

Older Patient Perspectives on Long-Term Anxiolytic Benzodiazepine Use and Discontinuation: A Qualitative Study

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OBJECTIVE: The objective of the study is 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.

DESIGN: The design of the study consists of qualitative semi-structured patient interviews.

SETTING AND PARTICIPANTS: The participants were 50 anxiolytic benzodiazepine users, 61–95 years of age, recruited through referrals from primary care physicians who practiced in the general Philadelphia, Pennsylvania area.

RESULTS: Many older chronic users have come to rely and psychologically depend on benzodiazepines for their unique soothing properties, attributing to these medications characteristics that extend beyond an ordinary medication, i.e., affording control over daily stress, bringing tranquility, and even prolonging life. Most of the patients denied or minimized side effects and expressed resistance to taper or discontinuation, ranging from subtle reluctance to outright refusal and fear of being left suffering without these medications.

CONCLUSIONS: The reluctance of older chronic benzodiazepine users to taper or discontinue use highlights the importance of prevention and early intervention strategies to avoid the development of chronic use. Suggestions for curbing chronic use are presented.

KEY WORDS: geriatrics; qualitative research; benzodiazepines; primary care.

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INTRODUCTION

It has been well established that sleep disturbance, cognitive difficulty, impairment in activities of daily living, motor vehicle crashes, and problems with gait are potential negative side effects of benzodiazepines on older adults.^{1–5} Drug-disease

interaction and chronicity of use are two other common problems associated with benzodiazepine use in this population.⁶

As Oude Voshaar et al.⁷ point out, there is limited evidence suggesting the long-term efficacy in two specific diagnostic groups: panic disorder and social phobia, and the prevalence of these specific disorders among those who are long-term users is relatively low. Indeed, many community-residing older long-term benzodiazepine users do not have any mental health problem.⁸

Recommendations defining appropriate benzodiazepine use have been promulgated within the specialty medical literature, with explicit cautions against prolonged use by older adults. By the American Psychiatric Association standards, use is justified if it is intermittent, brief, and for purposes of symptom relief.⁹ Others, including a National Institute of Health Consensus Conference, have cautioned against prescription in treating primary insomnia.^{10, 11}

However, benzodiazepine use in community-residing and institutionalized older adults remains high. Prevalence in community-dwelling geriatric populations range from 9.5 to 20%.¹² In a study of older adults from 4 U.S. communities, 1 in 10 reported taking a benzodiazepine, most frequently an anxiolytic.¹³

It is important to understand factors contributing to long-term benzodiazepine use in this population, a pattern that persists despite availability of safer alternatives for the complaints for which these medications are typically prescribed. Identifying these factors could assist in the development of strategies to reduce chronic use in older adults. Several randomized controlled trials have found that cognitive-behavioral therapy (CBT) can facilitate benzodiazepine taper and discontinuation. However, there are limitations to the generalizability of these trials, including restrictive entry criteria, usually focusing on a specific anxiety disorder or insomnia with current mood disorders as exclusion criteria.^{14–17} In addition, there is low accrual in these trials, with sometimes hundreds of potential participants contacted to yield a small sample, both eligible and accepting of the intervention. Substantial attrition further reduces final samples, limiting the scope, and perhaps, biasing the results. Thus, understanding patient perspectives, more in depth, may help identify and provide a foundation for the development of interventions with greater reach, sustainability, and effectiveness in primary care.

This study was part of a larger investigation examining both physician and older adult patient perspectives on long-term benzodiazepine use and discontinuation. A report on the physician perspective is available elsewhere,¹⁸ while this paper focuses on the older patients' perspective.

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METHOD

Participants

Inclusion criteria included: (1) over the age of 60, (2) currently taking an anxiolytic benzodiazepine on a regular basis for a minimum of a 3-month period, and (3) a score greater than 16 on the *Short Blessed Test*,¹⁹ a screen for cognitive functioning. Interviews were conducted by trained research assistants using an open-ended semi-structured guide in audiotaped telephone contacts.

