



Federal research programme on Drugs

POLICY BRIEF

Policy Brief n° [***]

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

Executive summary

The two-year BENZONET project studied the experiences of habitual users of benzodiazepines and Z-drugs in Belgium (Flanders), a so far understudied yet important group. Furthermore it was explored why and how online peer support can assist in withdrawal. The results led to three sets of recommendations: a solid focus on the prevention of chronic use, an all-inclusive approach to cessation (presented in a clover-leaf model) and tackling the stigma attached to long-term use of this medication. Moreover, patients should be involved in future health initiatives as a complete partner. Creating a Belgian support group would be a first step to achieve this goal.

Context and question(s) of research

Belgium is one of the leading consumers of BZD/Z in Europe and even worldwide. Despite various prevention campaigns and initiatives by the federal government, the long-term use of sleeping pills and tranquillisers, in particular benzodiazepines and Z products (further referred to as BZD/Z) remains alarmingly high. According to the latest national Health Survey from 2018 12% of the Belgian population had been using at least one prescribed tablet in this class of sedatives, hypnotics and anxiolytics, during the two weeks previous to the survey. Treatment with this medication is recommended for two to maximum four weeks. A longer use has myriad negative health effects such as physical and psychological dependence and withdrawal symptoms. Notwithstanding one in three users in our country still takes these medicines after eight years. Moreover, since the start of the COVID-19 pandemic, the majority of the Belgian population (73%) indicates to suffer from sleeping problems. Many of them retreated to medication to cope with these issues. Nearly a quarter (21%) used a BZD/Z of which 42% had started or increased their use since the beginning of the crisis. In the age group between 18 and 24 years 75% of those who use BZD/Z indicated that this use had started or increased since the pandemic. Subsequently there is a dramatic increase in the sale of BZD/Z. It is not unthinkable that a number of these first prescriptions will eventually lead to habitual or long-term use as well, even in groups that were traditionally not the main focus of health campaigns (such as young adults).

So far the perspectives of long-term habitual users, who have been taking BZD/Z for more than six months at least four times a week, have not yet been investigated in Belgium, although this is an important harder-to-reach group from a sensitization point of view. International studies show that once habitual users take a step to withdraw and quit their medication use, they often rely on online resources to help them taper off from BZD/Z. This online help seeking when tapering off has never been studied in Belgium before either.

Hence, BENZONET aimed to study (1) how habitual long-term users perceive their medication use and (2) how online communities can contribute to the cessation of BZD/Z use.

In order to do so, two online communities with relevance to the use of BZD/Z were selected: (1) an open-access discussion forum for older adults, an age group in which consumption of BZD/Z is traditionally highest compared to the rest of the population, and (2) a Dutch language peer support forum for people who want to withdraw. Furthermore a varied groups of 30 habitual and former long-term users of BZD/Z were interviewed individually about their experiences. The results were then presented in a series of focus groups to 16 professionals and expert patients to develop policy and practice recommendations.

Main findings

Cessation with online support of peers

The first online case study revealed that older adult forum users hold varied opinions on BZD/Z, yet all seem to strive for an improved sleep, preferably without taking any medication. Hence these forum users share numerous alternative ways to cope with sleeping problems. They warn each other of the risks of habitual BZD/Z use and specifically about possible dependence. Furthermore, they provide hopeful examples of cessation to inspire habitual users to stop as well. The latter retreat to all sorts of rationalisations and emotional motivations to defend their use. In general the forum overarchingly functions as a site of support for those who aim to withdraw or explore non-pharmaceutical solutions for sleeping problems. There is only very little open acceptance of habitual use, contrarily to what would be expected from general statistics that seem to support a widespread normalization of BZD/Z use in this age group.

The second online case study showed how withdrawing and former users support each other with different forms of detailed and specialised experiential knowledge to taper off. The Dutch language forum serves as a site for peer support and seems to address a gap in the existing health care sector for those who want to withdraw. Some former withdrawing users prefer the site for its anonymity or the mental support of likeminded. Many discuss their disappointment in the medical establishment and the prescribers of the medication on which many eventually became dependent. The cessation stories described on this forum differ from the more hopeful and positive brief withdrawal accounts on the previous forum. Specialised forums thus fill a knowledge gap for BZD/Z users when withdrawing that is not covered by their general practitioner or other health care provider. Partially because the latter are seen as part of causing the BZD/Z dependence.

