

# Patients' attitudes to discontinuing not-indicated long-term antidepressant use: barriers and facilitators

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*Ther Adv Psychopharmacol*

2019, Vol. 9: 1–9

DOI: 10.1177/  
2045125319872344

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## Abstract

**Background:** Long-term antidepressant use has increased exponentially, though this is not always according to guidelines. Our previous randomized controlled trial (RCT) showed that participants using antidepressants long term without a proper indication were apprehensive to stop: only half were willing to attempt to discontinue their antidepressant use. The objective of this study was to explore participants' barriers and facilitators for stopping long-term antidepressant use without a current proper indication.

**Methods:** Semistructured interviews with participants from the intervention group of our RCT, a cluster-RCT in general practice in the Netherlands. The latter study was a stop trial with patients on long-term antidepressant use without a current indication (no psychiatric diagnosis). Participants of the intervention group of the RCT had been provided with advice to stop antidepressants. Participants of the current interview study were purposively sampled (from the intervention group of the RCT) to ensure diversity in age, sex, and intention to discontinue the antidepressant. Analysis was performed as an iterative process, based on the constant comparative method. Data collection proceeded until saturation was reached.

**Results:** A total of 16 participants were interviewed. Fear (of recurrence, relapse, or to disturb the equilibrium) was the most important barrier; prior attempts fueled these anticipations. Also prominent as a barrier was the notion that antidepressants are necessary to counter a deficiency of serotonin. Facilitators were information on duration of usage given at the time of first prescription and confidence in a successful attempt. We found many participants struggling between barriers and facilitators to discontinue and participants not discontinuing while experiencing no barriers (ambivalence).

**Conclusion:** Fear is an important motive for patients considering discontinuation of antidepressants. Serotonin deficiency as explanation for antidepressant effectiveness promotes life-long use and hinders discontinuation of antidepressant treatment. The prospect of discontinuation at first prescription can facilitate a future discontinuation attempt. General practitioners should be aware of their patients' fears, expectations, and attributions toward antidepressant use/discontinuation, and of new developments in taper methods.

**Keywords:** antidepressant agents, anxiety disorder, depressive disorder, discontinuation, general practice, inappropriate prescribing, primary health care

Received: 2 May 2019; revised manuscript accepted: 2 August 2019.

## Introduction

Antidepressants are an evidence-based treatment for depressive and anxiety disorders.<sup>1–4</sup> However,

with prescribing of antidepressant drugs rising exponentially,<sup>5</sup> the appropriateness of these prescriptions has been questioned.<sup>6–8</sup>

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A number of factors have been suggested to contribute to the increasing numbers of antidepressant prescriptions, including increased prevalence and improved recognition and management. Long-term usage has been found to contribute greatly to the growing amount of antidepressant use.<sup>6,9,10</sup> Guidelines on the duration of long-term antidepressant prescriptions differ in detail, but, in general, recommend continuing medication after adequate first response. The duration of this continuation is set at between 6 and 12 months, depending on the guideline.<sup>1,4,11</sup> Maintenance therapy is recommended for patients with recurrent depression, with recurrent being defined as either two or three episodes.<sup>1,4,11</sup> Maintenance therapy could also be suggested for patients with other risk factors for relapse. Although guidelines concerning antidepressant treatment duration are based mainly on consensus rather than evidence, and although the advice for a certain duration of the treatment is not the same as advice to stop treatment after that period, general practitioners (GPs) are strongly committed to stop drug therapy when not strictly indicated.

We therefore sought to minimize long-term ( $\geq 9$  months) antidepressant usage without current indication with our RCT.<sup>12,13</sup> This study demonstrated the difficulty in discontinuing long-term antidepressant use without current indication. Participants were reluctant to accept discontinuation advice despite continued use of the antidepressant not being deemed congruent with clinical guidelines.<sup>3,4</sup> In almost half of the cases the discontinuation advice was rejected by the participant. Of course, patients might, in hindsight, actually be right not to stop treatment, but there is insufficient evidence about this problem.

