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A systematic review and meta-synthesis of patients' experiences and perceptions of seeking and using benzodiazepines and z-drugs: towards safer prescribing

Running heading: Benzodiazepines and z-drugs: towards safer prescribing

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Sirdifield led the study and contributed to all stages of the analysis and write-up

Chipchase contributed to all stages of the analysis and write up

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Siriwardena had the idea for this study, and has contributed to the design, conception, analysis and drafts of the paper (including final revisions).

Abstract

Background: Benzodiazepines and z-drugs are used to treat complaints like insomnia, anxiety and pain. These drugs are recommended for short-term use only, but many studies report long-term use, particularly in older people.

Objective: To identify and synthesise qualitative studies exploring patients' experiences and perceptions of receiving benzodiazepines and z-drugs, and through this identify factors which perpetuate use of these drugs, and strategies for achieving safer prescribing.

Methods: A systematic search of six databases for qualitative studies exploring patients' experiences and perceptions of primary care benzodiazepine and z-drug prescribing published between January 2000 and April 2014 in a European language, and conducted in Europe, the United States, Australia or New Zealand. Reference lists of included papers were also searched. Study quality was assessed using the Critical Appraisal Skills Programme qualitative checklist. Findings were synthesised using thematic synthesis.

Results: Nine papers were included and seven analytical themes were identified relating to patients' experiences and perceptions and, within that, strategies for safer prescribing of benzodiazepines and z-drugs: 1) patients' negative perceptions of insomnia and its impact, 2) failed self-care strategies, 3) triggers to medical help-seeking, 4) attitudes towards treatment options and service provision, 5) varying patterns of use, 6) withdrawal, 7) reasons for initial or ongoing use.

Conclusions: Inappropriate use and prescribing of benzodiazepines and z-drugs is perpetuated by psychological dependence, absence of support and patients' denial/lack of knowledge of side-effects. Education strategies, increased availability of alternatives, and targeted extended dialogue with patients could support safer prescribing.

Key Points

- Long-term use of benzodiazepines and z-drugs can have adverse consequences, but research reports long-term use, particularly in older people

- We identified seven themes from published qualitative research which add to our understanding of patients' experiences and perceptions of seeking and using these drugs, and factors perpetuating their use
- Safer prescribing could be supported through education strategies for patients and healthcare professionals, increased availability of alternatives, and targeted extended dialogue between patients and healthcare professionals

1 Introduction

Benzodiazepines (e.g. diazepam, temazepam, lorazepam [BZDs]) and z-drugs (e.g. zopiclone, zolpidem, zaleplon) are commonly prescribed for insomnia, and are also used to manage anxiety and pain. Guidelines suggest that if these drugs are prescribed, they should only be used short-term [1-4]. However, research indicates that they are often prescribed long-term [5, 6]. This is concerning, as BZDs and z-drugs are known to have limited long-term therapeutic benefits, and also have adverse consequences for patients, such as dependency, daytime sedation, cognitive impairment and increased rates of falls and accidents [5]. Despite the risks, use of these drugs is particularly common in older people [7]. In a previous study, we conducted a systematic review and meta-synthesis which identified influences on general practitioner (GP) prescribing of these drugs. Here, findings suggested that GPs were more tolerant of long-term use in older compared with younger patients [8].

In this study, we present a systematic review and meta-synthesis of literature from the perspective of *patients*, aiming to explore their experiences and perceptions of receiving BZDs and z-drugs in primary care. We sought to identify factors which perpetuate the use of these drugs and to make recommendations for supporting safe, effective and patient-centred approaches to prescribing.

2 Methods

We conducted a systematic search for qualitative studies exploring patients' experiences and perceptions of primary care benzodiazepine and z-drug prescribing. The search encompassed six databases: MEDLINE, CINAHL, Social Science Citation Index, Science Citation Index, PsycINFO, and AMED. A search strategy was initially developed for MEDLINE (Supplementary Table 1), and subsequently adapted for the remaining databases. All databases were searched by May 2014.

2.1 Inclusion and Exclusion Criteria

Studies were included if they: involved qualitative analysis of patient experiences of receiving BZDs and z-drugs; were published between January 2000 and April 2014 to ensure relevance to current practice and the historical context of benzodiazepine prescribing; were published in a European language; and were conducted in Europe, the United States, Australia or New Zealand.

Studies which were not relevant to the focus of the review or were published outside these dates, languages and settings were excluded.

The initial search identified a total of 3975 papers. After removing duplicates, NS, CS and SYC examined either the title, abstract or full paper (where relevance was unclear), and identified 7 papers for inclusion. Following a review of the reference lists of included papers and correspondence with the author of one of the included papers, two additional papers were identified for inclusion (Figure 1). One of these [9] was published after the cut-off date for the original search, but was included as it contained relevant data and had been accepted for publication in March 2014.

[Figure 1 Search Results here]

2.2 Data extraction and quality assessment

Three researchers (CS, RP and SYC) independently extracted data from included studies on their aims, sample, method(s) of data collection and analysis, and theoretical perspective using a data extraction form created for the study; and assessed them using the Critical Appraisal Skills Programme (CASP) qualitative checklist [10]. A fourth researcher (NS) independently assessed all of the included papers for comparison. Agreement on ratings was reached after discussion as a group.

2.3 Data Synthesis

Data were analysed in NVivo 10 using thematic synthesis [11]. Initially, two researchers (CS and SYC) independently coded the 'results' sections of the included papers line-by-line, allocating codes based on the meaning of each line using an inductive approach. This resulted in the data being coded into 26 themes as free nodes in NVivo. We then met to discuss this initial coding, and make amendments required to ensure consistent coding into all of these themes across all papers. Next, as a group (CS, SYC, NS) we organised the codes into higher-level descriptive themes that encapsulated the meaning of groups of our initial codes. Finally, we considered these themes in relation to our research question – developing our final analytical themes (see below, and see Supplementary Table 1 for further details of this process).

3 Results

3.1 Data Extraction

The nine included studies were published between 2003 and 2015 and were from four countries (Australia, Belgium, UK, USA) [12, 13, 9, 14-19]. Participants in these studies were mainly older adults that were frequent users of BZDs. Most studies contained a mixture of men and women, but there were more female participants overall. Studies were based on both semi-structured interviews and focus groups. Some studies employed mixed-methods, in which case only the qualitative component was included in the meta-synthesis presented here. Various methods of analysis were employed in the studies including content analysis, thematic analysis and the constant comparative method (Table 1).

