FEDERAL RESEARCH PROGRAMME ON DRUGS

SUMMARY

BENZONET

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

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1. Context

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- a class of sedatives, hypnotics and anxiolytics, remains alarmingly high in Belgium. Treatment with this medication is recommended for up to two and maximum four weeks, since with longer use the benefits do not outweigh the disadvantages. Notwithstanding one in three users in Belgium still takes these medicines after eight years.

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

According to the latest national Health Survey from 2018, 12% of the adult Belgian population reported using a BZD/Z in the two weeks prior to the survey (Gisle et al. 2020). These figures indicate a slight decrease in BZD/Z use compared to the national Health Surveys from 2013 (13%) and 2008 (18%), which probably indicates an effect of the ongoing efforts of the federal government to reduce the consumption of BZD/Z.

Zoomed in on those who had been using a BZD/Z in the 24 hours prior to the survey, results show that 4,3% of the Belgian population had been using a benzodiazepine and 1,2% a Z-product, of which the majority reported long-term habitual use, respectively 93,4% for benzodiazepines and 90,7% for Z-products (Van der Heyden et al. 2020). Generally, the use of BZD/Z is higher among women and people over 65, while there is also a remarkable peak in use around retirement age especially among men (Van de Straat et al. 2018). BZD/Z usage is especially troublesome among people over 75, with 37% of all women and 28% of all men using BZD/Z in this age group (Gisle et al. 2020). BZD/Z are now considered one of the most common 'potentially inappropriate medications' for these older age groups (Bourgeois et al. 2012, Anrys et al. 2018). Chronic use of BZD in specific in people over 65 is estimated at 112 per thousand persons, which is more than three times the OECD average. As such Belgium ranks indisputably high in international comparisons, also for younger age groups. Gisle and colleagues (2020) state that Belgium is probably one of the countries with the highest (over)consumption of these medications, with a daily delivery of 1,260,034 daily doses (DDDs) of BZD/Z by Belgian pharmacies in 2016 (according to figures of APB).

Despite the slight decline noticed, it seems that the recent COVID-19 pandemic has lead once again to an alarming increase in the use of BZD/Z. The 5th COVID health survey (December 2020) reveals that the majority of the Belgian population (73%) suffered from sleeping problems, which is an extremely high number (Sciensano 2020). Furthermore, overall 21% of the respondents used a BZD/Z, of which 42% indicated having started or increased their use since the beginning of the crisis. In the age group between 18 and 24 years 75% of those who use BZD/Z indicated that this use started or increased since the start of the pandemic.

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

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

2. Objectives

BENZONET is a qualitative study on

1) the experiences and perspectives of individuals who have used or have used long-term sleep and tranquillizers more specifically benzodiazepines and Z products (hereafter abbreviated to BZD/Z), and

2) the role of online forums in tapering off, withdrawing and cessation.

The aims of this study are trifold:

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

3. Methods

Methodologically, this study relied on a combination of:

(1) online nethnographic case studies
(2) in-depth interviews with 30 (former) habitual BZD/Z users to explore the patients' perspective
(3) focus groups with peer and professional experts to develop recommendations.

4. Highlights of case study 1 '*And they slept happily ever after*'

- The use of benzodiazepines and z-drugs increases with age and is thus believed to be normalised in older age groups. In this case study we explored discourses on the use of medication for sleeping problems constructed by adults over 50 in an online peer discussion forum, including both former and current habitual BZD/Z as well as fervent non-users.

- Following a social-psychological discourse analysis, we discerned five different interpretative repertoires used in online forum data. The different discursive techniques are explained and illustrated in-depth.

- All repertoires depart from a tacit agreement on the undesirability of BZD/Z use.

- While, either a 'rationalisation' or an 'emotionalisation' repertoire are used to defence one's own habitual use, the majority of older adult forum members relies on a 'risk and addition', 'alternative pathways' and 'cessation' repertoire (or a combination thereof) to convince others to stop or to prevent them from using this medication.

- These repertoires offer a broad and encompassing overview of possible positions regarding the long-term use of sleeping medication.

- The ethos of healthicisation that -sometimes implicitly- underlies these different discursive repertoires, shows how a depharmaceuticalised sleep is set as the preferable moral standard for healthy ageing.

- As such, the members active on the forum seem to be -unintendedly- susceptible to post-ageist ageism. Rather than being accepted, age-related sleeping problems are resisted and fought with all means possible.

- Specific discursive elements of each repertoire can be used in tailoring future health campaigns to increase recognisability for this age group.

5. Highlights of case study 2 *'Best of luck on your journey to healing'*

- Long-term dependence on benzodiazepines (also BZD) is an often underestimated health problem as BZD are hardly effective after a few weeks of use, side and adverse effects are numerous, and reducing or entirely tapering off BZD can come with intense withdrawal symptoms. Research shows BZD users may seek online support to reduce/taper off benzos, but little is known what the online communication looks like.

- This case study thus explores how benzodiazepine users talk about and construct the process of reducing or tapering off this medication on a Dutch-language BZD/Z online forum for withdrawing users using corpus-assisted discourse analysis that combines frequency analyses with further qualitative discourse analysis of examples.

- Our analysis pointed to a number of trends in language use relating to the use of pronouns, different drug names, items that express temporality, and lexical items relating to the process of tapering off.

- Withdrawing users' extensively share experiential expertise of using and reducing BZD/Z.

- A collective identity is shaped through the ways in which forum members express their shared experiences in relation to these pharmaceuticals. Forum members construct a medical(ised), health professional-like expert identity, both in relation to their own situation, but also in interaction with other forum members, as advisors to each other. I

- As such, the forum not only serves as a site for emotional support, community building and peer interaction, but also for informational support, which is traditionally offered by health professionals. This is especially pervasive as, forum users also express indignation about the medical establishment and its lack of institutional knowledge support in the process of tapering off.