Patients' experiences of antidepressant use were summarized in a large meta-ethnography.<sup>14</sup> In summary, patients constantly evaluate their antidepressant use by balancing risks and benefits, hopes and fears, and positive and negative self-images. A tension was found between 'feeling well' and 'being well', further described as the difference between self-determination and psychological dependency. When focusing on long-term antidepressant users, antidepressants were seen as a threat to autonomy. Antidepressants doubled the stigma, with the antidepressant as the evidence of failure to cope with everyday problems. On the other hand, antidepressant use also reduced stigma, with depression being seen as a

physical illness and the 'serotonin deficiency' being treated with antidepressants. This was congruent with a general belief that the neurotransmitter 'serotonin' played an important role in the development of depression. The fear of relapse and withdrawal symptoms is considered more frightening than the prospect of continuing unnecessary medication, leading to continued use: 'better safe than sorry'.<sup>15</sup> Some patients believe their condition to be chronic and requiring of life-long treatment, while at the same time feeling uncomfortable with this prospect.<sup>15-17</sup> Research on nonadherence to antidepressants (after initial acute phase treatment) has found similar beliefs: harmful beliefs and necessity beliefs are weighed, and this trade-off results in adherence.<sup>18-20</sup> At the time this study was designed, it was unknown whether patients using long-term antidepressants without a current indication for continued use have the same attitudes towards their use.

With this study, we aimed to explore the attitudes of these specific patients, who are using antidepressants long term without a proper current indication, towards the discontinuation of these drugs, and to explore their attitudes towards the discontinuation advice they received when participating in the RCT.<sup>12,13</sup> We were looking for experiences and cognitions of patients towards which counseling to discontinue antidepressant use without indication according to guidelines could be directed.

## Methods

### Design

We performed a qualitative study using in-depth semistructured interviews. The study was exempt from evaluation by the institutional ethics committee, as it was considered an addition to the approved RCT (Institutional Ethics Committee Nijmegen registration number NL29718.091.09). Both the current qualitative study and the RCT were performed in the Netherlands between 2010 and 2014. We reported this study according to the consolidated criteria for reporting qualitative research (COREQ) guidelines.

### Participants

Participants were selected from our cluster-RCT on long-term antidepressant use.<sup>12,13</sup> This RCT included patients who used antidepressants for

9 months or longer, that is, long-term antidepressant users. These patients underwent a psychiatric diagnostic evaluation to determine whether they still had an indication for antidepressant use according to the clinical multidisciplinary guidelines in the Netherlands.<sup>3,4</sup> Patients were excluded from the RCT in case of: current treatment in a psychiatric in- or outpatient clinic; indication for use of long-term antidepressants according to the Dutch guidelines for depressive and anxiety disorders [i.e. a history of recurrent depression ( $\geq 3$  episodes) or a recurrent psychiatric disorder with at least two relapses after antidepressant discontinuation]; history of psychosis, bipolar disorder, or obsessive compulsive disorder; current diagnosis of substance use disorder (including tobacco); nonpsychiatric indication for long-term antidepressant usage, for example, neuropathic pain; hearing impairment or insufficient understanding of the Dutch language.

Patients who had been assigned to the intervention group in the RCT were selected for this qualitative study.<sup>13</sup> Thus, only those patients using antidepressants long term ( $\geq 9$  months) without a current indication for continued usage were included. These patients had received from their GP the recommendation to discontinue their antidepressant use. We had provided the GP with information about the current diagnosis and the method for discontinuing the medication. Patients who did not consent to be contacted for further research after the RCT were not approached for participation in the current interview study (24%,  $n = 17/70$ ). Participants were purposively sampled to ensure diversity in age, sex, the intention to comply with the advice, and actual discontinuation of the antidepressant during the course of the RCT. The GPs played no role in the sampling procedure. Data collection proceeded until saturation was reached. The psychiatric condition of the participants of the current interview study was not assessed again at the start of this study.