[Table 1 Description of studies included in the review here]

Whilst all of the included studies contained data about patients' experiences and perceptions of receiving BZDs and z-drugs, there was some variation in the primary focus of the papers. For three studies [12, 16, 17] the primary focus was on insomnia, whilst for others the primary focus was on broader aspects of the use of these drugs and (in some cases) implications for service development.

3.2 Quality Assessment

The CASP criteria for qualitative research were applied to each paper. This checklist supports critical appraisal of research by asking reviewers to score papers against questions about ten domains that should be considered in qualitative research. Papers receive ratings of either 'zero', or 'one' in each domain. Papers only received a score of zero if the domain had not been addressed at all in the paper. The scores received ranged from eight to ten, indicating high quality. No studies were excluded on the basis of the quality assessment (Supplementary Table 2).

3.3 Data Synthesis

After initial coding and development of descriptive themes, we developed seven analytical themes as detailed below (see Supplementary Table 3 for more on this). These focused on patients' experiences and perceptions of receiving BZDs and z-drugs. Within our data analysis we focused on insights gained from the data on strategies for encouraging safer prescribing of BZDs and z-drugs. We organised the themes chronologically into a model representing a patient's journey from identifying that they have a health problem, through to using BZDs or z-drugs, withdrawing from them, or (in some cases) continuing to use these medications contrary to medical guidelines [Figure 2].

[Figure 2 Model of themes here]

3.3.1 Patients' negative perceptions of insomnia and its impact

Several studies, specifically those that focused on the management of insomnia, discussed the start of the patient journey – in this case, patients perceiving that they had a problem with sleep. Although other studies included patients using BZDs or z-drugs in relation to other conditions (e.g. anxiety), we were unable to create equivalent themes for these conditions from the data available. Three studies [12, 17, 16] gave insight into patients' perceptions of insomnia, its causes and consequences, and the relationship between this condition and medical help-seeking.

Patients perceived insomnia as involving difficulty falling asleep or waking after sleep onset:

“They described difficulty with falling asleep...comments included...”I toss and turn”, “It takes me four or five hours to fall asleep”...waking after sleep onset was also common” [12]

“Many reported being able to get to sleep, but then waking in the early hours of the morning and being unable to return to sleep” [16]

The condition was attributed to a variety of causes including depression, shift work, post-traumatic stress disorder and lifestyle factors.

The studies pointed to the relationship between insomnia and other health conditions. This relationship was two-way – firstly, insomnia was cited as causing other health problems:

“I said to my doctor recently, “when I die...I don't want breast cancer on my death certificate, I don't want emphysema, I want insomnia because I am sure that's at the root of all my problems”” [17]

“I think a lot of it is because I'm so tired, that is what causes the depression” [17]

Secondly, insomnia was cited as being caused *by* other health problems. For example, arthritic pain and heart failure were cited as causing/precipitating insomnia; and patients viewed insomnia as being perpetuated by other comorbid physical and mental health conditions such as back pain, nocturia and anxiety. In one paper, adverse reactions to medication and the position of devices such as pacemakers were also said to perpetuate insomnia [12].

Insomnia was seen as having a deep and wide-reaching negative impact on patients' quality of life in both health and psychosocial areas, including patients being unable to enjoy activities because they were too tired:

“I was having marriage problems because of this thing of not sleeping” [17]

“Insomnia often led to inability to do or enjoy previously enjoyable activities, such as concerts, travelling, shopping or visiting with grandchildren” [12]

“They were plagued with memory problems, stating that their ‘minds were not what they used to be’ and perceived that their memory problems are worse after ‘a bad night’” [12]

The perceived severity of this negative impact of insomnia was one factor which led patients to seek medical help.

3.3.2 Failed self-care strategies

Studies showed that, prior to seeking help from a healthcare professional, patients with sleep problems and with difficulties coping with ‘life stressors’ [19] had tried to cope with their health problem in other ways including attempting to distract themselves, lifestyle changes, and using alternatives to prescription drugs:

“Night time routines included playing “mind games” to distract themselves from insomnia, worries and fears. The most common was going to bed late and watching television until falling asleep...Others used distraction through music, reading or driving in the car” [12]

“Many patients had tried a range of alternatives to prescribed drugs for sleep problems for considerable periods before consulting. These included exercise, relaxation, over-the-counter drugs, herbal and miscellaneous

remedies, or complementary therapies. Some had even read about cognitive behavioural therapy” [17]

“...try this tape, calming tapes and all this crap, that I have already tried anyway, also herbal stuff. Tried all the herbal stuff, you know in chemists” [19]

The perceived ineffectiveness of these strategies in relation to insomnia could trigger a consultation with a GP [17].

3.3.3 Triggers to medical help-seeking

Medical help-seeking was often triggered by the perceived ineffectiveness of self-help strategies, or (in the case of insomnia), the perceived severity of the condition. Medical consultations were also triggered by significant life events, and pressure from others:

“Consultation was often triggered by significant life events or pressure from family and friends (social networks). By the time patients consulted with a GP or nurse prescriber, they had begun to see their problem as needing medical treatment rather than part of the range of normal human experience” [17]

‘Life events’ were also listed as a reason why people started using BZDs [19].

3.3.4 Attitudes towards treatment options and service provision

Eight studies included data on what patients wanted/expected when they sought help from a healthcare professional, both in relation to the specific type(s) of treatment offered, and other aspects of service delivery.

In terms of the specific type(s) of treatment offered, some patients were disappointed when a GP suggested treatments that they had already tried:

“...we’d tried [a sleep aid like] Nytol, the milky drinks at night, going to bed at a certain time and getting up at a certain time all that sort of thing, that’s about all they discussed, and we’d already tried those” [17]

Some patients hoped or expected to receive medication for their problem when they consulted a healthcare professional, whilst others preferred not to use medication due to fear of side-effects:

“Some patients welcomed a prescription they could use as needed. They found it empowering that a practitioner trusted them to take hypnotics appropriately. Others used the system to gain drugs as a fall-back for the future” [17]

“Others emphasised that they had not wanted sleeping tablets. Many patients preferred not to resort to hypnotic drugs because of fear of side-effects...Some found drugs unhelpful or counterproductive” [17]

“When asked about their potential interest in behavioural sleep treatment, one participant stated: “I’d eat a bucket of nails if you told me it would help me sleep.” This was greeted with a resounding chorus of “me too.” The majority of the group agreed that they would like to learn more about sleep and insomnia and behavioural strategies to address it” [12]

In terms of other aspects of service delivery, patients discussed a desire for continuity of care, more discussion with a health professional prior to receiving a prescription, and longer consultation times. Patients wanted more detailed information, and for their problem to be taken seriously:

