A qualitative study of patient views on discontinuing long-term selective serotonin reuptake inhibitors

Geraldine M Leydon, Lynne Rodgers and Tony Kendrick


Background. There is concern that patients may be remaining on selective serotonin reuptake inhibitors (SSRIs) longer than is clinically indicated. Previous research has explored patients’ experiences of taking SSRIs and decisions about starting medication. There has been less research into patients’ reasons for long-term use and their views and experiences of discontinuation.

Aim. To explore patient experiences of and beliefs about their long-standing SSRI use and understand the barriers and facilitators to discontinuation.

Design. Face-to-face semi-structured qualitative interview study.

Setting. One group general practice in Southampton, UK.

Findings. Three overarching themes were identified: (i) patient uncertainty about the benefits of, and continued need for, SSRI medication; (ii) barriers to stopping, including fear of withdrawal symptoms and fear of relapse; and (iii) the importance of the GP’s role in facilitating cessation. Uncertainty and fear about withdrawal symptoms and what patients would be like without their medication were key barriers to stopping, even among patients who felt no discernible benefit from taking SSRIs. Patients indicated a need to share the decision to stop with their GP. However, the majority of patients interviewed had received repeat prescriptions of SSRIs without being reviewed by the GP.

Conclusions. Patients prescribed SSRI medication need to be reassured that, as with starting medication, thinking about or actually stopping medication is a task that will not be managed in isolation, but with the support of their GP.

Keywords. Antidepressants, depression, discontinuation, patient management.

Background

More than 80% of patients with depression in the UK are managed in primary care.1 Antidepressant drugs are the mainstay of treatment in moderate and severe depression. They are as effective as psychological therapies, cheaper and more readily available.1

In the 5 years up to June 2005, prescriptions for antidepressants rose by 36% to around 30 million items per year, and the cost increased by 20% to around £380 million per year. The increase in prescriptions of selective serotonin reuptake inhibitors (SSRIs), by 45%, has been the major factor in this, while other antidepressants remained unchanged.2

There is increasing anecdotal concern that some patients may continue SSRI use for longer than is indicated and encounter problems when trying to discontinue.3 Although not defined as drugs of dependence, the occurrence of symptoms on discontinuing SSRIs is a well-recognized phenomenon. Commonly reported symptoms include dizziness, light-headedness, insomnia, fatigue, anxiety/agitation, nausea, headache and sensory disturbance,4 although the exact incidence of these is unclear. Gradual tapering of the dose over a month when stopping medication is recommended to minimize discontinuation symptoms.1

Current National Institute for Clinical Excellence (NICE) guidelines recommend a continuation phase of 6-month treatment after remission to reduce the risk of early relapse. Maintenance treatment for 2 years or more is indicated for those with two or more previous episodes.1 Current practice is to
continue treatment if symptoms are unresolved. As yet there is no clear evidence regarding the optimum length of treatment.\textsuperscript{5}

A small number of qualitative studies have explored patients’ experiences with SSRIs or other antidepressants. Maxwell\textsuperscript{6} focused on decisions to start antidepressants, finding that women needed support from their GP to justify use of this medication, which they viewed negatively. Knudsen \textit{et al.}\textsuperscript{7} explored how SSRIs affected users’ ‘sense of self’ throughout the course of medication use. They found that patients did not wish to rely on SSRIs long term but worried about relapse with discontinuation. Grime and Pollock\textsuperscript{8} reported that short-term use was seen as socially acceptable but long-term use brought fears of psychological dependency. While the small literature in this area provides valuable information, research evidence on long-term users’ beliefs about and experiences of discontinuation is limited.