- In doing all of the above, forum users thus construct BZD use as problematic; no traces are found of legitimizing discourses.

- Moreover, they assume the identity of a patient, and position their experience firmly in the domain of illness, rather than of addiction. As they experience that the medical establishment is not sufficiently helping them to taper off, they take up the role of their own and each other's medical expert and advisor, as well as advocate for the community. Although it has been observed in other contexts that experienced patients provide each other with expert informational support, our data point to a context in which this happens because of the (perceived) lack of recognition and medical expertise (rather than as an addition to formal care typically offered in other support groups).

6. Highlights of the in-depth interviews with current and former habitual BZD/Z users

- A total of 30 semi-structured in-depth interviews were conducted between July 2019 and February 2021 with persons who identified themselves as long-term user or former long-term user of BZD/Z (= more than 6 months more than 4 times a week). A narrative analysis following Bissell and Ryan was conducted on the full transcripts.

- The majority of the participants received their first prescription for sleep related problems (n=20), only a minority for an anxiety problem (n=4) or a combination of both (n= 6). None of the respondents used BZD/Z recreationally.

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

- Among the current long-term users, the majority were on zolpidem (n=9) or alprazolam (n=8).

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

- All medication stories had a similar starting point. Without an exception, all medication narratives, the reported sleep and/or anxiety issues can be directly linked to a major event in the life of the patient, either emotionally (loss of a loved one, child, family problems) professionally (stress due to study or heavy workload, serious incidents at work) or medically (a serious physical condition, unrecognized postpartum depression). These events all caused a sometimes unexpected major disruption or break in the life story of the patient. To restore the negative outcomes of that disruption in the life story, medication was started, either to be better able to deal with the consequences of the biographic disruption (sudden sleeping problems or anxiety attacks) and to continue 'daily life' as normally as possible and to have as little impact as possible on the regular daily functioning. Usually, the medication is therefore used rather to be able to continue to meet the demands of daily life (for example, to continue to function at work despite sleep deprivation caused by sadness after a break-up) and not so much with what caused these changed sleep patterns or anxiety (i.e. the biographical disruption in itself)

- Passing on, recommending or prescribing medication is by many considered as a ‘token of concern’.

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

- The role of the prescribing health care professional (GP-psychiatrist) at start-up varies from actively recommending the medication to a great reluctance to prescribe.

- Most interviewees indicated that their long-term use became a habit, gradually, and almost unnoticed and unconsciously.

- Even interviewees who had stopped taking BZD/Z also mentioned the personal added value. They talked about "comfort", "help", "support", "convenience". The medication also gives a feeling of "control" and thus security.

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

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

- Most former used explained how they gradually reduced their medication or tapered off. Some people who chose to quit "cold turkey".

- Withdrawal stories are highly individual, linked to contextual, personal and biological factors. There is not one type of withdrawing patient. Hence, cessation should rather be interpreted as a continuum, along the following different axes:
    - Type of support: alone- with formal professional support – with informal support
    - Mode of cessation: cold turkey - standard 6 weeks - many months or even longer
    - Organisation: fully functioning (while at work) - on (sick) leave - in permanent disability
    - Dosage: reducing therapeutic dose - prescribed yet increased dose - recreational (high) use

- A common thread throughout all conversations was the theme of the (negative) societal perception of BZD/Z. The ambiguity between the widespread use of BZD/Z and the apparent taboo that rests on openly discussing its use, appears to stem in part from the contrast between BZD/Z's status as "prescription drug" and the stigma that stems from a its addictive potential.

- The two most recent federal prevention campaigns were experienced by most interviewees as stigmatizing, or at least as too pedantic in tone. It is unclear that these are preventive campaigns.

7. Recommendations

- Based on a series of three focus groups with 16 professionals and experts by experience/patients to verify the above results, the following recommendations were developed. These recommendations are bundled in three clusters based on the core outcomes of the study: prevention of habitual use, cessation and destigmatisation. For a more detailed summary and overview of these recommendations we refer to the policy brief.

1. Prevention of habitual use

- develop an awareness-raising leaflet for patients at first prescription
- continue GP training on BZD/Z consults
- renewed attention for existing guidelines
- develop a common policy on prescription of BZD/Z in primacy care
- strive for a multidisciplinary approach
- limit the availability by creating smaller packages
- streamline monitoring through registration in Farmanet

2. Cessation: a clover leaf model

- A holistic approach towards cessation is summarised in a data-driven clover leaf model.

- For the clover to grow a seed need to be planted, i.e. patients have to be motivated to withdraw. Therefore we recommend further training for GPs, in the form of a separate module in the Benzoconsult e-learning to motivate patients to stop and to keep them motivated during tapering off.

- Each leaf of the model further addresses a particular form of support during withdrawal. These domains are interconnected, equally valid and should ideally all be covered:
    - Respecting the patient's pace of tapering off
    - Creating opportunities for peer support (through creating a Belgian online forum)
    - Offering psychoeducation on withdrawal
    - Assisting in finding alternative coping strategies

- For the clover to thrive and the recommendations to work, a fertile ground is needed. Motivating conditions to accomplish cessation includes firstly a non-stigmatising environment and secondly a supportive network that offers support, recognition, but also a critical voice.

3. Destigmatisation

- Provide training on addiction literacy in primary care and community pharmacy
- Include the patients' perspective and language in the development of future campaigns

Finally, as an overall concluding and transversal recommendation, it is advised to strive for an active engagement of patients at all levels.

8. References

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

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

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

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

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