“Pharmacists were seen as either not providing any information on the medications or inadequate information” [19]

“There was a general consensus that to get detailed information from their GPs, they had to ask ‘lots of questions’, and to ‘probe’ to extract information. There was some dissatisfaction with the quality of consultations with GPs, and it was said that the short length of a consultation was a barrier to receiving a quality service. The issue of time was also raised when talking about alternative methods, but they ‘would like to learn and receive information on them, as well as more information on the side-effects of the drugs they were already taking” [16]

“Patients valued clinicians’ empathy, listening, time given, and offer of explanations for treatment options...Continuity of care, a flexibility of approach, and a consistent or common approach within a practice were also found helpful” [17]

However, not all patients desired additional information/discussion:

“...the conflict between the need for medication and the negative connotations attached to taking BZDs might explain the absence of a stated need for information. If patients had received more information on their medications, they might have had to give more thought to taking the prescription” [13]

Patients’ knowledge of, and attitudes towards, potential side-effects from medication could influence their patterns of use. In some cases, learning that a proposed medication was addictive meant that patients preferred alternative treatments. In others, patients saw this as less important, or were willing to pay this price for an improvement in the quality of their sleep:

“When he said that the tablets were addictive I didn’t want to take the tablets. So I went another avenue, I went to the hypnotist” [17]

“My doctor took a lot of persuading to put me back on them [temazepam]. I said, “look at my age...what the hell does it matter I’ve been addicted for 20 years I might die tomorrow”...so, he let me have them” [17]

The extent to which patients viewed becoming addicted to medication as a problem, and whether or not patients were willing to try alternatives influenced their likelihood of withdrawal as shown under ‘withdrawal’ below.

Finally, discussion of what patients wanted from services also included the idea of establishing specialised withdrawal services:

“Some service users wanted a specialized benzodiazepine service: They should maybe have a place where they just...deal in benzos and nothing else...like the same as a methadone place” [18]

3.3.5 *Varying patterns of use*

Descriptions of patterns of medication use were included in most of the papers. With the exception of one paper [15] where the majority of patients were reported to be taking their medication as prescribed, they encompassed a continuum from patients who tried to minimise their usage either through taking a smaller dose than prescribed or by taking them only as needed, through to patients who took more than they were prescribed:

“Many said, ‘they do not like to take sleeping tablets, and so only used them when needed’” [16]

“Respondents said they used only small doses, they consumed less medication than prescribed, and they took it only when necessary” [13]

“...he said one spoonful and 2 hours later I took another and another. The next night I drank two-thirds of the bottle” [17]

Patients’ own awareness and fear of the dangers of addiction to BZDs contributed to a desire to take only the minimum dosage of BZDs by some patients:

“Perceiving that an increase in one’s prescribed benzodiazepine dose would result in addiction kept informant’s benzodiazepine use at regular, low doses. Evie: I’m afraid to take more than they tell me to of that kind of medicine (benzodiazepines)... because I would like to not be taking things that are addictive” [14]

3.3.6 *Withdrawal*

Several papers (particularly [14, 15, 19]) contained information on withdrawal strategies and enablers and barriers to withdrawal. Strategies for withdrawal included taking an individually tailored approach and focussing on alternative strategies for coping:

“Changes in cognition were the most prevalent strategy....individually tailored dose reduction schedules were reported as useful....continuing a non-using lifestyle was assisted by being involved in a range of activities such as yoga...” [19]

Reasons for withdrawal included a realisation that their use of the drugs was interfering with their life and the people around them:

“Participants typically said they ceased use when they became unhappy with their current lifestyle; realised their use of the drug was self-destructive” [19]

Numerous barriers to withdrawal were discussed in the papers. These included a perception from patients of being unable to reduce medication use and fear of what would happen if they did discontinue – either based on imagined negative consequences or past experiences. Psychological rather than physical dependence was the predominant concern:

“I really, I don’t really think I can handle things without my meds. I mean I’m just really, really, really dependent on them at this point. All of them” [14]

“I just can’t do it. Are you trying to tell me that I should stop or not take it? I’d be miserable. Are you gonna tell him [the physician] not to prescribe it anymore? Please don’t tell him not to give it to me” [15]

“With minimal probing, patients’ seeming willingness to consider tapering or substitution of alternative medications shifted to an admission that this would be an unacceptable option. Patients’ responses ranged from the more simply expressed reluctance, “I need it” or “I don’t want to change,” to more sophisticated explanations, i.e., anticipation that the taper process would be negative” [15]

Links between feelings and beliefs about dependence on medication and the ongoing use of medication were seen in two papers:

“Self-reported benzodiazepine dependence was associated with perceptions of being unable to reduce benzodiazepine use or a desire to discontinue use as well as feeling reliant on benzodiazepines to be comfortable and able to handle life.” [14]

“...too many other competing demands to address the benzodiazepine: I always have like some other issue other than, you know, that one pill” [15]

In addition to barriers internal to the patient, barriers that were external to the patient were also discussed, such as lack of support from GPs, a need for specialist withdrawal services, and absence of an appropriate support network:

“I wasn’t making contact with anyone who could give me some clues on how to deal with benzos. For me the lack of contact with people who had done it. I went to [Narcotic Anonymous] and at one time I was going to Al-Anon as well, but I wasn’t making contact with anybody who could give me some clues on how to deal with benzos” [19]

3.3.7 Reasons for initial or ongoing use

Reasons given for the initial use of medication included patient circumstances, life events, specific health conditions such as sleep problems, anxiety or pain; the perception that medication was effective; and the fact that the medication was prescribed by a GP. Anxiety around living alone could also be an important trigger for medication use, and a reason for ongoing use [9].

Many patients reported a lack of knowledge or concern about the long term use of medication:

“Patients viewed chronic stable benzodiazepine use as responsive to a need and as a great benefit. In doing so, they minimized, or even denied, physical addictive properties or potential for misuse or inappropriate use” [15]

Reasons for ongoing use included patients feeling that they could live their lives more normally whilst using medication:

“For the most part, patients saw benzodiazepines not as a life-enhancing luxury but as restorative and necessary to maintain a normal life, and anticipated that life without benzodiazepines would be of a decidedly lower quality” [15]

“Typically, participants found that benzodiazepines alleviated negative feelings enabling them to cope more effectively with stressful situations; control panic and anxiety symptoms; allowed them to relax; or reduced feelings of aggression...In addition, they felt better and more confident and coped with day-to-day adverse events” [19]

A passive feeling of trust in GPs was also described, such that patients expected that their GP would initiate a change in their BZD use if it were needed:

“Patients said that the relationship with their physicians was based on trust, thereby explaining why they did not need more information. They said they presumed the doctor would always act in their best interest: ‘I think it is like when you go to a caterer, we don’t ask him how he has made the food’” [13]

4 Discussion

This paper synthesised the findings of qualitative research into patients’ experiences and perceptions of receiving BZDs and z-drugs and produced a model of patients’ experiences and perceptions based on the patient journey. Whilst variation across the studies in terms of their participants produced some subtle differences in findings (for example heart failure patients cited pacemakers as a cause of insomnia), we were still able to identify a number of common themes.

