The experiences and perspectives of patients who use or have used antidepressants regarding the antidepressant discontinuation process: a qualitative study

Research Project FA-MA203 | Amsterdam UMC | University of Utrecht | Frederique Claessens [6128327] | February 2023

ABSTRACT

Background: Discontinuation of antidepressants possibly involves risks for patients such as experiencing withdrawal symptoms. Therefore patients should be properly guided and educated by health care providers (HCPs) in this process. The aim was to assess patients' perspectives and needs who use or have used antidepressants regarding the antidepressant discontinuing process.

Methods: Six semi-structured, in-depth interviews were conducted with patients who use or have used antidepressants for at least six months. These interviews were audiotaped, transcribed verbatim, coded openly with MAXQDA and thematically analyzed.

Results: Themes that emerged from the interviews, were in relation to perceptions and relations, expectations, reasons, initiative for discontinuation, education and guidance. It appeared that these factors influenced the decision-making in patients and therefore influenced the course of their discontinuation process. They made suggestions for improvement in these areas.

Conclusion: The needs of patients for guidance during the process of discontinuation of antidepressants are not fully met yet. There is a lack of initiative, knowledge and time of HCP's. Education and guidance should involve perceptions, expectations and good relationships. Future research should prospectively examine whether adapting patients' wishes affects being able to discontinue successfully.

INTRODUCTION

The number of people who are using antidepressants over an extended period of time has increased in the past few years. In 2021 in the Netherlands, 1.1 million people were using antidepressants of whom 43,7% use antidepressants for longer than 15 months. The use of these medications is often prolonged compared to recommendations in treatment guidelines after sustained remission (1). According to the Dutch Multidisciplinary guideline for depression (2013), a period of 6-12 months of treatment after remission of initial depression is recommended and at least 1-2 years after relapse episodes. After this, the advice is to discontinue the antidepressant (2, 3). Continued use of antidepressants is advised only in patients who have a high expected risk of relapse (4). Long-term use of antidepressants has several disadvantages. Side effects such as weight gain, sexual dysfunction, emotional flattening and an increased risk of metabolic syndrome are common side effects and can lead to medicalization and prescription cascades (5-7). In addition, several antidepressants have interactions with other drugs and this is, especially in the cases of polypharmacy, unfavorable (2). Finally, long-term use causes unnecessary healthcare costs (4).

Yet people often take antidepressants for long periods of time because of several barriers to discontinue, such as fear of relapsing into depression or experiencing withdrawal symptoms when discontinuing (3, 7-10). Discontinuing antidepressants abruptly can cause a neuropsychiatric syndrome including withdrawal symptoms. This is called

antidepressant discontinuation syndrome (ADS). The withdrawal symptoms that may occur are; flu-like symptoms, sleep disturbances, gastrointestinal symptoms, balance problems, sensory disturbances, psychological complaints, and extrapyramidal symptoms. Some of these symptoms are similar to those associated with depression (11, 12). Therefore, it is important to distinguish ADS and relapse of depression properly to prevent not-indicated continuation of antidepressants (3).

Knowledge of the occurrence of ADS lacks and more research is needed on this issue, but tapering versus abruptly stopping antidepressants provides a lower risk of developing ADS (3, 12). Other factors contributing to the risk of developing ADS on discontinuation include: a short half-life of the antidepressant, previously failed discontinuation attempts, having previously experienced withdrawal symptoms on a missed dose, and having used higher doses than were needed for therapeutic effect (3, 11, 13, 14). These risk factors for ADS are consistently reported in the literature, but these are mainly based on expert opinion with limited scientific support (12).

So despite there being risks with long-term use of antidepressants, there are also risks with discontinuing antidepressants. Because of these potentially present risks, it is important that patients are properly guided in and informed about the process of discontinuation. This should be patient-centered and with shared decision-making (15). This guiding and informing process is the task of the involved HCP such as the general practitioner (GP), the pharmacist and the psychiatrists. GPs or psychiatrists prescribe the antidepressant and have a treatment relationship with the patient (12). Pharmacists dispense the medication, educate patients on the use, and have knowledge of side effects, tapering schedules, and consulting (3).

A 2022 study by Sorensen et al. demonstrated that current clinical guidelines provide little support for HCPs to guide patients with discontinuing antidepressants (9). Bosman et al, and Nederlof et al. showed that patients expected the initiative to stop being taken by GPs (1, 16). In contrast, GPs assumed that patients would come up with this initiative themselves (4). It also revealed that some patients felt that GPs sometimes lacked knowledge and time to provide supportive guidance during discontinuation. This sometimes leads to patients being left to fend for themselves. Additionally, there currently is a lot of work pressure on GPs due to staff shortages (17). Another study showed that patients sometimes did not know which HCP was responsible for the patient care; the GP, the psychiatrist, or the pharmacist (16).

A multidisciplinary group of HCPs drafted a document in 2018 with recommendations guiding patients with tapering off antidepressants. They did this based on expert opinion, experience, and the available literature, among other things (3). However, due to the lack of agreements in primary care and cooperation between primary and secondary care, the document is still not applied on a sufficient scale in practice

A study from 2019 by Eveleigh et al showed facilitators and barriers of patients to discontinue antidepressants (18). Another study from 2021 by Wentink et al. explored what topics patients considered important in a consultation about whether or not to discontinue antidepressants (8). A 2017 study by Nederlof et al, researched patients' needs and suggestions for improvement of guidance by physicians and pharmacists for antidepressant use (16). All these studies stated some important perspectives of HCPs and patients on long-term antidepressant use and guidance with use in general. However, it lacked information about the specific component of discontinuation antidepressants.

