Should I, can I, dare I? Patients' view on stopping long-term antidepressant use, a qualitative study

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Abstract

Background and aim

The rise in long-term antidepressant use is concerning. Long-term antidepressant (AD) use, much longer than recommended by guidelines, can result in risk of adverse events and generate unnecessary costs. In order to mitigate these risks, patients views about their antidepressants and how to discontinue need to be taken into account. We aimed to explore patients' experiences and views of discontinuing long-term AD, barriers and facilitators of discontinuation and required support.

Methods

Semi-structured face to face interviews were conducted with 14 patients with long-term AD use in primary care. Interviews were analysed thematically.

Results

Participants describe various perceptions about discontinuation. There is fear of returning to their depression, even in those who were ambivalent about the effectiveness and safety of AD continuation. Participants describe low confidence in their own coping resources, fear of stress, and previous negative experiences with stopping. This enhances their perception of AD dependence. Participants indicate the importance of the support of their GP and their social network to help them withdraw.

Conclusion

Discontinuation of long-term antidepressants is a complex issue for patients. More awareness of the lack of evidence and the potential risks of long-term AD continuation is required. By raising the issue and offering support during discontinuation GPs can help their patients stop AD. A greater focus on non-pharmacological approaches of depression in primary care is needed to reduce unnecessary AD use.

Keywords: antidepressant discontinuation, depression, general practice, long-term antidepressant use, qualitative research

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Background

The rise in long-term antidepressant (AD) use is concerning. In the UK, nearly half of the AD users (8% of the total population) (1) and in the US two thirds (2,3) have been taking them for more than two years. In Belgium, 12% of the population take an AD and nearly 30% for more than one year (4). Guidelines for the management of depression recommend AD treatment up to 6 to 12 months after remission and up to 2 years after remission in those at high risk of relapse or with a history of recurrent depression (5). Due to lack of evidence for the optimal duration of treatment, guidelines

are based on expert opinion. There is no recommendation that AD should be taken indefinitely in the primary care population.

Antidepressants that are not discontinued after the recommended duration, can result in unnecessary harm (6-11) and can generate unnecessary costs (12). Use of AD can put people at risks of adverse events, such as sleep disturbance, weight gain, sexual dysfunction, and gastrointestinal problems, alongside feeling emotionally numb (6-11), and risks persist during prolonged treatment (6-11). ". A study of patient-perceived side effects found that 63% of patients reported, on average, 2.9 side effects during the 1–2 years of follow-up period, with dry mouth, profuse sweating, sexual dysfunction, sleepiness during the day and weight gain more frequently reported (9). AD also have the potential to cause serious adverse events such as upper gastrointestinal bleeding, hyponatremia, falls, osteoporosis and fractures, and diabetes mellitus (13-16). Moreover, qualitative studies show that long-term antidepressant use for depression may also impair patients' autonomy and increase their dependence on medication (17).

Successful discontinuation of AD depends on patient-related and doctor-related factors (18-19). Although a recent review addresses patients' barriers and facilitators to discontinuing long-term AD use (17), health systems and cultural factors can play a role (20). There is little information about the perspectives of Belgian patients which is needed to develop interventions for reducing unnecessary AD treatment in Belgium. Therefore, we aimed to explore the perspectives of Belgian AD users about their AD and how they view discontinuation of long-term use.

Methods

Study design and participant recruitment

We conducted a qualitative study with participants recruited from seven GPs in two group practices in a suburban and rural region in East-Flanders. All participants receiving AD prescriptions for 12 months or more for major depressive disorder (as initial diagnosis) were identified from computer records by one of the researchers (RDB). Participants were eligible if they were identified by their GP as stable and well while using AD, longer than recommended, and without a clear indication to continue AD. Participants were purposively sampled to ensure diversity in age and sex. Eligible participants were contacted by their GP by phone about the study and invited to participate. When participants agreed to participate, they were contacted by a researcher, and additional information was provided. All participants provided informed written consent. Participation was voluntary.

Ethics approval was obtained from Ghent University, Belgium (reference EC/2019/0409).

Data collection

A General Practice (GP) trainee (RDB) who had received training in interviewing, conducted semi-structured face-to-face interviews between November 2019 and October 2020 using an interview guide based on the literature (see box 1). In brief, participants were asked about their experiences with long-term use of AD, how they view discontinuation and the support they required. Open-ended questions were followed with prompts to elicit further detail. The interviews were audio-recorded, transcribed verbatim, and transcripts were checked for accuracy and anonymized. The interviews took place at a place and time that suited the participant.