4.1 Strengths and Limitations

This is the first meta-synthesis of literature on patients’ experiences and perceptions of BZD and z-drug prescribing. The studies identified through the systematic review were conducted in a range of settings between 2003 and 2014. The studies mainly included older adults that were frequent users of BZDs for insomnia, but there was some variation between studies in how the populations were selected and the primary focus of the paper. For example, one study was based on the perceptions of patients with heart failure [12], whereas another focused on experiences of isolation and loneliness in older BZD users [9]. There is a risk that the particularities of the individual studies are lost in a meta-synthesis. To prevent this we have provided descriptions of each study in Table 2.

As with all thematic syntheses, we offer our interpretation of findings and attempt to ‘go beyond’ the literature to answer a particular question. We have employed a number of techniques to enhance the validity of our findings. The analysis was undertaken by reviewers from different backgrounds and discussed with a wider multi-disciplinary team to consider any bias that may have been introduced. We also included direct quotations from the papers to enable critical appraisal of our interpretations and to show the range of studies that contributed to each theme.

4.2 Comparison with the Wider Literature

Numerous factors influence how we monitor, interpret and respond to bodily indicators ('illness behaviour') [20]. Previous research shows that many people with insomnia or anxiety disorders do not seek medical help for their disorder, and often people seek advice from informal helpers or try self-help treatments prior to seeking medical help [21-24]. Our findings echo and add to such previous research on the determinants of help-seeking, in particular in relation to insomnia. Data from our included studies showed that help-seeking for insomnia is triggered by patients viewing the negative functional impact of insomnia as 'severe enough' to justify medical intervention, the perceived ineffectiveness of those self-help strategies that were used, significant life events and pressure from others.

Our findings show that several factors perpetuated the use of BZDs and z-drugs. Firstly psychological dependence – the 'withdrawal' and 'reasons for initial or ongoing use' themes showed that patients viewed their medication as effective and expressed fear that tapering use would have negative consequences, and that withdrawal would leave them unable to cope. Secondly, absence of support – the 'attitudes towards treatment options and service provision' and 'withdrawal' themes showed that some patients were dissatisfied with GP consultations and there were a number of things that could be done to improve service provision. There was a perceived lack of support from GPs to discontinue use, and the 'reasons for initial or ongoing use' theme indicated that patients trusted their GP to recommend withdrawal if it was the best option for them, and GPs had not done this. Some patients expressed a desire for a specialised support network or service for withdrawal from BZDs. Finally, the 'reasons for initial or ongoing use' theme showed that patients reportedly denied, or stated that they were unaware of the side-effects of medication.

These findings resonate with work on patient barriers and enablers for deprescribing [25] which, amongst other things, identified the extent of a patient's agreement with the 'appropriateness' of cessation, fear of cessation and the presence or absence of a process for cessation as key themes.

4.3 Implications for Future Practice and Research

Exploring this literature has enabled us to identify points throughout the patient journey where strategies could be introduced to support both healthcare

professionals¹ and patients to reduce misuse of BZDs and z-drugs, and find effective alternative ways to manage their health condition(s). These are summarised in Table 2.

[Table 2 Strategies for improving patient experience of insomnia management and reducing misuse of benzodiazepines and z-drugs here]

Through considering the implications of our analytical themes and the wider literature around strategies for reducing inappropriate use of BZDs and z-drugs and supporting patients with conditions for which these drugs may be prescribed, we identified three main strategies which may support safer prescribing.

Firstly, creation of educational resources could be helpful. Direct patient education has previously been shown to be effective in encouraging patients to discuss discontinuing BZD use with physicians or pharmacists and achieving desistance or dose reduction when compared to usual care [26]. Our study showed that patients perceived their own self-help strategies to be ineffective prior to consulting a healthcare professional and that, in some cases, patients denied or were unaware of the side-effects of BZDs/z-drugs. Educational resources could detail what guidelines recommend in terms of support for insomnia, anxiety or pain, outlining appropriate self-care strategies and how to implement them, helping patients to have realistic expectations of what treatments might achieve e.g. what 'normal' or 'good quality' sleep is, and directing patients towards alternative treatments such as (online) cognitive-behavioural therapy (CBT). These resources should also detail the potential side-effects of using BZDs and z-drugs, and stress that they are only recommended for short-term use followed by staged withdrawal at a pre-determined time. Appropriate dissemination of such resources (online, and via healthcare professionals such as GPs, practice nurses and community pharmacists) would raise both patients' and healthcare professionals' awareness of alternatives to medication and the risks of prescribing or taking medication, particularly for older adults, thus modifying demand for pharmacological interventions both prior to and at the point of access. Resources could include a sleep diary that could be used to develop tailored provision of alternative treatments and/or stepped withdrawal.

¹ By 'healthcare professionals', we mean a wide variety of roles including GPs, psychiatrists, psychologists, practice nurses, community pharmacists and other allied health professionals

Secondly, as suggested in our previous research [8], alternatives such as CBT that have been shown to be effective and are recommended in clinical guidelines need to be made more widely available. One reason for medical help-seeking is that patients perceive the negative impact of a condition to be serious enough to warrant medical intervention. CBT techniques can be used to identify and reframe negative views about health conditions (referred to as 'cognitive restructuring', 'cognitive reframing' or 'positive reframing') [27]. Research in pain management has found that a patient accepting their condition can itself lead to positive outcomes [28], and (computerised) CBT has been shown to be effective for patients with anxiety disorders and for patients with insomnia [29-31]. Alongside directing 'new' patients to alternatives, further research is needed to ascertain the efficacy of different approach(es) to deprescribing (e.g. patient education, group therapy, mixed interventions). Here, consideration needs to be given to the influence of patient characteristics (including things like comorbidities) on this [32]. Findings of such research should be shared with a wide range of healthcare professionals.