Therefore, the aim of this study was to assess patients' perspectives and needs who use or have used antidepressants regarding the antidepressant discontinuing process.

METHODS

Design and Setting

A qualitative exploratory research was performed. Six patients were interviewed who were recruited from pharmacies in Amstelveen and Nijmegen in the Netherlands. These

particular pharmacies were chosen because of the multidisciplinary connections the researchers have in these areas. Data was collected by conducting in-depth, semi-structured interviews with patients who use or have used antidepressants. These interviews were designed to explore participants' experiences, perspectives, wishes, needs (19). In this study, saturation was not achieved after six interviews because new codes emerged during the coding of the last interview (19-21). Saturation is often observed in approximately 15 interviews so for the further course of this research, at least 9 more participants will be interviewed in order to reach saturation.

All procedures performed in this study involving human participants were in accordance with the ethical standards of the Medical Ethic Commission of VU Medical Center.

All interviews were audiotaped with a voice recorder and were stored in the secured VUmc environment. The interviews were transcribed verbatim. Patient characteristics were asked during the interviews.

Participants and recruitment

For recruiting participants in this study, purposive sampling was used, for maximum variation (22). Patients who have already discontinued as well as those who have not discontinued their antidepressants were selected. Both groups were interviewed to get as broad a picture of the perspectives and needs as possible.

The following **inclusion criteria** applied:

- Age over 18 years
- On the antidepressant for at least 6 months or used for at least 6 months in the past
- Willing to give informed consent and follow procedures to participate

The following **exclusion criteria** applied:

- The use of antipsychotics
- The use of lithium
- Insufficient command of the Dutch language

The participants were identified using a search extraction in the PIS. Not all criteria could be incorporated into the search strategy so the list of patients was manually juxtaposed with the criteria afterwards by the pharmacist (JH, WG), creating a new list of patients. Based on this, a new list of patients to be approached was created. Then the pharmacist approached the patients by telephone, explained briefly about the study, and asked if they were interested in being contacted about it. If interested, they were approached by the researcher by telephone to participate in an interview. Then the Subject Information Form (PIF) was sent by e-mail. At least 1 week after this call, the patients were interviewed. The PIF was signed by the patient and the researcher prior to the interview. Participants were informed that participation was voluntary and that withdrawal was possible at any given time. Names and other identifiers were changed to protect the participant's privacy.

Interviews

The interviews took place at community pharmacies in Nijmegen and Amstelveen and had an average length of 45 minutes. Prior to the interview, participants were briefed on the topics and practicalities of the interview and there was time for questions from the participants. The interviews were conducted by the researchers FC (5) and SB (1).

The semi-structured questionnaire that was conducted during the interviews is attached in appendix 1. The interview consisted of three main topics; Pharmaceutical history of the SSRI and the treatment (I), previous processes of discontinuation (II), and lastly, guidance and support during phasing out (III). These topics were discussed in detail through various sub-questions. At the end of each topic, the participant was allowed to discuss issues that he or she still found noteworthy. This topic-list was pilot tested with someone connected to the researchers with experience on discontinuation of antidepressants.

The questions were initially developed based on existing interviews or questionnaires conducted in other studies that also investigated deprescribing and patients' or HCPs' views on it (4, 8, 23-26). The researchers in this study discussed the formulated questions in detail and modified them based on their opinions and experiences.

One patient was emotional during the interview. The day after the interview, the researcher called the patient for a welfare check

Data analysis

These interviews were audio recorded and afterwards, the recordings were listened back, transcribed verbatim, and coded with MAXQDA. For the analysis of the interviews, thematic analysis and open coding was chosen. This qualitative analysis method was well suited because it allows exploring the experiences, perspectives, needs, and ideas of the patients (27, 28). In addition, many studies that also investigated patients' or HCPs' perspectives on deprescribing opted for thematic analysis (15, 23, 24, 29, 30).

Two interviews were coded independently by two of the researchers (SB, FC) and the remaining four interviews were coded by only one researcher (FC). Codes were generated based on aspects that; were mentioned by the interviewee; were surprising; were recognized from literature; or were reminding of particular theories or concepts. Afterwards, these codes were discussed by the researchers (SB (pharmacist, JH pharmacist and PhD, WG pharmacist, FC, master student) and were arranged into meaningful themes. Exemplary quotations were selected and translated from Dutch to English in order to demonstrate the findings. This was followed by a short description of the cited participant. These are also listed in appendix 3.

Furthermore, the consolidated criteria for reporting qualitative research checklist (COREQ-32) was used to report information on the research team, study methods, results, analysis and interpretations of the study and is attached in appendix 2 (31).

RESULTS

Of the six interviewed participants, five were female (83%) and the mean age was 58 years with a range of 24-74 years. Four participants had already discontinued their antidepressants and two still used them and had no intentions to discontinue. The participants used a variety of different antidepressants and the majority used the antidepressant for longer than 10 years.