Data-analysis

Following each interview, the interviewer reflected on data collection with EVL (GP, qualitative researcher). All transcripts were uploaded in NVIVO v12 and coded thematically by two researchers (EVL, RDB). EVL and RDB independently read five interviews and made notes on key topics and potential themes to develop an initial framework. To ensure robustness of the findings, the analysis (coding, developing categories and themes) was discussed in the wider team. For the subsequent interviews codes and categories were refined and defined at different stages in an iterative manner by EVL and RDB. The initial framework was further amended and adapted. The main themes were identified, discussed, and agreed by the full study team. Interviews continued until data saturation occurred, with no new ideas identified in responses. To enhance the validity and reliability, we followed the Consolidated Criteria for reporting Qualitative research to guide reporting (COREQ) (21).

Results

Of the 16 participants contacted, 14 agreed to participate. Demographics of the participants are provided in Table 1. Ten were female and ages ranged from 26 to 69 years (average 54 year, mean 58 year). Of the 14 participants, 2 had successfully discontinued the AD and 1 was in the process of tapering. The duration of current AD use ranged from 1 to 35 years (average 11.2 years, mean 4.5 years). Seven had consulted a psychiatrist for their depression at some stage and 11 had seen a psychologist (8 in the past and 3 currently). The interviews lasted 30 to 60 min. Of the 14 participants, 11 chose to be interviewed at the GP practice.

We identified three main themes: 'To stop or not to stop? Various perceptions of AD', 'Can I stop?' and 'What would help me stop'.

Theme 1 To stop or not to stop? Various perceptions of AD

Fear of relapse

The main concern of all participants is a return of the depression. They expressed fear that discontinuation could put them back to where they came from. They fear the consequences of discontinuation on their relationships with family or friends and becoming a burden to them again. As one participant explained: *'…that year when I was feeling so bad and did not do anything in the house anymore, that has been a disaster, … So I hope I don't relapse as I'm afraid that might be the end of my relationship'* (M, 57years, 18 years AD use). They remember how they lacked the ability to be a good partner or parent when the AD was first started.

They all referred to a specific moment when they had sunk so low that they needed help and AD were necessary. In fact, some saw the AD as the only solution at that moment and they only remember its positive effect. Some assign real life-saving properties to the AD ('a Nobel prize'), while others were more moderate and describe them as 'not a miracle cure'. In line with their believe that the AD was responsible for their improvement, 'not knowing' what the future holds and worrying about needing AD again in the future is another reason to continue. Similarly, in case the depression returns, and they need an AD again, the delay before the AD effect kicks in is an additional barrier for discontinuation.

The fear of relapse was so important that it seemed to persist after discontinuation. One participant who had stopped two years ago reported he still keeps the AD at home as a safety net. Another

participant mentioned she restarted AD six months after discontinuing because she was afraid of relapsing when she went through a stressful time.

My antidepressant is good for me and it won't harm me

Many participants believe they feel well because the AD is still effective, even after many years. They mention the AD helps them remain stable and functioning. ADs are believed to correct a biochemical deficiency in the brain that affects different aspects of functioning and lifelong continuation is therefore necessary. Others see their depression as a chronic condition requiring lifelong treatment, similar to treatment of diabetes or hypertension. Some participants still experienced low mood or distress from time to time. They say that feeling sad is a warning that the 'problem' is still present and the AD prevents them from feeling worse, confirming the need to continue the AD.

Overall, they did not perceive AD as a problematic drug. ADs are considered safe and well-tolerated with no or few side effects. The side effects are not perceived as serious, but rather 'a small disadvantage'. When asked specifically about side effects, participants report a wide range of effects, such as difficulty concentrating, weight gain, sexual disfunction, emotional numbing, not feeling themselves, impaired alcohol tolerance and impaired vision. Most accept the side effects because the benefits of the AD outweigh the discomfort. Concern about (future) harm was minimalised by how much AD they take; 'I use only a low dose' or 'only a half tablet'.

In general, participants who believe the AD is effective and safe do not see a reason to risk discontinuation. As one patient said: '*I actually never thought about quitting. No, I really wouldn't know why I would want that, I am feeling well right now*.' (F, 64yr, 24yr AD use).