Thirdly, this study suggests extending the healthcare professional-patient dialogue in a targeted way at the point of help-seeking to explore and encourage the use of non-pharmacological treatments, clarify issues around self-help strategies and how best to implement them, encourage open and honest dialogue, and ensure that patients know that sleep problems are taken seriously. Adherence to self-help treatments is an important consideration, with previous research showing this to be at approximately 50% for technology mediated insomnia treatments (i.e. those delivered via technology rather than face-to-face) [33]. Part of the ongoing dialogue between the healthcare professional and patient may be to try to maintain a higher level of adherence to ensure maximum effectiveness of non-pharmacological treatments.

As set out in NICE guidelines [1-3], pharmacological interventions should be a last resort. Previous work shows that GPs sometimes *assume* that patients want medication or would be resistant to the idea of withdrawing from medication [8, 34]. GPs and other healthcare professionals should be made aware of the potential influence of perceived patient expectations on prescribing and should be encouraged to directly discuss patients' preferences with them. As the literature reviewed here shows, patients' patterns of use and likelihood of withdrawal are influenced by their understanding of and attitude towards the risk of addiction. Not all patients want medication, and whilst some patients are not concerned about the risk of addiction, others would prefer to try alternative treatments to avoid this risk.

At follow-up appointments various healthcare professionals, including community pharmacists can focus on medication management, ascertain patients' patterns of medication use (rather than assuming that they use it as directed), discuss the need for staged withdrawal, and discuss issues around psychological dependence and any changes in patients' circumstances.

GPs and patients both identify short consultation times as a problem, and work pressures may pose a barrier to extending the GP-patient dialogue. However, personalised support can be delivered by a range of healthcare professionals including community pharmacists, and in the long-term, this may save time as patients will not be returning for repeat prescriptions. The potential benefits of this could be the subject of future research.

Differences in perspectives from healthcare professional and patient of the problem and its solution are important when considering how to reduce inappropriate prescribing. Some of these differences come to light when comparing the results of this meta-synthesis of patient perspectives to our earlier meta-synthesis on GP perspectives [8]. GPs expressed concerns that there were a lack of alternatives to medication, and when these were available they were time-consuming and difficult to access [8], whereas in this meta-synthesis we identified that patients felt they had tried alternatives to medication before seeing their GP, but that these were ineffective. However, the alternatives tried were not necessarily those that would be recommended by a healthcare professional. Establishing a shared concept between patient and GP of the value of alternatives to medication and likelihood of success could help patients to then re-explore these avenues under the guidance of their GP, leading to greater success in their use.

5. Conclusion

Benzodiazepines and z-drugs are often inappropriately prescribed long-term for the treatment of insomnia, pain and anxiety disorders, particularly in older people. Inappropriate use is perpetuated by patients' psychological dependence on these drugs, an absence of support to discontinue use, and patients' lack of awareness of, or denial of, the side-effects of these medications. Safer prescribing could be achieved through the creation of educational resources, increased availability and use of effective alternatives recommended in clinical guidelines like CBT, and an extended GP-patient dialogue.

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Table 1 Description of Studies Included in the Review

Study	Aims	Sample	Method of Data Collection	Method of Data Analysis	Theoretical Perspective
<p>Andrews et al., (2013), (USA) [12]</p>	<p>To evaluate the perceptions of patients with heart failure about “1) insomnia and its consequences; 2) predisposing, precipitating, and perpetuating factors for insomnia; 3) self-management strategies and treatments for insomnia; and 4) preferences for insomnia treatment”</p>	<p>A purposive sample of 6 men and 5 women from one outpatient heart failure programme</p> <p>Ages: 50-91 years</p> <p>All had New York Heart Association class II or III heart failure and a variety of comorbid conditions</p> <p>All were taking medication for insomnia</p>	<p>A mixed-methods study combining self-completed questionnaires and two focus groups</p> <p>The focus groups used a semi-structured interview guide based on Spielman’s 3 P Model of insomnia</p> <p>Also kept notes of participants’ responses, body language and group processes</p> <p>Four participants attended a second focus group to review and</p>	<p>The recordings of the focus groups were transcribed and content analysis was conducted in Atlas.ti</p> <p>“The PI and PhD student conducted initial coding to organize the narrative data into mutually exclusive categories and then clustered the resulting codes to identify central themes”. Results were then reviewed by two further investigators reviewed the results and confirmed the clustered results</p>	<p>Unclear</p>

			verify findings		
Anthiere ns et al., (2007), Belgium [13]	“To explore patients’ views and expectations regarding their first prescription for benzodiazepines”	15 family practice patients (13 female, 2 male) Ages: 18-76 years All had received prescriptions of BZDs for the first time Patients were recruited from general practices in the regions of Ghent and Brussels. Both daily and intermittent users were included	Semi-structured interviews Interviews were based on open ended questions with participants at home	Interviews were transcribed verbatim. “Data were analysed using the principles of thematic analysis and incorporating the data-driven inductive approach”. Two researchers used the constant comparative method to identify emerging themes then categories for analysis. A third researcher was used to improve consistency and reliability of the analyses. Field notes were also used	Phenomenol gical
Canham, S.L. et al., (2014), USA [14]	To "investigate the subjective experiences and meanings of benzodiazepine dependence in a sample of women age 65 and	English-speaking White-European women Ages: 65-89 years Self-identified as using a	Multiple-visit semi- structured interviews All interviews were conducted by the first author	Interviews were transcribed verbatim and analysed in Atlas.ti. Transcripts were iteratively coded into themes by two researchers working independently.	Phenomenol ogical

	<p>older who self-identified as chronic benzodiazepine users. Our focus was on whether women who are chronic benzodiazepine users identified themselves as dependent, how users perceived dependence to benzodiazepines, and how meanings and understandings shaped individual experiences of benzodiazepine use"</p>	<p>benzodiazepine on a near daily or daily basis in at least the 3 months prior to data collection for a sleep or anxiety problem</p> <p>15 people participated, and 12 of these specifically discussed their perceptions of benzodiazepine dependence</p> <p>The paper also provides details about marital status and living arrangements, self-identified dependence on benzodiazepines and length of usage</p>	<p>Kept a "detailed notebook of memos, observations, and impressions"</p>	<p>Coded data were then discussed to reach consensus</p>	
<p>Canham S.L. (2015), USA [9]</p>	<p>To examine data from a larger study of experiences and perceptions of benzodiazepine use for descriptions of loneliness and social isolation in older women. The analysis presented here</p>	<p>7 White European women</p> <p>Ages: 65-86 years</p> <p>All participated in the parent study and had used benzodiazepines at least five days a week for at least the previous three months and shared experiences of social isolation and</p>	<p>Semi-structured multiple-visit interviews</p> <p>Interviews were based on open ended questions, some of which were developed in prior research. Conducted in</p>	<p>The transcripts were entered into Atlas.ti and iteratively coded by two independent qualitative data experts. Data were discussed in-depth to resolve any discrepancies. The analysis conducted here relates to the theme</p>	<p>Phenomenological</p>