Characteristics	*N*	*%*
Gender		
Male	1	17
Female	5	83
Age		
Used antidepressant		
Paroxetine	1	17
Sertraline	1	17
Trazodone	1	17
Citalopram	1	17
Clomipramine	1	17
?		
Therapy status		
Current user	2	33
Past user	4	67
Duration of AD usage		
0 – 6 months	1	17
6 months – 1 year		0
1 – 5 years	1	17
5 – 10 years		0
> 10 years	4	67
Time since discontinuation		
0 – 6 months	2	50
6 months – 1 year	1	25
1 – 5 years		
5 – 10 years	1	25
Amount of discontinuation attempts		
1 time	3	50
2 times	1	17
3 times	1	17
4 times	1	17
Co-medication use		
Yes	5	83
No	1	17

Table 1: Characteristics participants

Three main themes emerged from the interviews and these were subsequently divided into subthemes, which are discussed in the following paragraphs.

Perceptions & relations

Experiences with use of antidepressants

Aspects such as perceptions about antidepressants, the reason for prescribing and the impact of the condition were discussed extensively between the participants and researchers. These aspects varied among the participants. However, part of the participants felt that GPs prescribed antidepressants too easily, and stated that it should be considered carefully before starting.

''I actually think it's too easily prescribed''- man, 73 years

This view originated, among other things, by the idea that antidepressants more severe types of medication than other types, because it affects the brain. This opinion was shared by a majority of the participants. Three participants indicated that they were not in favor of medication use in general. It was several times even referred to as junk or garbage.

''Well I personally think no medication is better. They say if the doctor says so, it's no big deal. It doesn't hurt you, it helps you. But if you can avoid it, then I would do it.'' – woman, 63 years

The effect of the antidepressants also varied a lot between participants. Some experienced a benefit from the use of these medications, it gave them a feeling of calmness and stability, while some did not experiences benefits or not enough, to them. Patients' experiences with the use of medication strongly influenced their decisions about continuing or discontinuing. One prominent opinion about the effect of antidepressants was that they caused the participants to feel emotionally flattened. A few also indicated that after stopping antidepressants, they felt more emotions.

''When I look back, I had a blunted, dulled feeling. My mind was kind of shut off from a lot of things. It did not reach me as much anymore''- man, 73 years

''I noticed that when I discontinued the antidepressant, I started to feel like myself again and my feelings and interests came back.'' - woman, 24 years

Emotions

When making decisions about antidepressant use such as starting, continuing, or discontinuing, emotions played an important role. Participants mentioned that emotions such as fear, panic, shame, and stress influenced their behavior and decision-making.

''For example, when we wanted to go camping with the grandchildren, I would panic beforehand.'' – woman, 64 years

A big barrier to discontinuing antidepressants seemed to be fear of relapse. They feared experiencing the negative feelings and symptoms they had in the past.

''I'm not so open to that. Of course, I want to get rid of this medication, but I have my experiences and it was not fun. It's hard to describe how you feel then, but I collapsed.'' – woman 63 years

This fear of discontinuing also seemed to be present in the period of starting antidepressants. Participants were anxious before starting or discontinuing because they heard or read negative stories about this. They did not know what to expect and what they could potentially feel during the treatment or process of discontinuation, and this would cause fear within the participants. However, some realized that this could turn out differently for them.

''Of course I read some reviews about the medication, there are often only negative things in there, and once in a while someone writes something positive.'' – woman, 64 years

Two participants reported that while using, they felt dependent on the antidepressants. The idea of not being dependent on this medication after discontinuing gave them a nice feeling.

''It was also a kind of a relief for me, see, I'm not dependent on pills''- woman, 64 years

Beliefs

Participants' beliefs about their antidepressant use also influenced their behavior and decision-making during the treatment. Two participants stated that the antidepressants would supply a substance that was deficient in their brains. This belief about a deficiency made them feel dependent on the drug. It was striking that these beliefs were especially present among participants who had been educated about the antidepressant longer than 10 years ago.

''He told me, that because of what I experienced in my childhood, certain substances were not being produced enough and that this drug would act on it.''- woman, 56 years

''I believe, also because my doctor said so, that maybe I just need this substance''- woman 63 years

Beliefs and perceptions about one's capacities also influenced the decision-making process among participants. These perceptions sometimes lived up to their expectations but sometimes it did not. Some participants felt that they were capable of tapering their

antidepressants by themselves and carried this out. One participant tried to discontinue but failed and experienced discomforting symptoms. Two participants managed to discontinue successfully on their own. Yet the majority of participants believed that they are unable to discontinue antidepressants on their own and need professional guidance during this process.

''Then I discontinued the antidepressant under the guidance of the GP. At first I thought I could do this by myself, but I can't.''- man, 73 years

Stigma & taboo

Participants also mentioned some social implications of using antidepressants. The majority of the participants stated that they could discuss their antidepressant use with their partner or close social surroundings, but not with acquaintances who they are less close with. According to the participants, people would not understand this and often gave them reactions which they considered useless. One participant explained that people around her thought it was whining and felt she could not talk about it.