I am unsure about continuing my antidepressant

In contrast to participants who believe the AD is beneficial and necessary, some question the need for AD continuation. Indeed, participants who were feeling well with the AD and who were not experiencing stress mentioned doubts about the actual effectiveness of AD. They wondered about the necessity of continuation: "*…what if I could go a while without taking it …, because I have been taking it for more than 20 years, and sometimes I think "does it still work?"* (F 51yr, 24yr AD use) In their opinion, feeling well was a signal of recovery and a possible reason to discontinue. Others who are unsure about continuation regarded the AD as a temporary support giving them the energy to change things and feel better, and not as a solution to all their problems. It is unclear to them whether the AD makes them feel better or whether it is because of their own efforts or changed life circumstances. They also wonder about a placebo-effect. Some participants assumed that the effect of the AD diminishes after long-term use, which influences their willingness to discontinue.

In addition to their concerns about effectiveness, participants express negative feelings towards continuing their AD. They fear future harmful effects on their brain and body. Perceiving AD as 'not natural' and 'not healthy' to use lifelong was a major reason to discontinue.

Concerns about addiction and dependence are widespread. Participants want to stop the AD to avoid becoming dependent. However, some think they have already become 'dependent' because they feel unable to function on their own without AD. One participant even mentioned regretting the decision to start the AD in the first place.

However, in the end, most tend to continue the AD because they fear the consequences of discontinuation. They dislike discontinuation more than the uncertainty related to continuation.

Theme 2 Can I stop?

Lacking the confidence

Confidence in one's capability to discontinue is important. Participants describe themselves as 'weak' and unable to manage life issues by themselves without medication. One participant explained:" *I often have difficult moments. I really am not strong enough to handle that on my own. And to cope I take half a pill daily (F, 61yr, 35yr AD use)*

Hence, they think they can only discontinue their AD if they replace it with something else, a natural product or vitamin that can act as an alternative for the AD and keep them stable.

Some people reported that they have learnt coping skills from psychotherapists to deal with stressful life situations without AD. However, not all participants had positive experiences with psychotherapy. Personal circumstances and timing play an important role in the motivation to discontinue. Work related issues, behavioural problems of children, relationship stress, caring for parents, loneliness and the feeling of being unable to cope or to change these situations, were reasons to continue the AD. Ascribing the responsibility for discontinuation to external circumstances suggests an overreliance on AD and a feeling of not being able to cope with daily problems without AD. On the other hand, a strong belief in one's own resources and effective coping facilitates AD discontinuation.

Previous experiences with discontinuation

Experiencing symptoms during discontinuation attempts (with or without support from a GP) affirms the fear of destabilisation and can result in restarting the AD. Such a negative experience can reduce motivation to discontinue again. In addition, unsuccessful discontinuation attempts can confirm the perception of 'AD dependence' and lead to abandoning the idea of ever stopping. Withdrawal symptoms after accidently forgetting a few tablets, was already a reason to dismiss discontinuation. However, others said they did not feel different after missing some tablets (without the intention to stop), but people around them noticed a difference in their behaviour. Their reaction made them uncertain about future attempts.

Some mention it is difficult to differentiate between symptoms of withdrawal and return of depression due to reduced intake of serotonin. Therefore, the difficulty of distinguishing between withdrawal symptoms and relapse can make them unsure and hence they prefer to be safe and restart the AD: "*I have tried to taper 3 or 4 times ….tapering is difficult. Each time I get a lot of headaches, stomach problems, flu-like symptoms…. But at the same time, you get a feeling like "I am getting negative again…" It is probably in my head, I think, because I know "I am getting less of this substance and it will make me more depressive". So, I don't know which of the two is right actually. That is why I never reach the endpoint." (F, 45yr, 26yr AD use).*

Theme 3 What would help me stop

The role of the GP and other health care professionals

The GP can help participants make up their mind about discontinuation. Most believe it is the GP's responsibility to raise the issue of discontinuation. *One participant argued: 'We are not going to take the initiative ourselves. It is not that I blame anyone, but if no one says "stop taking it" I won't do it if I feel fine on them." (M, 61yr, 4yr AD use).*

A doctor's advice to discontinue was perceived as a strong facilitator due trust in their GP. Participants reported they will not raise the issue themselves. One participant reported that she was only able to raise the issue because she was feeling well and encouraged by her psychologist who confirmed her stability.

A doctor supporting the patient's idea of discontinuation and advising on discontinuation was seen as necessary to discontinue, however this does not usually happen. Indeed, some were explicitly told to continue the AD by their GP (or psychologist) even if they had asked for discontinuation and were thus discouraged to try discontinuation in the future. Despite regular visits to their GP, many participants mention they usually receive an AD prescription without any review, which implies the medication is still necessary. Others received a prescription after discussing their wellbeing, however, without discussing AD discontinuation. One participant with long-term use initiated by another doctor wonders whether the GP even knew why she was prescribed an AD in the first place, because she always receives a prescription without her GP asking. Another participant restarted the AD because their GP did not provide follow-up and support to stay motivated during the tapering period.