### Methods

Patients were recruited from one group practice within Southampton City Primary Care Trust (PCT). In the quarter year immediately before the study took place, the practice prescribing rate for SSRIs was below the average for the PCT, but above the national average (see Table 1). All participants receiving prescriptions for an SSRI for 12 months or more were identified from computer records by a clerical member of the practice staff. Only those patients deemed well enough by their GP were contacted by a letter from their GP about the study. Patients opted in by replying direct to LR via a reply slip. Prior to interview, participants gave fully informed, written consent. LR conducted the semi-structured qualitative interviews. Interviews lasted for an average of 1 hour.

Participants were invited to tell their ‘story’ of SSRI use and in this way many of the issues of interest were raised spontaneously by patients. The topic guide ensured that all areas of interest were covered in each interview. Interviews were audiotaped and transcribed verbatim.

Thematic analysis was carried out both by hand and with the use of a word processor, allowing close scrutiny of and familiarization with transcripts. Analysis began once data collection commenced and followed an iterative process derived from the ‘constant comparative method’.\textsuperscript{9} Independent coding of a sample of transcripts was carried out by two of the authors (LR and GML). This was followed by a series of ‘data sessions’ between all authors to derive a consensus-coding framework. Exemplary quotations were selected to demonstrate key findings.

The study was approved by the Local Research Ethics Committee for Southampton and South West Hampshire (reference: 05/Q1704/136).

### Results

In total, 87 patients were identified and 85 were sent a letter of invitation by their GP. The other two patients were deemed to be too unwell to participate by their GPs. Seventeen individuals agreed to be interviewed (20%). They included 7 men and 10 women, aged between 28 and 64 years. Eight had seen a psychiatrist about their depression at some stage, and three of these continued to see one regularly. Seven described this as their first and only episode of depression. Of the rest, six talked in terms of previous distinct episodes, while four described their depression as ‘ongoing’ or ‘long term’. The length of time of taking their current SSRI ranged from 1 to 11 years, average 4 years.

In their narratives, patients traced the journey of their depression from pre-diagnostic moments through diagnosis and treatment. Many spoke of their initial reluctance to start antidepressant treatment, despite realizing they were having problems. In brief, reasons for reluctance varied. Some described themselves as not being the sort to take medication. Most had initial concerns about the stigma often associated with antidepressant medication. Negative media reports of adverse effects (including increased suicide, relating to Prozac) and addiction also fuelled patients’ reluctance to commence SSRI medication. The GP role as a trusted advisor was described as pivotal in helping patients to overcome such reluctance and validating patient decisions to start medication.

As discussed, patient experiences of starting SSRIs have been described elsewhere.\textsuperscript{6} Thus, this paper focuses on patient views and experiences of long-term SSRI use and discontinuation. Overall, three key themes were identified: (i) patient uncertainty about the benefits of, and continued need for, SSRI medication; (ii) barriers to discontinuation; and (iii) the importance of the GP’s role in facilitating cessation.

---

**Table 1** SSRI prescribing rates for the practice and PCT, compared to the national rate for the quarter immediately before the study took place (July–September 2005)

<table>
<thead>
<tr>
<th></th>
<th>Average daily quantity usage for the Specific Therapeutic Area Prescribing Unit for all SSRIs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study practice</td>
<td>1995.36</td>
</tr>
<tr>
<td>Average for practices within</td>
<td>2150.15</td>
</tr>
<tr>
<td>Southampton City PCT</td>
<td></td>
</tr>
<tr>
<td>Average for all practices in England</td>
<td>1529.69</td>
</tr>
</tbody>
</table>

Source: Prescribing Analysis and Cost data from the Prescription Pricing Authority. Per denominator figures are multiplied by 1000 for this denominator, based on top 100 records.
Patient uncertainty about the benefits of, and continued need for, SSRIs

A striking theme throughout the data was patient uncertainty about whether taking SSRI medication had led to an improvement in health.

I can’t categorically say yes I feel better with them, you know, I mean, I’ve been taking now for, I suppose, a couple of years, so um, sometimes ... you think, well, are they doing you good or is it ... I don’t know. (Participant 5: 57-year-old male)

Some interviewees seemed unsure about the degree of improvement one might reasonably expect. For example, one participant was certain of some functional improvements, “I think it allowed me to continue my life. I think that’s what it did”, but the degree of improvement did not equate with a real sense of happiness.