''Yes, I haven't talked to many people about it because you hear things like, you don't need it at all, and you're so good. Then you get all that kind of whining.''- woman, 56 years

However, one participant indicated that the stigma of antidepressant use became less present compared to the past and that people are talking about it more openly.

Relationship with HCP

The relationship with the HCPs seemed to be very important for the course of the antidepressant use and the decisions that were made during the discontinuation process. In general, participants trusted their HCPs and valued their judgments and recommendations. Even when they had some doubts beforehand, they decided to give it a chance because of the trust they in had them.

''That's why I was like, is it smart to start this? But I thought the doctor will know, so I thought I'll follow her advice and we'll see how it goes''- woman, 24 years

On the other hand, a few participants expressed some doubts about their GP's knowledge. They felt that they lacked specific knowledge about the medication or psychological symptoms. Some mentioned that a pharmacist had more specific knowledge about medications, but they also had doubts about whether every pharmacist is suited to guide patients during discontinuation of antidepressants, because they felt that GPs know them better.

''I think it would be very helpful if I know right away, how the medication works, and the pharmacist knows that, I think.''- woman, 64 years

''My GP knew how I was. And that's nice too, that you can do that with someone so familiar, you know. Otherwise, I wouldn't have dared.'' woman, 63 years

A striking barrier mentioned by one participant when having a relationship with a HCPs was the constant changing of HCPs in the practice. According to this participant, this caused a feeling to her that she was being treated as a patient instead of a person.

A few participants also felt that their GP or psychiatrist sometimes lacked time, and did not always take their complaints serious. This affected their relationship negatively and hindered having a conversation about potentially discontinuing their antidepressants.

''When I told my GP I wanted to discontinue my antidepressant, it took a month before she figured something out, so I started phasing the medication out by myself.''- woman, 24 years

Relationship with social environment

A theme that consistently recurred throughout the participants' interviews was the influence and involvement of their social surroundings in their antidepressant use. It differed among patients what this influence consisted of but it appeared that this influence was rather large, because they were often involved in decisions about the use. This influence could relate to decisions about starting and stopping the antidepressants.

''If it weren't for her I might not have started again, let me put it this way. I wasn't aware of anything and I felt good, for me, it was not necessary'' – man, 73 years

Discontinuation of antidepressants

Expectations

It appeared that the expectations participants had beforehand, played a substantial role in the decision-making process during the antidepressant use and the process of discontinuation. The type of expectations, to what extent they were present, and how they met the reality differed among participants. Some participants, for instance, had expected the antidepressants would have a greater effect on them. Consequently, this also influenced the decision to discontinue them.

''But I didn't have the wow effect, now if I really had the wow effect I might have continued with it.'' – woman, 64 years

Even during the process of discontinuation, expectations did not always meet reality. This could sometimes cause unpleasant situations.

''Then I wanted to phase-out the medication and so I did that myself at first and it didn't go well. I got really sick. I thought I could do that myself but I couldn't.'' - man, 73 years

Reasons

Participants had different reasons for discontinuing their antidepressants. Often, it involved an event in their lives that caused them to start contemplating their antidepressant use. This could be an influence from their social environment, but also, for example, experiencing an adverse reaction. It was often mentioned that having more free time was facilitative to discontinue. Some participants reflected after discontinuing on their use in the past and stated they might have been able to stop earlier.

''Now that I no longer use it, I think maybe I could have done this earlier. But I don't know''- woman, 56 years

Initiative for discontinuing

Two participants felt the initiative to suggest stopping or reducing the antidepressants lies with them. They indicated that they are in charge of their bodies and what happens to them. On the other hand, most participants indicated that they believe this initiative lies with the HCP. They felt that there should regularly be an evaluation of whether it is still indicated or perhaps the antidepressants could be reduced or discontinued.

''You don't see the psychiatrist anymore and the general practitioner prescribes it. Actually, you get it if you don't say anything until you die. I think that's a bad thing.'' Man, 73 years

''I think if there should be conversation or check or something from time to time where you discuss whether you still need the medication or if you could also take it less.'' - woman, 56 years

Most participants felt that this initiative should then lie with the GP. A few indicated that the pharmacist could also play a role in this process, since they are also involved in dispensing the medication

''A pharmacist might also say; listen, we have been dispensing this medication for 20 years, is it not advisable to speak to the GP? Or that the pharmacist and the GP have contact, I don't know how that works.'' – man, 73 years

There was a detailed discussion of what a successful discontinuation attempt requires. Three participants indicated it would be helpful to have a care provider specifically skilled in antidepressant discontinuation. The advantage would be that this care provider would have the accurate knowledge and time for it. One factor consistently mentioned by participants was motivation. They stated motivation to discontinue the antidepressant was very important, and that it was a predictor for success.

''If you're not 100% behind it, you can't be helped. Then, in my eyes, you're going to relapse anyway'' – woman, 74 years

''For discontinuing, I think you have to be motivated to do it.''- woman, 64 years

Education & guidance

Contact moments

The amount of guidance that patients needed

and in which form varied among them. One felt that it was something they had to do by themselves, but the predominant majority indicated that discontinuing the antidepressants is a serious process that requires help from a professional.

It was consistently reported by patients that having the possibility to reach out to the HCP if they had questions during the process of discontinuation was very pleasant. These moments did not have to be intensive, but could also be in a low-threshold way, such as a simple phone call or an email. Most of the time, they did not use this contact possibility, but the idea that they could reach their HCP when something was wrong or when they had a question gave them a feeling of safety.