### Data gathering and analysis

Individual semistructured interviews were conducted in January and February 2014. According to the preference of all participants, we conducted interviews by telephone. Each interview lasted 15–20 min. RE (physician, trained interviewer) performed the interviews. All interviews were recorded and transcribed verbatim. Thematic analysis was carried out inductively using a qualitative software package (Atlas.ti, version 7.1.5).

Analysis began once data collection commenced as an iterative process, based on the ‘constant comparative method’.<sup>21</sup> Coding was carried out independently by two of the authors (RE, PL), followed by a series of discussions to derive the coding framework. When no consensus could be reached, a third author (AS) was consulted. Exemplary quotations were selected to demonstrate the findings, followed by a short description of the cited participant: gender, age, acceptance or rejection of the discontinuation advice given in the RCT, and actual discontinuation of antidepressant use.

### Results

We interviewed 16 participants; 11 were female (69%), mean age was 57 years with a range of 31–76 (women) and 51–79 (men). Seven participants intended to comply with the discontinuation advice during the RCT; five of these actually discontinued their antidepressant (during or after the RCT). The participants used a great variety of antidepressants before the discontinuation advice in the RCT (Table 1).

Several themes emerged, which we have grouped into barriers, facilitators, and ambivalence towards discontinuing long-term antidepressants (Table 2). After 14 participants, no new codes emerged.

### Barriers

Participants mentioned the following factors that complicated discontinuation of the antidepressant: attributions, fears, and prior attempts.

*Attributions.* Participants described their antidepressant use as supplying an otherwise deficient substance. This substance was perceived as ‘needed’ to function normally as this deficiency caused the depression, resulting in the acceptance of lifelong dependency. The comparison with diabetes was also made.

*‘I just need it. For me this isn’t a psychological illness, it’s physical. And my body isn’t able to make enough serotonin, so I take the pill to supply it.’* (ID 129: female, 66 year, rejected advice and did not discontinue).

*‘She (the GP) told me, you should see it like you have a deficiency in your brain, you miss a certain substance and the medicine supplies it. She told me, it’s just like*

**Table 1.** Characteristics of participants.

| Gender | Age | Intended to comply with discontinuation advice | Actually stopped antidepressant use | Successful discontinuation | Antidepressant before discontinuation advice |
|--------|-----|--|-------------------------------------|----------------------------|--|
| Female | 64  | no   | no                                  | no                         | Clomipramine                                 |
| Female | 43  | yes  | no                                  | no                         | Sertraline                                   |
| Female | 43  | yes  | yes                                 | no                         | Fluvoxamine                                  |
| Female | 31  | no   | no                                  | no                         | Paroxetine                                   |
| Female | 62  | no   | no                                  | no                         | Amitriptyline                                |
| Female | 50  | no   | no                                  | no                         | Fluoxetine                                   |
| Male   | 66  | yes  | yes                                 | no                         | Venlafaxine                                  |
| Male   | 57  | no   | no                                  | no                         | Paroxetine                                   |
| Female | 45  | yes  | yes                                 | no                         | Paroxetine                                   |
| Male   | 79  | yes  | no                                  | no                         | Fluvoxamine                                  |
| Female | 32  | no   | no                                  | no                         | Sertraline                                   |
| Male   | 61  | no   | yes                                 | no                         | Citalopram                                   |
| Male   | 51  | yes  | yes                                 | yes                        | Citalopram                                   |
| Female | 72  | no   | no                                  | no                         | Venlafaxine                                  |
| Female | 76  | no   | no                                  | no                         | Venlafaxine                                  |
| Female | 53  | yes  | no                                  | no                         | Paroxetine                                   |

*someone with diabetes, who needs insulin for the rest of their life. Well, I kind of believe that, so never questioned my use since.’ (ID 302: female, 74 year, rejected advice and did not discontinue).*

Another attribution that played a role was the belief to be suffering from a chronic condition, and thus in need of lifelong medication. Antidepressants were also described as being a natural and bodily substance, thus ‘it surely could do no harm.’