	asked “what is the subjective experience of loneliness and social isolation for older women who regularly use a benzodiazepine for a sleep or anxiety problem?”	<p>loneliness</p> <p>“Participants were recruited through newspaper advertisements and flyers distributed in independent and assisted living senior residences in a large metropolitan area” in the USA</p> <p>The paper also provides details of marital status, specific medication used and length of usage</p>	<p>participants’ homes or private meeting rooms</p> <p>Also used fieldnotes</p>	and sub-themes around social isolation and loneliness	
Cook et al., (2007), USA [15]	“To understand patient factors contributing to the chronicity of benzodiazepine use by older adults as a first step in the development of acceptable intervention strategies for taper/discontinuation or prevention of chronic use” from the perspective of older patients	<p>50 regular anxiolytic benzodiazepine users, 85% female</p> <p>Ages: 61-95 years</p> <p>Recruited through 33 primary care physicians from the Philadelphia Pennsylvania area.</p> <p>81% Caucasians and 19% African-Americans</p> <p>Also provides details of marital</p>	<p>Semi-structured telephone interviews</p> <p>Based upon reviews of the literature and pilot interviews</p>	<p>Interviews were audiotaped and professionally transcribed. The study used thematic content analysis in NVivo. Investigators met as a group to “abstract and condense themes, identify common themes and reconcile conflicting observations”</p>	Unclear

		status, employment status, specific drug types, dosage and frequency, and reason for prescription			
Dollman et al., (2003), Australia [16]	"To identify strategies needed to increase use of non-drug interventions in the management of insomnia in the elderly"	<p>16 focus group participants</p> <p>Recruited for focus groups through an advertisement placed on a notice board in a local government community centre</p> <p>209 GPs completed questionnaires</p> <p>The paper details their sex, and various details about their practice and patient population</p>	<p>A self-administered questionnaire and 3 focus groups</p> <p>The questionnaire was sent to all 425 GPs in the Southern Division of General Practice and included open-ended questions</p> <p>Focus groups were held for older people to clarify enabling factors that may assist GPs and consumers in encouraging non-drug alternatives</p>	For the focus groups a member of the research team took notes and discussions were tape recorded, transcribed and analysed using thematic analysis	Unclear
Dyas et al.,	"To explore patients' and primary care practitioners'	30 patients participated, split across 11 focus groups. 11 male and 19	Focus groups and field notes	"Interview data were managed using	Phenomenological

<p>(2010), (UK) [17]</p>	<p>expectations, experiences, and outcomes of consultations for sleep difficulties, as a basis for improving the treatment of insomnia in primary care"</p>	<p>female</p> <p>Ages: 25 -70 years</p> <p>Participants had consulted with insomnia during the previous 6 months and were "selected from eight general practices taking part in a quality improvement collaborative"</p> <p>Recruitment was via postal invitation, waiting room posters, and newspaper advertisements</p> <p>The sample was selected to ensure "that participants were of different sex, age, work, and socioeconomic status". The paper provides data on these characteristics, the duration of their sleep problems, and the remedies tried</p>	<p>"Separate focus groups for practitioners and patients"</p> <p>"Semi-structured scripted question schedules were used...Field notes were made and group proceedings were tape-recorded and transcribed verbatim"</p>	<p>MAXQDA2007. Constant comparative analysis was used, employing a coding template agreed by three authors for the subsequent transcript analysis. A priori themes implicit in the focus group schedule were not used in the template"</p>	
<p>Kapadia et al., (2007),</p>	<p>"To conduct a survey of healthcare workers and high-dose</p>	<p>The focus group that included patients "consisted of community drug workers (n=3) and high-dose</p>	<p>Focus groups</p> <p>"Both focus groups were</p>	<p>The audiotapes were transcribed verbatim and analysed using thematic</p>	<p>Unclear</p>

UK [18]	benzodiazepine-dependent users to gauge opinion on improving services for this client group". Focus groups were conducted to inform the questionnaire development	benzodiazepine-dependent clients (n=9) who accessed their services Recruitment was achieved by contacting all five community drug services covering one inner-London borough." Clients were recruited by the community drugs workers	facilitated by an independent non-clinical researcher and audiotaped. Two further researchers took notes to track turn-taking so that each individual's speech could be identified on the audiotape"	analysis in NVivo	
Parr et al., (2006), Australia [19]	To gain a more detailed understanding of perceptions by GPs and benzodiazepine users of starting, continuing and stopping benzodiazepine use	28 GPs and 23 benzodiazepine users from around Cairns, Australia. 14 female, 9 male Patients had at some time been prescribed daily BZD for 3 months or more. Mean age = 50 years. The paper also details the reasons for the prescription	Semi-structured interviews	Full transcription (apart from 4 interviews). Domains and categories developed on 3 interviews from GP and user, then refined and applied to remaining data with additional auditing	Unclear, but cites 'Consensual Qualitative Research approach.

*BZDs = Benzodiazepines; GP = General Practitioner; PI = Principal Investigator; UK = United Kingdom; USA = United States of America

Table 2: Strategies for improving patient experience of insomnia management and reducing misuse of benzodiazepines and z-drugs

Theme/Point in Patient Journey	Strategy for Healthcare Professionals	Strategy for Patients
1. Patients' negative perceptions of insomnia (or anxiety or pain) and its impact	Direct patients towards (online) Cognitive Behavioural Therapy (CBT) and/or educational resources to change their attitude (for example, ensuring realistic expectations of 'normal' sleep) and support cognitive reframing of its impact	Attend CBT and/or access educational resources
2. Failed self-care strategies	Discuss the coping strategies that a patient has tried prior to consulting. Establish whether or not these are 'recommended' coping strategies and/or have been implemented well. Suggest next steps accordingly	Discuss coping strategies tried to date with the healthcare professional. Try any non-pharmacological strategies recommended by the healthcare professional that have not been tried already/modify how these are implemented
3. Triggers to medical help-seeking	Follow steps set out in educational resources – discussing non-pharmacological forms of treatment first as recommended by National Institute for Health and Care Excellence (NICE) guidelines	Access online information re: what steps healthcare professionals should follow to support patients
4. Attitudes towards treatment options and service provision	Modify demand for pharmacological treatments at the point of access. Direct patients towards educational resources and raise awareness of side-effects and that benzodiazepines (BZDs) and z-drugs should only be taken in the short-term followed by staged withdrawal at a pre-determined time	Access educational resources recommended by the healthcare professional
5. Varying patterns of use of medication	Ask patients how they use their BZDs/z-drugs – do not assume that they use them as directed	Discuss patterns of use honestly with the healthcare professional
6. Withdrawal	Discuss the need for staged withdrawal with patients	Create a plan for staged withdrawal with the

		healthcare professional
7. Reasons for initial or ongoing use	Discuss psychological dependence with patients and establish whether the circumstances that led to an initial prescription have changed	Reflect on circumstances which led to beginning BZDs and consider whether any life stressors have changed since this time