''Calling in between, asking how it's going, whether you are having a setback, or that it's not going too fast. That worked perfectly and very confidentially.'' – man, 73 years

''That you can get in touch if you notice that things are not going as well, or if you notice that things are going differently than you expected''- woman, 24 years

Trust

Participants also stated that trust was an important factor during the process of discontinuation. This trust was, among other things, gained when it appeared that the HCP was knowledgeable. The knowledge that patients indicated as important was about the medication and the process of discontinuation. Most of them are curious to know how the antidepressant works, how it affects their body, what side-effects could occur and what period of use it would possibly include. Some participants indicated they expected more guidance and education because the person behind the antidepressant carries a whole story with them.

''I find with this type of medication, that a little more knowledge and ability is needed, also because not everybody reacts the same.'' – woman, 64 years

They also preferred it when the HCP had a background in psychiatry or at least some knowledge on the subject. This gave them a sense of being better understood and, as a result, better helped.

''I think it's obvious with the use of this kind of medication, there's a whole story behind it, with all due respect, you can't be helped by everyone equally''- woman, 56 years

Having a connection with the care provider who guided the process of discontinuation process created trust. The small-scale and personal feeling of knowing someone gave them confidence before and during the process.

''She also knew what I was like, and it's nice to do that with such a trusted person. Otherwise, I wouldn't have dared to phase out my antidepressants.'' – woman, 63 years

Education

Participants indicated that education about discontinuation of antidepressants should contain information about expectations, duration of the process, what they might encounter, information about resources and a warning that one should not be guided by experiences read or heard from their environment. This would provide them insight into the course of the process and minimize the chance of running into unexpected problems.

''Of course, you can have setbacks but I think the person who is going to guide you needs to discuss what the expectations are. And also what expectations you might have about it, which you might overestimate.''- man, 73 years

Methods

Successful discontinuation attempts in most cases involved taking small steps over a long period of time, often weeks to months. This varied between the participants and two of them stated that they discontinued their antidepressants in a few weeks by themselves. In terms of resources, many mentioned that having an tapering schedule is helpful. Another resource that was mentioned a couple times was the use of a liquid dosage form. This was described as an easy way to lower the dosage in small increments. Some indicated they did not need any resources. For some participants, it

was a nice feeling that they could step back if things were not going well. Again, this made them feel familiar and safe.

''Sure you find it anxious to stop, but she said if it doesn't go well you just go back up, and we'll see how we can help you. That gave me more trust.'' - woman, 64 years

DISCUSSION

Summary of the findings

Perceptions and beliefs had a substantial influence on the decisions regarding continuing or discontinuing their antidepressants. These beliefs applied to antidepressant use in general, but also to their own abilities. Fear appeared to be a crucial barrier to discontinuing antidepressants, but it was present when starting antidepressants. Participants experienced the presence of stigma and taboo when bringing up the use of antidepressants.
The way participants perceived their relationships with HCPs and social environment influenced decisions they made regarding their antidepressants use.
For the process of discontinuation, factors such as expectations, reasons and initiative for discontinuation appeared to be important. Expectations participants had, did not always meet reality. Subsequently, this affected the course of treatment and choices made. For instance some participants expected a stronger effect from their antidepressant than they perceived during their use. Furthermore, initiative for a conversation about possibly discontinuing or reducing antidepressants was expected from HCPs, both GP and pharmacists. The participant's motivation before discontinuation seemed to be an encouraging factor for success.
On the other hand, when it comes to guidance and education, trust in the HCP was relevant to the participant. Contact moments and having a good relationship with the HCP created this trust. Additionally, using a liquid dosage form of antidepressants and having the possibility to take a step back during the discontinuation process were also stated as conducive factors for successful discontinuation.

Comparison with existing literature

To date, no other studies investigated the experiences, expectations and needs for discontinuation of antidepressants. However, research on barriers and enablers for discontinuation, guidance in antidepressant therapy in general, and perspectives of patients and GPs was performed (4, 8, 15, 16, 18).

Eveleigh et al. and Nederlof et al. stated that certain beliefs about the effects of antidepressants and fear of relapse were a barrier to discontinue antidepressants. Fear of relapse is consistently mentioned in previous research as a barrier to discontinuation (4, 8, 15, 16, 18). Our study showed that the perception of being dependent on antidepressants influenced this fear to discontinue negatively. This feeling of dependency was also reported by Nederlof et al and Eveleigh et al (16, 18).

Eveleigh et al. mentioned the stigma surrounding the use of antidepressants in correspondence with our findings (18).

In terms of relationships with HCPs, Bosman et al. expressed that knowledge about medication of HCPs and the amount of time they had for patients were important factors. Our study indicated the importance of the influence of these factors on the relationship as well as knowledge about psychological symptoms. Nederlof et al. and Bosman et al. found, that patients perceive a lack of knowledge under GPs and pharmacists. This is partly in contrast with the findings of our study, which shows that several participants felt pharmacists had more specific knowledge about antidepressants (4, 16).