**Fear.** Fear of recurrence or relapse was a great barrier to attempt to discontinue. Participants were afraid of reliving the negative feelings they had in the past, and anticipated this recurrence if they were to discontinue.

*‘That’s my biggest fear. The misery I was in, before I got these medicines. I never want to relive that. I never want*

*to go back to how I felt then. And because of this fear, I just can’t attempt to stop them.’ (ID 129: female, 66 year, rejected advice and did not discontinue).*

*‘. . .if I would remain to feel well, I would quit tomorrow, but . . . to go through the hell I went through again? No.’ (ID 170: female, 64 year, rejected advice and did not discontinue).*

Others described the fear of disturbing the balance or equilibrium they had achieved.

*‘I have found a balance, emotionally, that is. Well, and I don’t want to disturb this balance.’ (ID 262: male, 63 year, rejected advice and did not discontinue).*

*‘Well, I’m feeling very well, I am very stable. I’m in harmony, I don’t have any mood swings or anything. I don’t think I could feel any better than I do now. Also, mentally. So, I won’t risk it. I won’t attempt it, maybe*

**Table 2.** Emerging themes concerning the discontinuation of long-term antidepressant use.

| Barriers                   | Facilitators  | Ambivalence                                 |
|----------------------------|---|---|
| Attributions               | Information   | Trade-off between barriers and facilitators |
| Serotonin deficiency       | Known limited duration of use at first prescription |   |
| Chronic condition          | Professional's opinion use is no longer indicated   |   |
| Antidepressants do no harm |   |   |
| Fear                       | Fear  | Lack of motivation despite no barriers      |
| Recurrence or relapse      | Addiction   |   |
| Disturb the balance        | Stigma  |   |
| Effect on relationships    | Shame   |   |
|                            | Long-term adverse effects                           |   |
| Prior attempts             | Self-confidence in success                          |   |
|                            | Trust in GP (safety net, counsellor)                |   |
|                            | Practical motives (e.g. driver's license)           |   |

*it would be successful, but I won't dare to try.*' (ID 302: female, 74year, rejected advice and did not discontinue).

Another fear was the effect an antidepressant discontinuation would have on their relationship with their partner.

*'I don't really want to take the risk. If I stop with the antidepressant medication, that A the symptoms would come back, but also B there would be more tension in my relationship, and I would keep getting into a fight.'* (ID 262: male, 63year, rejected advice and did not discontinue).

*'She (my wife) really does understand that I would like to try to taper, it's not like she doesn't want me to. But she said please take the pills, because you're so much easier to handle. . . ha-ha. So, I just keep taking them.'* (ID 219: male, 59year, rejected advice and did not discontinue).

**Prior attempts.** Fears and attributions were sometimes fuelled by experiences during prior discontinuation attempts. Because of the difficulty in

tapering and discontinuation symptoms, attributions concerning lifelong need and anticipation fear were reconfirmed. Attempts to discontinue were frequently made without informing, or receiving guidance from, their GP.

*'Yeah, well, then (prior attempt) my tolerance level lowered, and I became agitated. I also had more feelings of loneliness and abandonment, so I didn't feel well at all and didn't know what to do. Yeah, that kept coming back. I started to think, what good is this? Why am I doing this? Why should I stop? Then I restarted the medication.'* (ID 262: male, 63year, rejected advice and did not discontinue).

### Facilitators

Mentioning the limited duration of antidepressant usage at first prescription was found to facilitate the tapering process.

*'So, from the start I knew that we would stop (the antidepressant) as soon as it was possible.'* (ID 186: male, 68year, accepted advice but did not successfully discontinue).

*'My GP made it very clear, it (the antidepressant) is only a temporary solution, it will help, but the problem lies elsewhere.'* (ID 228: female, 47 year, accepted advice but did not successfully discontinue).

The antidepressant discontinuation advice was seen by some as the nudge needed to start tapering their antidepressant.