Thirty-three primary care physicians from the Philadelphia, Pennsylvania area, who were interviewed separately regarding their benzodiazepine prescription practices,¹⁸ provided a total of 223 patient referrals for potential inclusion in this study. Of these, we were able to contact 163 patients; with 67 refusing to participate and 46 not qualifying for study inclusion either because they never started taking the benzodiazepine, had stopped using it prior to the study, or did not use it regularly. There was a modest but statistically significant age difference, with the refusers slightly older ($X=73$; $SD=5.41$) than participants ($X=71$, $SD=5.78$); however, there were no gender differences between groups. A total of 50 patients met eligibility criteria, signed informed consent, and were interviewed.

Qualitative Measure

The interview guide (Appendix) was based upon review of the literature^{20, 21} and pilot interviews. The interview inquired about: the rationale and circumstances for initial and current use of benzodiazepine; patient’s perceptions of family members and physicians’ perspectives on their current use; knowledge of potential side effects; experience of skipped doses; psychological and physical reliance on benzodiazepines; thoughts on taper-discontinuation; and interest in finding alternative strategies for which benzodiazepines were prescribed.

This study utilized thematic content analysis, a qualitative analytical technique in which themes are identified inductively.^{22, 23} Inductive analysis involves the independent close and repeated reading of transcripts and generation of preliminary themes through open coding. To assist in organizing the themes and identifying their connections, the software package QSR NVivo 7 was used. As a group, investigators met to abstract and condense themes, identify common themes, and reconcile conflicting observations. The creation of summary statements for each theme was developed through consensus. Numerous procedures were used to ensure internal validity of this qualitative investigation including semi-standardization of the patient interview, audiotaping and professional transcription, standardized data coding, and an iterative approach to thematic extraction.

RESULTS

Participant Characteristics

The age of participants ranged from 61 to 95 years ($X=71.13$, $SD=7.73$). Women comprised the majority of the sample (85%), with two ethnic groups represented, 81% Caucasians and 19% African-Americans. Although most of the participants were married (44%), the number of widowed respondents was also high (31%). The remainder was either divorced/separated

(12%), or had never been married (4%). Seventy-five percent of the participants were retired, but some still worked part-time (14%). Most (40%) reported that their yearly income did not exceed \$20,000; 24% reported yearly income between \$20,001 and \$50,001, 14% reported earning over \$50,000 a year, and the rest did not report on their income.

Specific benzodiazepine usage, frequency, and reasons given for use were assessed via self-report and are indicated in Table 1. The majority took benzodiazepines at least once daily, while 19% reported taking them occasionally (“as needed”). Only 14% had been taking the benzodiazepine for less than a year, and 8% had passed a 20-year mark. Anxiety was the primary reason given for initial benzodiazepine prescription (44%), followed by sleep disturbances (38%). Bereavement was also a frequent reason for an initial prescription, i.e., 12% of participants reported that they began taking benzodiazepines after the death of a significant other, mostly a spouse. Depres-

Table 1. Benzodiazepines: Type, Frequency and Reasons for Use

Variables	Number of participants	Percentage (%)
Benzodiazepines		
Ativan (Lorazepam)	18	36.0
Klonopin (Clonazepam)	6	12.0
Serax (Oxazepam)	1	2.0
Valium (Diazepam)	5	10.0
Xanax (Alprazolam)	15	30.0
Valium and Xanax	2	4.0
Valium and Ativan	1	2.0
Valium and Klonopin	1	2.0
Respondent uncertain	1	2.0
Milligrams expressed in diazepam equivalents		
1.25 mg	2	4.0
2.50 mg	9	18.0
5.00 mg	22	44.0
10.00 mg	2	4.0
15.00 mg	1	2.0
Respondent uncertain	14	28.0
Frequency of use		
Less than one daily	9	18.0
One daily	14	28.0
Up to two daily	10	20.0
Three to five daily	13	26.0
Respondent uncertain	4	8.0
Duration of use		
Less than or equal to 1 year	4	8.0
Between 1 and 5 years	9	18.0
Between 5 and 10 years	13	26.0
Between 10 and 20 years	9	18.0
More than 20 years	5	8.0
“Years”/(exact duration unknown)	5	10.0
Respondent uncertain	6	12.0
Primary reason for prescription		
Anxiety (panic attacks, nerves)	24	48.0
Sleep problems	18	36.0
Bereavement	6	12.0
Depression	1	2.0
Pain	1	2.0
Psychiatric diagnoses		
None	27	54.0
Depressive disorders, current	6	12.0
Anxiety disorders, current	3	6.0
Depressive and anxiety disorders, current	8	16.0
Other	2	4.0
Unknown	4	8.0