Figure 1 Search Results

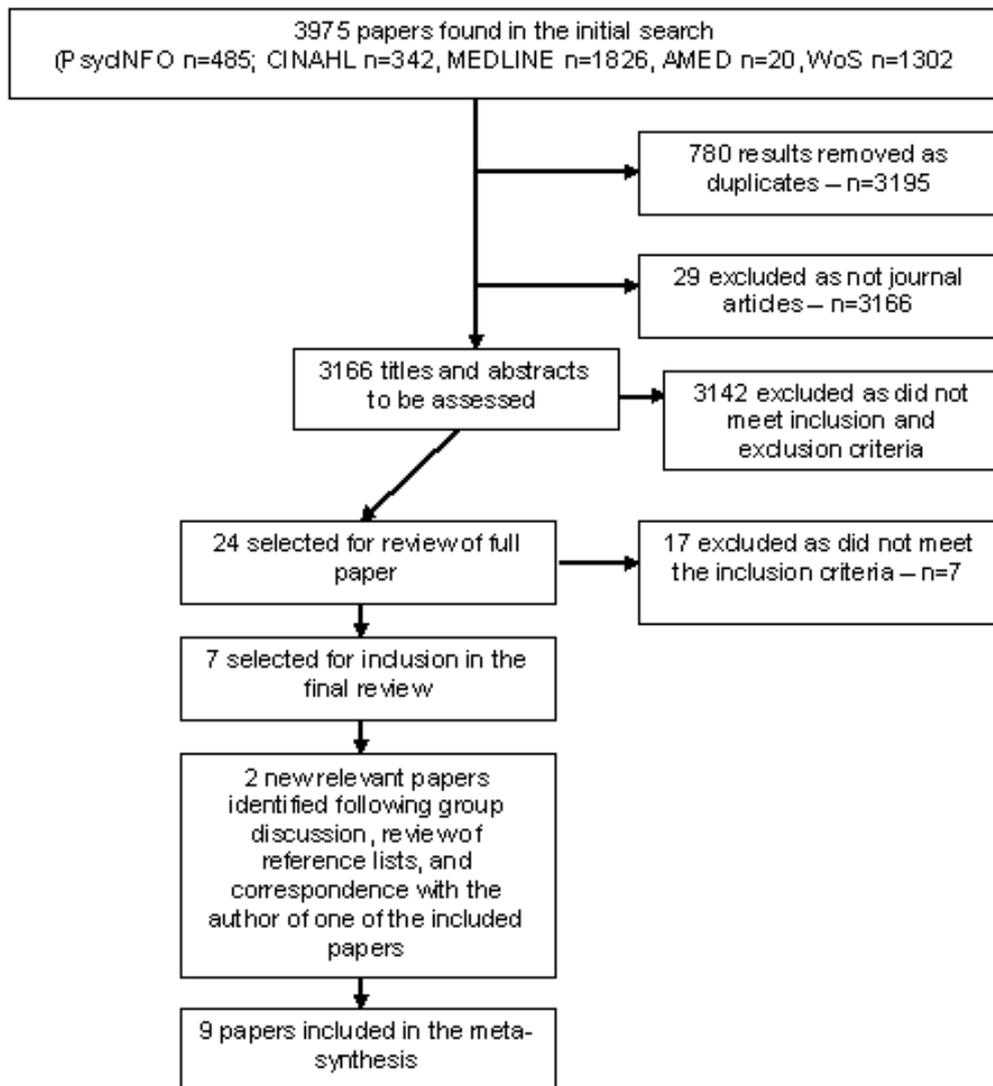
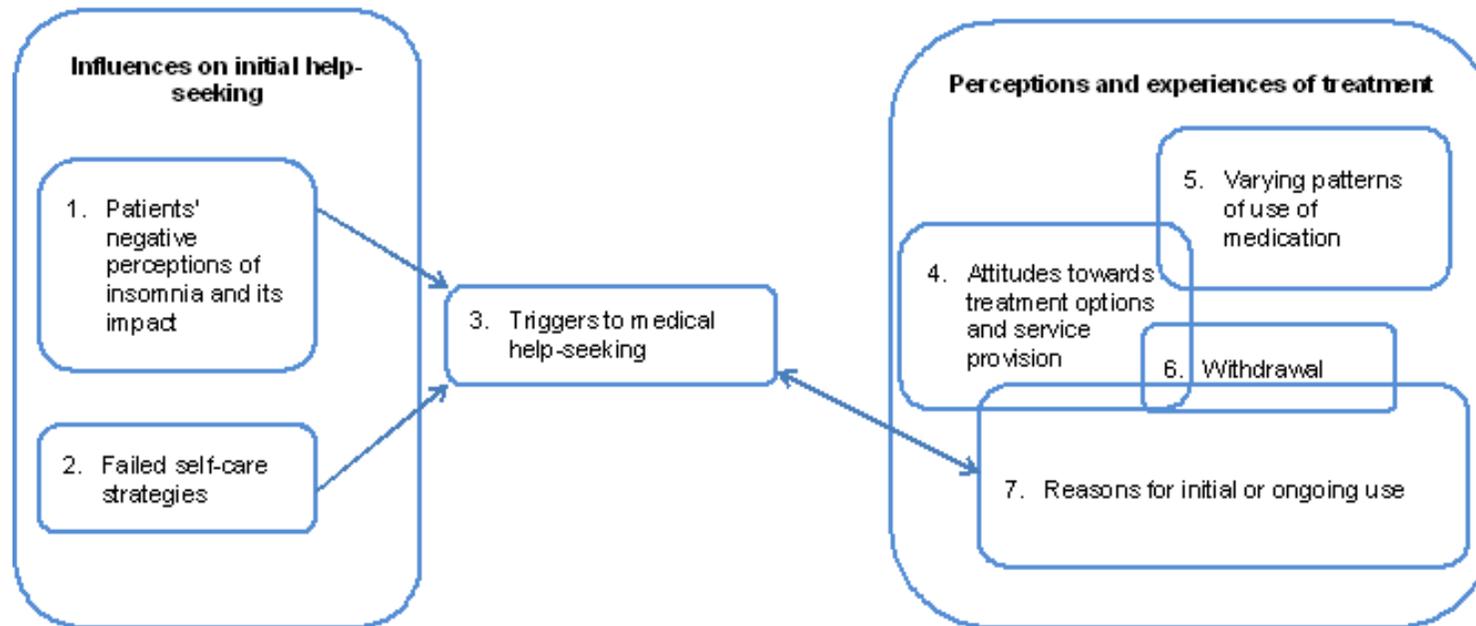