Social support

Support from family and/or friends can facilitate discontinuation. Participants (who stopped the AD) mention that talking to trusted people about their issues helped them deal with the fear of relapse during discontinuation. One participant used significant others as a safety net to prevent relapse, especially when struggling with stressful life events. Others believe that social connection helped them recover from depression and remain stable, confirming its importance for successful discontinuation.

On the other hand, some lacked support from family or friends. They feel that others do not empathize with their situation and disapprove their AD. This was perceived as unhelpful for discontinuation. Moreover, loved ones can reinforce self-perceived weakness and create a barrier to discontinuation. The AD enables our participants to cope with the behaviour of other people (for example partner, child). They said they would only discontinue if the other changed and became more supportive.

Experiences of others can increase as well as reduce motivation to discontinue. Success stories suggest that discontinuation is possible and this increased confidence in their own successful discontinuation. However, seeing others struggle with discontinuation confirms the fear of disturbing their wellbeing and is used to justify continuation.

Discussion

Summary

Our study provides insights into the perceptions of long-term AD users regarding the decision to discontinue AD.

The fear of relapse was an important barrier to discontinuing the AD for all participants. A strong belief in the effectiveness and few concerns about the potential harms when feeling well with the AD feed the desire to continue the AD. In contrast, there is also ambivalence towards continuing, with doubts about effectiveness and safety of AD. A lack of self-confidence, fear of stressful situations, and unsuccessful discontinuation attempts are barriers to discontinue and enhance the perception of 'AD dependence' and fear of relapse. Our participants feel their GP is responsible to raise the issue and GP guidance and social support can facilitate discontinuation.

Comparison with existing literature

Our study confirms the barriers and facilitators reported by Maund et al (17). Our study also included participants who had successfully stopped long-term use and adds that fear of relapse persists after discontinuation. We also found that the time to effect after starting an AD is a barrier to discontinuation, especially in early discontinuation (22). These two findings are related to fear of relapse and illustrate the pessimistic view of discontinuation success.

As in previous studies, many of our participants were not concerned about adverse events (22-24). They were much more concerned about the risk of relapse (17, 22, 24-25), which seems to be overestimated (26). Their fear of relapse may be explained by the perception that it is the AD which makes them feel better. They do not consider their own coping resources or psychosocial interventions to be contributing. Factors such as the impact of changed circumstances or the spontaneous remission and overall positive outcome of depression in primary care are not taken into account, resulting in over-reliance on the AD (27). This suggests patients are not well informed about the effectiveness of AD in depression. A Cochrane review concludes that for depression in primary care, the number needed to treat (NTT) for an SSRI is between 7 to 8 and for a TCA between 7 and 16 (28), which means that only a minority benefit from the AD. There is no evidence for a long-term clinically meaningful effect of AD (29). Additionally, up to 50-80% of depressive disorders in primary care are self-limiting within three to twelve months (30).

Fear of stressful experiences hinders discontinuation (). People feel they need the AD to deal with stress. This sense of 'dependence' on AD was also found in other studies (17, 31). Perhaps the low confidence in their own coping resources is implicitly confirmed by the doctor continuing the AD. This is concerning as AD do not solve psychosocial problems and psychological therapies to improve coping skills are recommended in combination with AD initiation (32).

Like in other studies (17,25), our participants wanted the GP to initiate conversations about discontinuation. However, our previous research suggests that Belgian GPs were not inclined to do so (33). Mixed opinions about this responsibility were also found elsewhere (34-35); if a patient does not express a desire to discontinue there was no reason for the GP to raise the issue. GPs also want to make sure their patient is in a stable situation and ready for a discussion about discontinuation before they raise the issue (36). As a result, patients and GPs are expecting the other to mention discontinuation, meanwhile the status quo is maintained. Long-term use of AD is associated with reduced agency (37). This implies that we cannot expect patients to initiate discussions and that the

GP, being responsible for appropriate prescribing, should take the lead by regularly reviewing the AD and considering discontinuation proactively. However, GPs perceive discussions about discontinuation as difficult and do not want to rock the boat (33). Recently developed tools can support these conversations (38). But as many GPs don't consider AD as a major problem (23, 33, 36), relying on their initiative as the key solution to reducing AD use is overoptimistic.