Table 2. Categories Underlying Chronic Benzodiazepine Use and Discontinuation in Elderly

Purpose and Importance of Benzodiazepine
Means to cope with stress and anxiety; aid in falling/staying asleep
Lifeline or life-transforming properties
Lack of awareness, underestimation or disregard of side effects
Attitudes Towards Taper/Discontinuation
Negativity towards or resistance to taper/discontinuation
Rejection of psychological interventions
Power and influence in physician-patient relationship

sion was mentioned as a primary reason only by 4%, and the remaining prescriptions (2%) were to alleviate physical pain.

Thematic Content

Consensus was found for three predominant themes that were distinctive, but interconnected (Table 2).

1. Purpose and importance of benzodiazepines

The interview data indicate that many older long-term users have become psychologically dependent on benzodiazepines in a variety of ways to the point where these medications had come to play an important and integral part in their lives, which would be otherwise difficult (“That pill is very important to me.”). Interestingly, although most patients were clear about the purpose and importance of benzodiazepines in their lives, the majority appeared to have difficulty recalling the milligram dosage they were taking. Most said they took the benzodiazepine as prescribed (e.g., “what you’re supposed to do”).

Three recurring subthemes supporting the purpose and importance of benzodiazepines in the lives of older chronic users were identified:

a. Means to cope with stress/anxiety and aid in sleep

Almost half of the patients explained that they used the benzodiazepine as a strategy for coping with stress ranging from minor annoyances (e.g., misplacing their handicapped sticker) to major adversities (e.g., caregiving for ill spouse).

Sometimes my life gets so up in the air that I say to my children, right now I wish I had a wafer-sized Valium.

Some explained that they needed to take benzodiazepines for long-standing anxiety, which they attributed to their temperament.

It just seems like my mind won’t take too much.

I am an anxious person by nature.

b. Lifeline or life-transforming properties

Patients described benzodiazepines as having the ability to make them feel more like themselves (i.e., like they “should be”). They explained that benzodiazepines had an important function in their lives, ranging from

soothing properties providing peace and emotional control to miraculously extending life.

I think if it wasn’t for the chemicals I wouldn’t be chugging along.

I don’t mentally think I would have survived without it and that’s the truth.

It makes me feel like I wanna go on living.

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.

c. Lack of awareness, underestimation, or disregard for side effects

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. In addition, most patients reported that their doctors rarely informed them of potential negative side effects. Patients appeared to find tacit approval of the safety of benzodiazepines in the fact that they even received the prescription from their physician and said things like:

He [the physician] wouldn’t have given it to me if he thought it was gonna hurt me.

Patients further minimized the potential negative effects by minimizing the pill size, dosage, potency, and therefore, adverse impact.

It’s just a small, little, tiny white pill.

It’s the lowest dose that they make.

Most patients stated that they did not experience any negative side effects. Several said that they could not identify the source of side effects, if they observed any, because they were taking so many other medications. A few others acknowledged that they had noticeable side effects, which they attributed to the benzodiazepine, particularly some reduction in mental acuity.

My head always feels foggy.

Another patient noticed being “slower mentally.”

However, they reported that they felt “it was worthwhile” to avoid struggling with their mental health symptoms. Some participants also experienced sleepiness, but for most, this was a welcome side effect of, if not the primary reason for, their benzodiazepine use.

Most patients explained that their physicians inquired about their general functioning and health but did not specifically ask about the benzodiazepine after the initial prescription. Patients provided the explanation that there

were too many other competing demands to address the benzodiazepine:

I always have like some other issue other than, you know, that one pill.

No patient stated that there were difficulties in obtaining refills/renewals.