*'... if you get the advice, that it should be possible, then you start to think, maybe I should try. Because you do want to live without. It gave me the extra nudge that I needed to give it a try. I already questioned my use frequently, like, you think that this tablet works well, but you're not sure, are you? I'm glad I participated in this study, that I got the validation I needed, that I could do without.'* (ID 165: female, 45 year, accepted advice and successfully discontinued).

*'Without the advice, I would just have kept taking the medication.'* (ID 186: male, 68 year, accepted advice but did not successfully discontinue).

The confidence a participant had beforehand in the success of a discontinuation attempt was important. If the participant could be convinced the attempt would be successful, the fear to discontinue would diminish. The GP played an important role in this, both as a 'safety net' and as a 'partner or counselor during the attempt'. Patients need to have trust in their GP to be able to commence a discontinuation attempt.

*'... And that my GP is willing to say, no we won't wait and see, but will take my symptoms seriously. Then I thought, now I can try (to taper), if I have a kind of safety net. I had more confidence in myself, so I gave it a go. It was scary.'* (ID 238: female, 34 year, rejected advice and did not discontinue).

As a motivator to discontinue their antidepressant use, participants mentioned fear of addiction. In addition, they felt it could not be healthy to use antidepressants forever and were worried about long-term adverse effects. Other motivating factors to discontinue were the amount of stigma and shame the participant felt by having to rely on antidepressants. The ability to be able to function on their own without being dependent of antidepressants was also a contributor.

*'I really wanted to be able to do it on my own. To live my life and not stay standing because of medication.'* (ID 239:

female, 34 year, rejected the advice and did not discontinue).

One participant mentioned a practical reason why she wanted to discontinue. She experienced the hassle of the medical examination to extend her driver's license, after declaring to use antidepressant medication.

### Ambivalence

We found a great ambivalence in the use of antidepressants. Some participants described the struggle between barriers and motivators to discontinue, but others did not recognize this struggle when prompted. These participants had no motivation to discontinue, despite the lack of any barriers.

*'Well, you just can keep the medicine as maintenance therapy. But I haven't had any symptoms for a long while, so there isn't really any reason not to try to stop using it, is there? Sometimes I even skip one, just because I don't feel taking it. But I do always call for a repeat prescription. I just haven't done it, stop completely.'* (ID 161: female, 45 year, accepted advice but did not successfully discontinue).

### Discussion

We found barriers and facilitators to discontinue long-term antidepressant use without a proper indication. Fear (of recurrence, relapse, or to disturb the equilibrium) was the most prominent barrier, and prior attempts fuelled these anticipations. These fears have previously been described in the literature for all antidepressant users,<sup>15-17</sup> and our study confirmed that long-term antidepressant users, who, according to the guidelines do not have an indication, and, accordingly, could consider discontinuation, face the same fears. As facilitators for an attempt, participants mentioned a known limited duration of usage at the time of starting the drug and the confidence in a successful attempt, which could be enforced by guidance and reassurance by the GP. Also, participants felt that being able to live without their antidepressants empowered them. Another qualitative study has shown that GPs also face fears in the process of discontinuation.<sup>23</sup>

Another important barrier was the notion that antidepressants are necessary to supply the deficient serotonin. This serotonin deficiency resulted in patients expecting continued use of their

medication. Presumably this is the result of the explanation the GPs gave to their patients at first prescription, or at least what patients (choose to) remember. The biological model for depression seems to backfire,<sup>22</sup> making it difficult to persuade the patient to discontinue the drug. This is an important and new finding. GPs must keep this in mind while explaining the course of treatment for depressive and anxiety disorders. On the other hand, uneasiness with the perception of a biological cause could enhance attempts to stop antidepressants.<sup>23</sup>

In addition, we also found ambivalence towards antidepressant use. With the lack of motivation to discontinue, most participants just kept on using them, even when no barriers were apparent. Malpass and colleagues describe that patients find a balance between pros and cons.<sup>14</sup> In this study, we also found this trade-off. Participants described motivators and facilitators to discontinue, but these were overruled by the barriers they perceived and thus did not actually discontinue. Our results also show that for some, but not all, participants this is a conscious choice. The willingness to discontinue seems to be important. Some participants only needed a little 'nudge', while others plainly refused to discontinue their antidepressant. The importance of willingness to discontinue has also been indicated in long-term benzodiazepine use.<sup>24</sup> Where benzodiazepines are seen as addictive, antidepressants are not. However, some patients do seem psychologically dependant.