Interviews with current and former long-term BZD/Z users

On average the interviewees had been using BZD/Z for 11 years. Among the current habitual users that were interviewed, some were willing to stop, but lacked self-efficiency. Others were not contemplating at all and can rather be described as contented users. Different strategies might be needed to raise awareness and create behavior change in these types of users. They show a high degree of agency when withdrawing and many did so independent from any health care professional (and thus not in line with current guidelines, for example cold turkey rather than by gradually reducing the dose).

Shame and stigma hamper many to openly discuss their actual BZD/Z use, sharing of medication, experienced side-effects or a wish to withdraw with their health care provider. Stigma thus indirectly also limits help seeking. Remarkably the federal prevention

campaigns have an unintended stigmatizing side-effect on habitual users (a group for whom these campaigns were initially not developed).

Conclusion and recommendations

Preventing habitual use by supporting expanding existing initiatives

Given the large numbers of habitual or chronic BZD/Z use, and the current rise in BZD/Z due to the pandemic also in younger age groups, it is firstly highly recommend to continue working on the **prevention of habitual use**. An updated version of a patient awareness-raising leaflet to hand out with a first prescription is recommended, as well as continued training for GPs on BZD/Z consultations, and renewed attention for existing guidelines that offer myriad opportunities for non-pharmaceutical alternatives. Multidisciplinary collaborations between prescribers and providers in primary and secondary care is an essential boundary conditions. A common policy on BZD/Z prescribing in group practices can further support preventive steps. Pharmaceutical companies should further be urged to produce smaller packages as these do not only physically limit the availability, but create a psychological awareness indirectly among users. Finally, a registration of BZD/Z in Farmanet can facilitate further monitoring of the BZD/Z use in the general population and the potential impact of policy initiatives.

A clover leaf model on cessation

Secondly, based on the success stories of withdrawal, we have developed a data-driven clover leaf model for BZD/Z cessation. Each leaf of the model reflects a particular form of support during withdrawal. These domains are interconnected, equally valid and should ideally all be covered. To plant a seed and motivate patients to withdraw it is recommend to add two specific modules to the **Benzoconsult** e-learning module, that are specifically targeted at 1) motivating patients to withdraw and 2) difficult taper and withdrawal. The first leaf of the clover refers to respecting and following the **patient's pace** during tapering off. This includes offering and reimbursing correct dosages to taper. The second leaf refers to **psychoeducation** about withdrawal, ideally by spreading an updated version of an existing patient information brochure with specific information on withdrawal and by evaluating the potential added value of a broader promotion of the Ashton Manual for patients. The third leaf refers to supporting the development of a **Belgian peer support group**. Fourthly, guiding towards alternatives for coping with sleeping problems, stress and anxiety should be fully supported, including financially. To continue the clover leaf metaphor, a fertile ground for the clover to thrive (or to accomplish cessation) can be found in a supportive network (that offers support, recognition, but also a critical voice) and secondly, in a **non-stigmatising environment**. The former can be achieved by sensitizing a patient's close network, but also by supporting a peer support group.

Tackling stigma

Thirdly, our results provide important insights into the mechanisms of stigma attached to chronic BZD/Z use. For people to seek help, this barrier has to be tackled. Two important strategies for **destigmatisation** are awareness raising among providers and attuning of future health campaigns.

Patient involvement

Overall in the development of all the mentioned initiatives it is crucial to **involve patients** or BZD/Z users and fully acknowledge their perspective. This is challenging, as there is no such thing as the BDZ/Z user, nor are their currently any patients groups organised around this topic (unlike for many chronic conditions for example). Hence, we end by underlining the utter importance of creating a local, Belgian group and online platform where peers with expertise regarding BZD/Z use and withdrawal can meet. More detailed and concrete suggestions on how to implement the above recommendations, can be found in the final report.

Read more

Ceuterick M, Christiaens T, Creupelandt H, Bracke P. Perception, habitual use and cessation of BENZOdiazepines: a multi-method NETnography. Final Report. Brussels : Belgian Science Policy Office 2021 – 104 p. (Federal Research Programme on Drugs)

Information

Contact

Melissa Ceuterick
Hedera (Health and Demographic Research) University Ghent
melissa.ceuterick@ugent.be