2. Attitudes towards taper/discontinuation

Patients had a range of complex responses regarding missed doses, consideration of taper/discontinuation, and alternative treatments to the benzodiazepine, particularly psychological interventions. Two recurring subthemes regarding their attitudes towards taper/discontinuation emerged:

a. Negativity or resistance to taper/discontinuation

Most patients explained that they rarely unintentionally skipped a dose because of real or imagined negative consequences such as:

If I don't take it sometimes it would really interfere. I mean who wants to be upset and, you know, not enjoy life?

Oh, I think I would jump out of my skin.

I'd probably be screamin' all the time.

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 because of questionable effectiveness of alternatives, advanced age, and unneeded suffering:

If it works I'm not touching it.

I don't think there would be anything better.

I'm not gonna experiment with myself, not at this age.

It's all probably psychological, but, you know, you have to go through too many things and I'm too old to do that.

I see no reason why I should put myself through hell. If it makes me feel better I'm gonna do it. I see no reason to suffer and struggle. We don't have that long to live and we might as well enjoy ourselves while we're here.

What started as a subtle reluctance to relinquish the benzodiazepine at times progressed to an outright refusal and even expression of fear of having the

benzodiazepine taken away. For example, nine participants became upset when the interviewer asked about their willingness to try other alternatives, at times even getting defensive and thinking that the study investigators were trying to get them to commit to a change.

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.

Don't you dare take that stuff away from me.

Some patients discussed physicians' past efforts to assist in taper or discontinuation of benzodiazepines. The main theme was their having refused outright, or tried and failed because of real or imagined unpleasant discontinuation reactions:

On numerous occasions I've tried to go off it. And the reaction is I can't sleep and I'm totally wired. I'm up all night.

I think I will shriek out if anybody took it away because I know that Dr. ___ wanted to put me on something else. Well, I thought I was gonna space out. Oh, man, I was sittin' here shakin'.

However, a majority of the patients discussed the continuation of the benzodiazepine in terms of psychological rather than physical dependence. This mechanism appeared to have little to do with the effects of the benzodiazepine on the body, but with feelings that life would not be bearable without the benzodiazepine:

One time I did run out of it... and I think it was mostly mental, not having it is what kept me awake more than not having it.

When I know that I don't have any in my little pillbox to take, then I kind of panic.

I feel safe having it in the house.

b. Rejection of psychological interventions

Only a handful of participants expressed even a superficial acceptance of psychological interventions to decrease use of benzodiazepines, and it was clear that this did not translate into uptake. Many either expressed that they did not know what an alternative to the medication would be or that they would be too afraid to try something different. A few mentioned that one way to taper or discontinue would be to use the "power of God." A few of the patients actually explained that they felt they needed a more frequent dosage of the benzodiazepine or even "stronger" medication.

I pretty much know that I'm dependent on these four pills a day but I don't wanna get dependent on something else. I've been on these for so many years and nothing has ever happened so I don't wanna.

For many of the patients, there was an explicit rejection of psychological intervention either to treat their underlying distress or to assist in taper/discontinuation.

I don't think counseling's gonna help me at this stage of my life.

I just don't want to. I'm not one of those people who can sit around and talk about my problems with strangers.

3. Power and influence in physician–patient relationship

Many of the older adults indicated a very strong alliance with their physicians.

I pretty much put myself in their hands. If I have a problem I go talk to them. And they tell me what to do.

I have complete faith in Dr. _____. I mean we go back a lot of years. Whatever he says, goes.

DISCUSSION

Long-term benzodiazepine use in older adults is a multifaceted public health problem. For prevention and intervention efforts to be successful, patient perspectives need to be taken into account. This study provided an exploration of several facets of the issue and the complex relationships between benzodiazepine–patient and patient–physician.

The qualitative analysis of older patients' knowledge, attitudes, feelings, and behaviors towards anxiolytic benzodiazepines revealed that although a majority of them denied physical addiction, they demonstrated a significant psychological dependence as evidenced by their underestimation or denial of potential side effects and robust resistance towards taper/discontinuation. Most patients demonstrated a strong psychological dependence on the benzodiazepine, minimizing their own coping efficacy and relinquishing the control of their functioning to the medicine, their physician, and at times, God. They expressed the belief that there was nothing other than the benzodiazepine that would help them as much or that they had tried something else and found it to be much less effective. Many described multiple physical, intrapersonal, or interpersonal stress problems, but explained they did not feel they needed psychotherapy or counseling. Only a handful of patients reported cautions from physicians about potential negative side effects, which they seemed to disregard or take less seriously. The potential

dependency is complicated by the ease of getting refills, i.e., most just called in for more prescriptions.