Eveleight et al., Nederlof et al. and Kelly et al. highlighted the involvement and influence of the social environment on patients who use antidepressants. This is consistent with the results of our study in which the predominant majority of the participants stated that their environment often were a prominent influence on the decisions they made during the course of the treatment. (4, 15, 16).

Wentink et al. indicated that patients felt that expectations were an important topic when discussing discontinuing their antidepressants (8). This study showed, corresponding to these findings, that expectations influence the process of discontinuation substantially.

In the findings of Bosman et al., Kelly et al. and Nederlof et al., patients felt it should be the GP's initiative to start a conversation about discontinuing or reducing antidepressants The findings of our study align with these, except in our study, a few participants mentioned that this initiative could also lie with the pharmacist (4, 15, 16).

In correspondence with the findings of this study, Bosman et al. showed that motivation is an important facilitator for discontinuing. In this study, part of the participants also indicated it is important to be motivated in order to discontinue successfully (4).

Nederlof et al. mentioned the importance of factors such as trust, education, and moments of contact (16). These factors also appeared to be important to the guidance in discontinuation according to the findings in our study.

In comparison with the findings of Wentink et al., our study indicates that participants have an additional desire to obtain information about reliable sources regarding the information on discontinuing antidepressants.

In addition to the above findings, many of which were already consistent with previous research, this study contributed a few extra aspects important for the discontinuation process. These were the use of a liquid dosage form, the ability to take small steps and also to go back to a higher dosage if necessary.

Strengths and Limitations

Participants were interviewed about their antidepressant use and experiences with discontinuing. These type of interviews allow to formulate wide range of research questions (20). In addition, this study provided insight into the status quo. i.e. what guiding during the discontinuation process looks like, what the patients' perspectives on it are, and what they additionally need within guidance during the discontinuation process. Furthermore, no other studies have investigated the guidance in antidepressant discontinuation, which highlights the needs of these findings and contributes to the literature on discontinuing antidepressants.

The biggest limitation to this study is the small number of participants. It appeared that six participants was not enough in order to reach saturation. Therefore, no complete statements can yet be made based on the results of this study. Another limitation to this study is that selection bias cannot be excluded. The participants were selected from pharmacies in two regions, of whom five were selected from the same region. This purposive selection provides insight in different types of participants, but it also creates a risk for selection bias. Three of the six participants were guided by a pharmacist during the discontinuation process. This may have influenced their opinion of the pharmacist's role in the discontinuation process and might not be representative to the true population. Furthermore, there is a potential risk of recall bias. Four participants used or had been using antidepressants for longer than 10 years. It was difficult for them to recall the start of their antidepressant use as this was a long time ago. This may have affected the accuracy, or the completeness of their answers during the interviews. There is an additional risk of confirmation bias, since topics were formed before the interview by the researchers. However, this was avoided as much as possible by open coding and interrogating the aspects that the participants mentioned during the interview.

Recommendations to practice and research

In order to guide patients with discontinuing antidepressants, it is important to discuss perceptions, beliefs, fears and expectations a patient might have, as these factors have shown to influence their decision-making. It is also essential to invest in having a good relationship with the patient, as this promotes a patient'-s trust in the process of discontinuation. Having knowledge, time and empathy are relevant

factors contributing to a good relationship. In addition, the social environment should be involved in the process of discontinuation as they have a substantial influence on the patient’s decisions. Furthermore, evaluation moments to discuss patient's antidepressant use should be planned regularly. This applies to every HCP who guides the discontinuation process. When necessary and possible, using a liquid dosage form for discontinuation can be helpful. During guiding, it is valuable for patients to be offered contact moments and the possibility to take steps back if necessary. Education about discontinuation should contain information about expectations, duration of the process, and information about reliable resources. Our findings also provide an opportunity for pharmacists to use their knowledge about medication and consultation and assist the GP in this process.

Future research should prospectively examine whether adapting patients' wishes affects being able to discontinue successfully. Due to lack of evidence on ADS, this should be also be examined more in patients.

CONCLUSION

When it comes to guidance with discontinuing antidepressants, the needs of patients are not fully met yet. From the patients point of the view, there is a lack of initiative, knowledge and time of HCP’s. On the other hand, proper education and guidance, which involves perceptions, expectations and good relationships, could facilitate the discontinuation process.

These recommendations expressed by patients themselves can be of help to HCP’s in order to improve the healthcare around the discontinuation of antidepressants.

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APPENDIX 1: TOPIC-LIST

BEGIN interview

Interview

I. **Farmaceutische geschiedenis SSRI en behandeling (om de patiënt te begrijpen als een ervaringsdeskundige)**

1. **Farmaceutische geschiedenis SSRI**
    a. Weet u nog wat de reden is voor het voorschrijven van dit geneesmiddel?
    b. Kunt u uitleggen hoe het gebruik van dit medicijn is uitgepakt?
    c. Wat heeft u gemerkt van het effect van het medicijn?
    d. Op een schaal van 1 tot 10: hoe effectief was het medicijn voor u?