Figure 2 Model of themes*



*This model shows our themes organised as a patient journey. It begins prior to medical help-seeking with two themes relating to patients' perception of their problem and steps that they take to address the problem before seeking medical help. It then shows how these themes can be triggers to medical help-seeking. The final group of themes relate to patients' perceptions and experiences of treatment

Supplementary Table 1 MEDLINE search strategy

Line Number	Search Term*
1	AB qualitative
2	AB interview*
3	AB focus group*
4	AB theme*
5	AB experience*
6	MH Qualitative Research
7	MH Interviews as Topic+
8	AB attitude*
9	AB perception*
10	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9
11	MH Benzodiazepines+
12	AB benzodiazepine*
13	MH Anti-Anxiety Agents
14	MH Hypnotics and Sedatives
15	AB z-drug*
16	AB z drug*
17	AB BZD
18	AB anti-anxiety agent*
19	AB anti anxiety agent*
20	AB antianxiety agent*
21	AB non-benzodiazepine*
22	AB nonbenzodiazepine*
23	AB non benzodiazepine*
24	AB temazepam
25	AB nitrazepam
26	AB lormetazepam
27	AB zopiclone
28	AB zaleplon
29	AB zolpidem
30	AB eszopiclone
31	S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR

	S29 OR S30
32	MH Patients
33	AB patient*
34	AB patient experience*
35	AB patient attitude*
36	AB patient perception*
37	AB service user*
38	AB service user experience*
39	AB service user attitude*
40	S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39
41	S10 AND S31 AND S40
42	S10 AND S31 AND S40 + Limiters: 2000-2014

Here, '' indicates a wildcard search for any words which begin with the letters that precede the asterisk, and '+' indicates that the search term has been 'exploded' to include all references indexed to that term and narrower terms beneath it

Supplementary Table 2: Quality Appraisal of Papers

Paper	Clear Statement of Research Aims?	Is a Qualitative Methodology Appropriate?	Design	Sampling	Data Collection	Reflexivity	Ethics	Analysis	Findings	Value	Overall CASP Rating
Andrews et al., (2013) [12]	1	1	1	0	1	0	1	1	1	1	8
Anthierens et al., (2007) [13]	1	1	1	1	1	0	1	1	1	1	9
Canham, S.L. et al., (2014) [14]	1	1	1	1	1	0	1	1	1	1	9
Canham S.L. (2015) [9]	1	1	1	0	1	1	1	1	1	1	9
Cook et al., (2007) [15]	1	1	1	1	1	0	1	1	1	1	9
Dollman et al., (2003) [16]	1	1	1	1	1	0	0	1	1	1	8
Dyas et al., (2010) [17]	1	1	1	1	1	0	1	1	1	1	9
Kapadia et al., (2007) [18]	1	1	1	1	1	0	1	1	1	1	9
Parr et al., (2006) [19]	1	1	1	1	1	1	1	1	1	1	10

Supplementary Table 3: Creation of Themes Using Thematic Synthesis*

Initial Themes	Descriptive Themes	Analytical Themes
<ul style="list-style-type: none"> • Lack of concern or knowledge of side-effects • Justifying initiation or help-seeking to GP • Reasons for ongoing use • Patterns of use - influences • Attitudes towards the drugs • Reasons for starting use other than insomnia • Patterns of use – patient vs GP led • Patterns of use - justifications 	<ul style="list-style-type: none"> • Reasons for use 	<ul style="list-style-type: none"> • Attitudes towards treatment options and service provision • Reasons for initial or ongoing use • Triggers to medical help-seeking • Varying patterns of use
<ul style="list-style-type: none"> • Pre-GP coping strategies • Ways of coping 	<ul style="list-style-type: none"> • Coping with insomnia 	<ul style="list-style-type: none"> • Failed self-care strategies
<ul style="list-style-type: none"> • Desired alternatives • Attitudes to alternatives 	<ul style="list-style-type: none"> • Alternatives to BZDs 	<ul style="list-style-type: none"> • Failed self-care strategies • Attitudes towards treatment options and service provision • Withdrawal
<ul style="list-style-type: none"> • Patterns of use • Patterns of use – self-minimising 	<ul style="list-style-type: none"> • How people take them/patterns of use 	<ul style="list-style-type: none"> • Varying patterns of use
<ul style="list-style-type: none"> • Provision of information from services • Views on GP services/what patients want • Withdrawal services 	<ul style="list-style-type: none"> • Services 	<ul style="list-style-type: none"> • Attitudes towards treatment options and service provision • Reasons for initial or ongoing use
<ul style="list-style-type: none"> • Withdrawal services • Barriers to withdrawal • Reasons for withdrawing • Ways of withdrawing and staying clean 	<ul style="list-style-type: none"> • Withdrawal 	<ul style="list-style-type: none"> • Attitudes towards treatment options and service provision • Withdrawal
<ul style="list-style-type: none"> • Insomnia description – can't sleep • Insomnia description – can't stay asleep • Causes of insomnia • Perpetuating factors for insomnia • Insomnia as cause of other health problems • Negative impact of insomnia 	<ul style="list-style-type: none"> • Patients' perceptions of insomnia 	<ul style="list-style-type: none"> • Patients' negative perceptions of insomnia and its impact

*Data were initially coded line-by-line into 26 themes based on the meaning of each line. We then discussed the overlap and relationships between these themes, and grouped them into higher-level descriptive themes to encapsulate the meaning of groups of the initial themes. Following this, we considered the

data within each of the descriptive themes in relation to the research question. Through specifically considering what the data tell us about why patients begin and continue to use BZDs and z-drugs, and potential strategies for supporting withdrawal and encouraging safer prescribing, we created the final analytical themes and organised them into a model. Note that it was possible for the lower-level themes to fit into more than one higher-level theme.