Our findings are consistent with those of Linden, Bar, and Geiselman.²⁴ Two-thirds of their 122 primary care patients receiving long-term benzodiazepines rejected the idea of taking a “drug-holiday” of at least 3 weeks in duration. Those individuals were less educated and were using a higher percentage of long-acting benzodiazepines than patients who accepted their proposal. In addition, those individuals were also viewed by their primary care physicians as more complaining, harder to satisfy, and less cooperative.

Patients' perception of the attitude of physicians towards continuous benzodiazepine use is an important factor affecting taper/discontinuation (e.g., prescription patterns, ease of access). In many ways, the qualitative patient data corresponds to the qualitative physician data.¹⁸ Both physicians and their older patients denied the presence of physical addiction, tended to downplay adverse side effects, highlighted patient suffering, and additional, more important, competing health care demands.

Moreover, similar to patients, physicians placed emphasis on the perceived effectiveness of the benzodiazepines over any other alternatives, which resulted in a rather pessimistic expectation of patients' failure to disengage from them.¹⁸ The majority of patients and physicians believed that attempting withdrawal would be time-consuming and likely futile. This might be the outcome of a variety of individual and organizational factors: the anticipated resistance from patients (possibly resulting from physicians' prior experiences with patients' intense psychological dependence), misguided empathy, and larger organizational constraints such as awareness of the patients' limited access to mental health services, lack of training in or referral sources to psychological treatments for anxiety, stress, and insomnia, and lack of time in clinical encounter for dealing with all of these issues. In summary, these factors together create a complex situation where both patients and their physicians play important roles in long-term benzodiazepine use/prescription.

We uncovered some discrepancy between patients' and physicians' attitudes towards benzodiazepine use.¹⁸ The disconnect was between some patients' reports of willingness to consider taper-discontinuation and the physicians' anticipated resistance from their patients. Some patients explained their acceptance of the prescription as deference to their physicians whom they trusted as an authority who knew their health needs better than they knew themselves. Yet, physicians explained that they had few choices in prescribing benzodiazepines to patients who felt that they needed such medication. Therefore, physicians were likely to underestimate their own influence over patients' decisions to accept and continue benzodiazepine use.

Our findings that the majority of patients reported they trusted their doctors implicitly is similar to study findings by Barter and Cormack,²⁵ who found that none of their older chronic hypnotic benzodiazepine users reported having clear knowledge of what their doctors thought of this use. Coupled with our own data, this suggests that the physicians' authority may not be utilized to its full potential in the prevention of chronic benzodiazepine use that some users might be willing or able to taper or discontinue use, and that patients need information and advice on how to do so.

For the majority of patients, family members seem to be less relevant in decision-making related to initial or sustained benzodiazepine use. According to patients, most family members do not know about their benzodiazepine use or knew but either did not have an opinion or supported their use. One half-joking female said that when she is feeling agitated, her daughter tells her to go take her “nice pill.”

As a qualitative investigation, the goal here was an in-depth characterization of the patients sampled, and thus, there is less basis for broad statistical generalization.²³ However, several limitations of this research warrant mention. Those who refused to participate were slightly older than those who participated, potentially indicating that these results are less generalizable to older adults who are more physically or functionally compromised. Although there were no differences in qualitative themes based on whether the participant was receiving a benzodiazepine for anxiety or for sleep, these groups did differ on gender and employment. Most men reported taking the benzodiazepine for sleep problems, and the majority of women reported taking it for anxiety reasons. As the attribution for why participants were taking the medicine was based on self-report, it is possible and perhaps likely that “sleep problems” were a more socially acceptable response for men. Most of those who were employed reported that they took the benzodiazepine for sleep problems, and those taking it for anxiety were more likely not to work. Additional limitations include that information on benzodiazepine usage was assessed via patient self-report, and there were few participants who were male or African-American. Certainly, more objective measures of benzodiazepine usage, such as pharmacy refill data, and additional representation of males and those of various ethnicities would strengthen the findings.