2. **Behandeling**
    a. Waarover zijn toen afspraken gemaakt over het gebruik van het geneesmiddel?
        i. Wat gebeurde er in de *apotheek*? Bij de *huisarts*?
        ii. *Wie* heeft u gesproken?
        iii. Was de *gebruiksduur* duidelijk voor u? [4]
        iv. Welke informatie over het *afbouwen* heeft u gekregen bij de start van uw behandeling?
        v. Waren deze afspraken voldoende? (Vraag naar ervaringen, concrete gebeurtenissen)
    b. Wist u goed wat u kon verwachten van het gebruik van het medicijn?
        i. Wat waren uw verwachtingen van het gebruik van het medicijn?

3. Ik ga nu even wat vragen stellen die bij sommige mensen wel van toepassing zijn en bij anderen van niet, dus geef gerust aan als dat zo is.

    a. Heeft u iets gemist in de voorlichting wat terugkwam bij u?
        i. Heeft u het internet moeten raadplegen?
    b. Sociale ondersteuning in de omgeving?
        i. Is er iemand die u helpt met de medicatie?
        ii. Welke rol speelt uw vriendenkring bij het gebruik van het medicijn?
        iii. Welke rol speelt uw familie bij het gebruik van het medicijn?
    c. Kunt u vertellen over andere behandelingen die zijn ingezet?
        i. Zoals bijvoorbeeld CGT?

4. **Is er iets wat u wilt vertellen over uw ervaring met het geneesmiddel of de behandeling, waar we het nog niet over hebben gehad?**

II. **Eerdere afbouwtrajecten**

1. **Heeft u eerder geprobeerd medicijn x af te bouwen? [2]**
    i. Zo ja, hoe vaak?
    ii. Hoe bent u toen op het idee gekomen om af te bouwen? Deze vraag moet eerder gesteld worden
    iii. Wat wilde u bereiken met het afbouwen?
    iv. Kunt u mij meenemen in het proces? Vanaf het eerste gesprek over het afbouwen t/m het resultaat?
        1. Wat zijn uw ervaringen hierbij? [2]
        2. Wat ging er goed?
        3. Wat ging er minder goed/Wat voor klachten ervaarde u?
        4. Wat heeft u doen laten kiezen om weer te starten met het medicijn x?
    v. Waarom denkt u dat het afbouwen wel of niet is gelukt?
        1. Als u het anders had kunnen aanpakken, wat zou u dan veranderen?

vi. Hoe kijkt u aan tegen een volgend afbouwtraject?

2. **Wat zijn/waren uw verwachtingen bij het afbouwen van medicijn x? [2]**
   i. Op welke manier denkt/dacht u dat dit zal/zou gaan?
   ii. Welke moeilijkheden verwacht/verwachtte u?
   iii. Wat verwacht u dat goed zal gaan?
3. **Bent u momenteel aan het overwegen om af te bouwen? [2]**
   i. Hoe verwacht u dat het afbouwproces zal verlopen?
4. **Hebben wij iets over eerdere afbouwtrajecten niet besproken, waar u wel graag wat over wil vertellen?**

In de praktijk is belangrijk dat zorgverleners samenwerken met u bij het afbouwen, daar ga ik nu een aantal vragen over stellen. We willen graag van u weten hoe de beste begeleiding er voor u uit zou zien.

III. Begeleiding en ondersteuning bij het afbouwen

1. **Wie zou er volgens u betrokken moeten zijn bij de beslissing om wel of niet af te gaan bouwen van uw medicijn?[4]**
   i. Wat is er begeleiding echt essentieel voor u om het afbouwen goed te kunnen volgen?
   ii. Vanuit wie verwacht u dat het initiatief komt om af te bouwen?
2. **Wat verwacht u van de begeleiding vanuit zorgverleners [4,6]**
   i. Wat verwacht u van de huisarts?
   ii. Wat verwacht u van de apotheker?
   iii. Wat verwacht u van de psychiater?
3. **Wat heeft u volgens u nodig bij het afbouwen?**
   i. Welke hulpmiddelen heeft u nodig om succesvol af te kunnen bouwen (bv: afbouwschema, app)? [6]
   ii. Hoe kan de omgeving (familie, vrienden) helpen bij het afbouwen?
   iii. Hoe wilt u dat zij betrokken worden?
4. **Welke voorlichting over afbouwen vindt u belangrijk? [1]**
   i. Bv: over terugval? Onttrekkingsverschijnselen?
   ii. Bij wie zou u dit aankaarten?
5. **Denkt u dat de apotheek een grotere rol zou kunnen spelen bij de ondersteuning bij het afbouwen van uw medicijn? Zo ja, op welke manier wilt u dat zij zorg verlenen? [4,6]**
6. **Hebben wij iets over de begeleiding en ondersteuning bij afbouwen niet besproken, wat u wel belangrijk vindt?**

APPENDIX 2: CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE STUDIES (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	Page 4
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Page 4
3. Occupation	What was their occupation at the time of the study?	Page 4
4. Gender	Was the researcher male or female?	Not reported: all female
5. Experience and training	What experience or training did the researcher have?	Not reported: JH & WG 30 years of experience as pharmacists and researchers. SB & FC only experience during research in masters education
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Page 3
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 3
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Page 9

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 4
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 3
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 3
12. Sample size	How many participants were in the study?	Page 3
13. Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Not reported: in the pharmacies in an enclosed space
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No