Globally, we observed the same barriers and facilitators in the Belgian population as reported in other (Western) populations (17).

Strengths and Limitations

To our knowledge, this is the first study to investigate patients' views on discontinuation of long-term AD in a Belgian context. Understanding their perspectives within the local cultural and healthcare context is essential for development of tailored interventions to reduce long-term use.
We purposely sampled 14 participants from 7 GP practices in 2 regions in Belgium to ensure we captured the breadth of opinions and experiences of long-term users in primary care and the data reached saturation. We may not have captured the opinions of long-term users from ethnic minority groups or people living in deprived areas, experiencing more poverty and other social determinants of mental health (39) and known for higher rates of AD use (40-41). As only 2 participants were aged over 65 years, we did not fully capture the views of older adults.

GPs selected participants whom they considered eligible to participate in the study, therefore the results may not adequately reflect the views of the full range of patients with long-term AD use, especially those with limited interest in being interviewed about it or those with a poor relationship with their GP. We relied on the GP's judgment whether discontinuation was appropriate.

Recommendation for practice and policy

Our study has some important implications.

An overly optimistic perception of the benefits of AD calls for better patient education regarding the lack of proven long-term effectiveness and the potential risks of long-term use. Moreover, patients can be reassured that discontinuation by slow tapering is safe and feasible and collaboration with a GP can help them discontinue successfully. Sharing positive discontinuation stories and seeing others coming off AD successfully can help by providing hope (42).

Education on strategies to cope with stressful experiences and social problems is important to minimise the potential risks of medication.

Given the trust that patients have in their GP, GPs can enable positive change by raising the topic and offering support during discontinuation. They should realise that repeat prescriptions are seen as confirmation of the need to continue the AD.

Conclusion

The decision to discontinue long-term AD is a difficult process for patients. Their fear of relapse after discontinuation and unsuccessful discontinuation attempts confirm the perception of 'AD dependence' and inability to cope without AD. Education about the lack of a long-term clinically meaningful effectiveness and the potential risks of long-term use is required. GPs should know that proactive support facilitates discontinuation. More attention to the advantages of a non-pharmacologically approach of depression in primary care is needed to reduce unnecessary long-term AD treatment.

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Box 1

Interview guide

Part 1: experiences with your AD

Could you tell me something about your AD use? How is it going? When did you start the AD? Did it help you? How does it feel to keep taking them? Are you satisfied with it? Do you experience any side effects?

How do you envision your future use? Do you intend to continue the AD? What questions do you have about it?

Have you ever discussed the AD with your doctor/GP? Have your GP or any other doctor ever talked about the AD? Do they review the AD? How is this going?

Have you ever discussed the AD with family and/or friends? Have your family/friends ever talked to you about taking AD?

Have you tried stopping before? How did that go? What was the reason you stopped? Was this the your GP's suggestion or did you suggest this to your GP? Did you discuss this with your friends/family, or did they suggest you do this?

Part 2: perspectives on AD discontinuation

How do you feel about discontinuation? What would be needed to enable you to stop taking the AD? What would support and help you discontinue? What factors and circumstances will enable you to stop? Why? What factors and circumstances make it difficult to stop? Why?

Table 1 Demographics of the 14 participants

Age, years	
Mean	54
Range	26-69
Median	58
Sex (n female/n male)	10/4
Living status	
Living together	12
Living alone	2
Education level	
Some high school education	7
High school graduate	
Bachelor or master degree	3 4
Area (rural/urban)	13/1
Indication reported by patient:	
Depression	9
Depression/anxiety	5
AD Initiated by	
GP	9
psychiatrist	5
Duration of AD (year)	
Mean	11.2
range	1-35
median	4.5
<5 years	8
10>x>5 years	0
10 years or longer	6
Current AD users: type of AD*	11
SSRI (escitalopram, sertraline, paroxetine)	6 (4/1/1)
SNRI (venlafaxine)	
TCA	3
Other AD (bupropion, quetiapine, mirtazapine)	0 3 (1/1/1)
(*1 patient used 2 AD: venlafaxine + mirtazapine)	
*Tried another AD before/no other AD before	7/7
Decided to discontinue/ continue	3/11
Stopped AD successful (SSRI: citalopram)	2
In tapering process (other AD: duloxetine, venlafaxine)	1

Follow-up by psychiatrist/Never follow-up Currently Past Never	7/7 1 6 7
Follow-up by psychologist/Never follow-up Currently Past Never	11/3 3 8 3