In situations where alternatives are available, BZRA could be substituted or complemented in accordance with the patient's preferences and agreement.

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

Deprescribing from BZRA has received a lot of attention from researchers in terms of initiating deprescribing (Tannenbaum et al., 2014), supporting the process (Coteur et al., 2022a) 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 (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.

1.1. 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 et al., 2007; Cook et al., 2007; Kapadia et al., 2007), content analysis of free-text responses (Lynch et al., 2024), and a quantitative analysis of an online survey (Reid Finlayson et al., 2022). Using different methodologies, these articles examine patients" perspectives when first prescribed benzodiazepines (Anthierens et al., 2007), factors influencing older patients" willingness to consider stopping benzodiazepines (Cook et al., 2007), patients' perceptions of current health services (Kapadia et al., 2007) or evaluate the experiences of individuals who are using, tapering off, or have discontinued BZRA (Reid Finlayson et al., 2022) and the impact of BZRA use on patients' lives, particularly symptoms, and barriers and facilitators to benzodiazepine withdrawal (Lynch et al., 2024).

The Interpretative Phenomenological Analysis (IPA) methodology facilitates the exploration of participants' lived experiences by allowing them to express their personal story (Smith & Nizza, 2021). This method delves into how participants construct meaning from their experiences, perceptions and perspectives (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 (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 stabilized, 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?

2. Methods

2.1. 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.

2.2. 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 (Supplementary data 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., 2021). Subsequently, it was presented to the follow-up committee of the research project, comprised of mental health and primary care stakeholders, pharmacists, and policymakers to gather their feedback. Following these inputs, the interview guide underwent revisions by the research team until a final version was achieved. The final version was then translated by MC into Dutch and by PV into French.

2.3. Adaptation of the life history calendar method

In order to facilitate the story telling of what, for some, was a long and complex experience we employed and adapted the life history calendar method. During the interview participants were invited to engage with a "life history calendar" (LHC) (Nelson, 2010) that we adapted and called Medication Calendar Method (MCM). The classical life history calendar typically covers a specified period, such as a year or several years, and prompts individuals to provide detailed information about various life events. LHC is 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 and 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, 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.

2.4. 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 organized 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, and 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.

2.5. Ethical statement

Prior to participating in the study, participants were provided with an information and informed consent letter, as well as a verbal explanation of the study's objectives by the researcher (MC or PV). They subsequently gave their voluntary and written informed consent and agreed to be recorded. All names and identifying information were removed from the transcription to maintain anonymity.

2.6. Data analysis

Interpretative Phenomenological Analysis (IPA) was employed for the data analysis. This approach requires an in-depth exploration of participants' lived experiences, aiming to uncover the ways in which they make sense of their experience. IPA enables exploration of patients' experiences with great depth and detail (Smith & 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).

3. Results

3.1. 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 I). 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.

3.2. Interviews findings

Although the participants had different withdrawal goals (stabilization, reduction or cessation), they shared

Table I. Socio demographic data.

Code	Date of the interview	Year of birth	Gender	Professional status	Reason for first presciption	Online or in person
RESP1	27-04-22	1980	M	Working	Anxiety	In person
RESP2	22-07-22	1964	M	Unemployed	Lexotan for acute psychosis due to drug abuse	Online
RESP3	29-07-22	1985	F	On sick leave	Insomnia	In person
RESP4	31-08-22	1989	M	On sick leave	Anxiety	In person
RESP5	02-09-22	1969	M	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	M	Unemployed	Anxiety	In person
RESP11	11-07-22	1970	F	Working	Anxiety	In person
RESP12	08-09-22	1949	M	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	M	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 II. Themes.

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'

common experiences in their histories. Five themes emerged from the analysis of the data (Table II): (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 ».

3.2.1. *"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.

3.2.2. *"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.

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

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

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

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

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

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

3.2.4. *"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

3.2.5. *"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

4. Discussion

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

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

Second, and linked to this need for information, a particular challenge with SUD to BZRA is the fine line between treatment and dependence. Patients are prescribed BZRA in response to certain symptoms but become dependent on the medication. When they decide to stop they must have understood that this is no longer a treatment plan for their symptoms but a dependence. The results presented in theme two, highlight the challenges for individuals with long-term BZRA use to question the "treatment" plan proposed by their provider. This could be interpreted as a trusting relationship between patient and provider but could also be characterized 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 Carrie 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 (Carrie & 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 recognizing 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 emphasizes the need to remain attentive to patients at each prescription renewal. It is therefore important that patients are warned of the adverse effects so that they can be supported and managed appropriately and talk about stopping the molecule at the first prescription.

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

Finally, adopting a goal-oriented care approach (GOC) could prove advantageous in tailoring care to the individual patient. GOC enables healthcare and social care professionals to collaborate innovatively, placing the priorities and life objectives of patients with complex medical and social requirements at the forefront of their care (Boeykens et al., 2022). Studies have analysed the characteristics associated with the long-term use of BZRA and have shown that users tend to have certain characteristics linked to long-term use, such as advanced age, multiple comorbidities, and psychiatric disorders (Kurko et al., 2015). These users may be considered to require complex medical and social support. Incorporating goal-oriented care principles into the management of BZRA disorders requires actively involving patients in decision-making, acknowledging their treatment preferences, and tailoring interventions to support their goals. This approach fosters a sense of ownership and empowerment among patients, ultimately leading to improved treatment adherence and outcomes (Boeykens et al., 2022; Reuben & 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-centred 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 (stabilization, harm reduction, total abstinence) we believe that GOC may be a helpful approach in this setting.

4.1. 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 rigour.

4.2. 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.

5. Conclusion

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

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 optimizing care delivery, particularly for patients managing multiple conditions, by aligning treatment strategies with individual goals and preferences.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Author contribution statements

Pauline Van Ngoc: Conceptualization, Investigation, Methodology, Writing—Original Draft; **Melissa Ceuterick**: Conceptualization, Investigation, Methodology, Writing—review & editing, Supervision, Funding acquisition; **Jean-Luc Belche**: Writing—review & editing; **Beatrice Scholtes**: Conceptualization, Investigation, Methodology, Writing—review & editing, Supervision, Funding acquisition.

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.

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