*Strengths and limitations.* This paper contributes to a relatively small amount of literature on long-term antidepressant usage. As part of the RCT, the sample was limited to participants of that study: long-term antidepressant users without a current clinical indication for this usage, who had received a recommendation to discontinue their use. By purposive sampling, we were able to provide a good mix of participants reluctant or willing to discontinue long-term antidepressants, in addition to gender and age. This resulted in a study of patients who are usually hard to reach in mental health research but are very relevant to general practice.

Prior to the interview for the qualitative study we did not assess the psychiatric condition of the participants again. During the intervention in the RCT, participants were not depressed, but they could have developed a new depressive episode by the time of the qualitative interview. This

could have influenced the results of the qualitative interview in the sense that they would report more facilitators.

Long-term antidepressant users are a selection of patients prescribed antidepressants, who have already gone through the process of acceptance and adherence to this medication. We can imagine these patients have found a balance between pros and cons, thus resulting in their long-term use. Therefore, the findings in this study cannot be extrapolated to all antidepressant users. In addition, as with all qualitative research, our findings may not be exhaustive.

*Recommendations for clinical practice.* At first prescription, GPs should realize that, by explaining the effects of antidepressants as a supplement for a deficiency in serotonin, patients could perceive antidepressants as a lifelong necessity. Discussing an anticipated duration of antidepressant usage at first prescription could facilitate a discontinuation attempt in the future. Before recommending the discontinuation of long-term antidepressant use without indication, an exploration of existing fears and expectations is constructive. Previous attempts to taper could have taken place without the knowledge of the GP, and without any guidance or counseling, possibly resulting in anticipation fear. Because patients and GPs have different expectations concerning the initiative for discontinuation and the time for support necessary during/after discontinuation, it is important to discuss these issues, both at the start of treatment and at the start of discontinuation.<sup>23</sup> Cognitive therapy could possibly be used as a supportive therapy before the start of the tapering process when fear is apparent; one study of patients with anxiety disorders showed that cognitive behavioral therapy (CBT) beginning at the start of discontinuation did not prevent relapse.<sup>25</sup> Stopping antidepressant use is difficult, and many patients experience a relapse.<sup>25,26</sup> Thus, the patient's fear might be totally justified in the light of problems experienced during prior attempts. A further issue in discontinuing antidepressants is the tapering scheme itself. Many tapering schemes advocate a duration between 2 and 4 weeks with linear reduction of the dose. Because many patients experience withdrawal symptoms several weeks after the discontinuation, which might be understood by the specific relation between the dose of the selective serotonin reuptake inhibitor (SSRI) and the level of serotonin transporters in the brain, a hyperbolic taper

scheme makes more sense than a linear scheme. In a hyperbolic scheme, the taper period is much longer while the dose reductions in the final weeks are very small.<sup>27</sup>

### Conclusion

Discontinuing long-term antidepressant usage without a current indication is difficult. Fear plays an important role. The serotonin deficiency as explanation for antidepressant effectiveness promotes life-long use and hinders discontinuation of antidepressant treatment. The prospect of discontinuation at first prescription can facilitate a future discontinuation attempt. GPs should be aware of patients' fears, expectations, and attributions towards antidepressant use/discontinuation when discussing antidepressant discontinuation. GPs also should be aware of new developments in tapering methods.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The whole study (RCT, cost effectiveness study and the current qualitative study) was funded by ZonMW (a governmental organisation for grants for studies in the medical field), (Grant number 170992906).

### Conflict of interest statement

The authors declare that there is no conflict of interest.

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