Summary and Future Directions

The long-term use of benzodiazepines in older adults poses a significant challenge to the U.S. health care system.²⁶ Findings from this study highlight the scope of the problem, including both physician and patient barriers to implementing interventions for reduction or discontinuation. It may help to identify the appropriate focus for intervention including the possibility that early intervention and prevention of chronic use may be more feasible than widespread efforts to reduce existing chronic use. The medical and mental health fields should not minimize the difficulties influencing physicians to change their practices even when underscored by recommendations.^{27–29} It is likely that the usual difficulties will be intensified by their anticipation of patient resistance and backlash. The ultimate goal is to find acceptable, effective interventions in which we can recruit and sustain patients from primary care, even if we may not be able to rely on physicians to deliver the intervention. However, results of this investigation demonstrate the task is formidable, and more clinical epidemiological or health services research may be needed before we design, implement, and evaluate interventions.

Our study of physicians found that the majority of them do not view continuous use of benzodiazepines in the older adults to be a public health problem.¹⁸ Many older chronic benzodiazepine users are psychologically dependent and unwilling to taper/discontinue. Thus, the field is faced with a dilemma. Should interventions to reduce use not be attempted in the face of

many competing demands on the physicians' time and the real and imagined reluctance of patients? One important line of investigation could be identifying “approachable” benzodiazepine users by determining the factors that predict willingness to consider taper/discontinuation, and, ultimately, factors predicting which patients will be successful in this endeavor. If such a predictive formula was found, physicians might use it to more efficiently and successfully approach benzodiazepine taper/discontinuation in older individuals.

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Conflict of Interest: None disclosed.

Details of Ethical Approval: This study had Institutional Review Board (IRB) approval from the University of Pennsylvania.

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APPENDIX

Semi-Structured Qualitative Patient Interview Guide

I want to thank you for agreeing to answer some questions for our project. We are very interested in knowing your ideas and opinions on medications. Of course, there are no right or wrong answers.

Can you please tell me the names of the medications you are taking?

Here is a medicine (the benzodiazepine) that you are taking...
What is it for?

What does it do for you?

How does it affect you?

How do you feel about taking it?

How do you feel if you don't take it?

Are there any problems that can be caused by this medication?

Do you remember when your doctor first prescribed it for you?

Can you tell me about that?

Important to do all probes: How did it come up? Who initiated conversation? What was discussed (i.e., purpose of medicine, side effects, how much and how long to take)?

Why do you think your doctor first suggested this medication to you?

If you think back to when you first started taking it, do you have a sense for how long you thought you'd be taking it?

What does your current doctor (if different than one who started them) think about you taking the medicine now?

What does your family think about you taking it?

Does taking/not taking this medication interfere with your day? With your night?

Does taking/not taking this medication affect your relationships with your family? How so?

How do you get more of this medication?

Have you ever by mistake or on purpose not taken the medicine? If so, what happened?

Have you ever changed the dose of the medicine?

If yes: How and why did that happen? Did you notice any difference?

What do you think would happen if you stopped taking the medicine completely?

Have you ever thought of other ways to deal with this issue?

If so, what? What happened if you tried?

Have you ever talked to anyone about this issue? (i.e. Spouse? Friend? Family member? Priest/minister? Counselor?)

These medicines have sometimes been used for sleep problems, anxiety, stress, and depression. Are any of these problems for you?

How does the medication affect these problems? (e.g., cure, symptom relief, no impact)

What if your physician mentioned other ways to deal with this issue?

Probe: Such as some kind of counseling? How would you feel about that? Would you be willing to try that?

If there were ways of reducing your use of the medication, would you be interested in hearing about them?

How much time and effort would you put into reducing your use of this medication if the chance were offered to you?

Are there things about your medication that you would like to tell me about that we haven't talked about? If yes, what are some examples?

Thank you so much for talking with me today.

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