16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 4
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 3
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 4
20. Field notes	Were field notes made during and/or after the interview or focus group?	No
21. Duration	What was the duration of the inter views or focus group?	Page 3
22. Data saturation	Was data saturation discussed?	Page 3
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Page 4
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 4
27. Software	What software, if applicable, was used to manage the data?	MAXQDA, word
28. Participant checking	Did participants provide feedback on the findings?	No
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Page 4 – 9 and appendix 2
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Page 9 - 10
31. Clarity of major themes	Were major themes clearly presented in the findings?	Page 4 – 9 and appendix 2
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 4 -9 and appendix 2

APPENDIX 3: THEMES AND QUOTATIONS

Theme	Quote	Respondent
Experiences with the use of AD	*'I actually think it's too easily prescribed''*	Man, 73 years
	'Well, I personally think no medication is better. They say if the doctor says so, it's no big deal. It doesn't hurt you; it helps you. But if you can avoid it, then I would do it.''	Woman, 63 years
	''When I look back, I had a blunted, dulled feeling. My mind was kind of shut off from a lot of things. It did not reach me as much anymore''	Man, 73 years
	''I noticed that when I discontinued the antidepressant, I started to feel like myself again and my feelings and interests came back.''	Woman, 24 years
Emotions	*''For example, when we wanted to go camping with the grandchildren, I would panic beforehand.''*	Woman, 64 years
	''I'm not so open to that. Of course, I want to get rid of this medication, but I have my experiences and it was not fun. It's hard to describe how you feel then, but I collapsed.''	Woman, 63 years
	''Of course, I read some reviews about the medication, there are often only negative things in there, and occasionally someone writes something positive.'	Woman, 64 years
	''It was also a kind of a relief for me, see, I'm not dependent on pills''	Woman, 64 years
Beliefs	*''He told me, that because of what I experienced in my childhood, certain substances were not being produced enough and that this drug would act on it.''*	Woman, 56 years
	''I believe, also because my doctor said so, that maybe I just need this substance''	Woman, 63 years
	''Then I discontinued the antidepressant under the guidance of the GP. At first, I thought I could do this by myself, but I can't.''	Man, 73 years
Stigma & taboo	*''Yes, I haven't talked to many people about it because you hear things like, you don't need it at all, and you're so good. Then you get all that kind of whining.''*	Woman, 56 years
Relationship with the caregiver	*''That's why I was like, is it smart to start this? But I thought the doctor will know, so I thought I'll follow her advice and we'll see how it goes''*	Woman, 24 years
	''I think it would be very helpful if I know right away, how the medication works, and the pharmacist knows that I think.''	Woman, 64 years
	''My GP knew how I was. And that's nice too, that you can do that with someone so familiar, you know. Otherwise, I wouldn't have dared.''	Woman, 63 years
		Woman, 24 years

	''When I told my GP I wanted to discontinue my antidepressant, it took a month before she figured something out, so I started phasing the medication out by myself.''	
Relationship with the social environment	*''If it weren't for her, I might not have started again, let me put it this way. I wasn't aware of anything, and I felt good, for me, it was not necessary''*	Man, 73 years

Theme	**Quote**	**Respondent**
Expectations	*''But I didn't have the wow effect, now if I really had the wow effect, I might have continued with it.''* *''Then I wanted to phase-out the medication and so I did that myself at first and it didn't go well. I got sick. I thought I could do that on my own, but I couldn't.''*	Woman, 64 years Man, 73 years
Reasons	*''Now that I no longer use it, I think maybe I could have done this earlier. But I don't know''*	Woman, 56 years
Initiative for discontinuing	*''You don't see the psychiatrist anymore and the GP prescribes it. You get it if you don't say anything until you die. I think that's a bad thing.''* *''I think if there should be a conversation or check or something from time to time where you discuss whether you still need the medication or if you could also take it less.''* *''A pharmacist might also say; listen, we have been dispensing this medication for 20 years, is it not advisable to speak to the GP? Or that the pharmacist and the GP have contact, I don't know how that works.''* *''If you're not 100% behind it, you can't be helped. Then, in my eyes, you're going to relapse anyway''* *''For discontinuing, I think you must be motivated to do it.''*	Man, 73 years Woman, 56 years Man, 73 years Woman, 74 years Woman, 64 years

Theme	**Quote**	**Respondent**
Contact moments	*''Calling in between, asking how it's going, whether you are having a setback, or that it's not going too fast. That worked perfectly and very confidentially.''* *''That you can get in touch if you notice that things are not going as well, or if you notice that things are going differently than you expected''*	Man, 73 years Woman, 24 years
Trust	*''I find with this type of medication, that a little more knowledge and ability is needed, also because not everybody reacts the same.''* *''I think it's obvious with the use of this kind of medication, there's a whole story behind it, with all due respect, you can't be helped by everyone equally''*	Woman, 64 years Woman, 56 years

	''She also knew what I was like, and it's nice to do that with such a trusted person. Otherwise, I wouldn't have dared to phase out my antidepressants.''	Woman, 63 years
Education	*'Of course, you can have setbacks, but I think the person who is going to guide you needs to discuss what the expectations are. And also, what expectations you might have about it, which you might overestimate.''*	Man, 73 years
Methods	*''Sure, you find it anxious to stop, but she said if it doesn't go well you just go back up, and we'll see how we can help you. That gave me more trust.''*	Woman, 64 years