I definitely wouldn’t have said it ever made me feel bright, breezy and happy. It never gave me that feeling but I think it just allowed me to tick over. (Participant 11: 48-year-old female)

Most who had experienced an improved mood were unsure whether improvements should be attributed to the ‘placebo effect’ (Participant 5), ‘psychological therapies’ (Participant 3), ‘changing life circumstances’ (Participant 11) or simply the ‘passage of time’ (Participant 15). Uncertainty about whether SSRI medication continued to sustain such improvements also led some to question their continued need for medication.

Sometimes I wonder if I actually need them anymore because I feel OK. (Participant 8: 50-year-old female)

For another participant, uncertainty about continued need also stemmed from their stable health despite deciding to cut their dose.

I must admit I’m not sure now whether it’s a necessity or whether it’s psychological, but, er, I only take half the original prescribed dose, er, and I only take that about every other day. (Participant 16: 64-year-old male)

In contrast to the majority who displayed uncertainty about whether they had improved, improved enough or whether SSRIs had been the cause of their improvements, five participants were certain that they had not benefited. When asked why they continued to take their medication despite the lack of perceived benefit, one oriented to a ‘hope’ that she might benefit in the future.

LR: What is it that ... makes you want to keep taking it?

P: To see if I feel any better.

LR: Do you think you might, in time?

P: Well, I don’t know. After a year I would have thought that I, you know ... they should be fully in my system now and they should be doing something. (Participant 2: 60-year-old female)

Fear of what might be, in contrast to hope, featured as a major reason for continuing medication for the others who had perceived little or no benefit.

Barriers to discontinuation

Just one interviewee described feeling comfortable with the prospect of indefinite use. Indeed, embedded in most of the patients’ narratives was a (moral) burden of responsibility to review their need for SSRI medication and to be able to ‘cope without pills’ once more. Three had already discontinued by the time of interview. However, wishes to discontinue were frequently thwarted by two factors: (i) unknown and uncertain consequences of stopping; and (ii) symptoms associated with discontinuation.

Unknown and uncertain consequences of stopping. Nine interviewees expressed concern that stopping the medication could precipitate a relapse of depression. Indeed, when discussing discontinuation a fear that stopping might leave them back in the initial distressing phase of depression was a recurrent theme.

I’m frightened that I’ll go down again ... and I don’t want to go down like that, because I really was low, very, very low, um ... yeah. I just don’t ever want to go there again. (Participant 9: 58-year-old female)

In addition to the anticipated problems described above, actual problems encountered during past attempts to stop instilled trepidation about future attempts to stop.

Discontinuation symptoms. Those who had not tried spoke in stoic terms, describing discontinuation symptoms simply as an inconvenience to be tackled by tapering the dose more gradually. This was not so for those who had experienced quite severe problems
associated with discontinuation. Eleven of the participants who had tried stopping reported bad experiences. One participant reported a relapse experience so bad that he regretted ever trying.

I have tried to stop, I did foolishly, foolishly try to stop and I just stopped taking them. That was a mistake, big mistake. I didn’t turn into a blubbering mess straight away, it was about four or five days afterwards. (Participant 15: 48-year-old male)

Experiences of withdrawal led one participant to restart their medication after 1 week. When asked “how long did you stop for?” she replied:

A week. Not because ... of the moods ... this wasn’t a moods situation. It was my body ... was reacting, not how I expected it to react. It had the shakes ... um ... bit like a junkie. (Participant 13: 43-year-old female).

In terms of severity, another described how it was difficult to say which was worse, the experience of withdrawal or the initial depressive symptoms.

In the end I didn’t know what was worse, um, having the ... withdrawal effects from it or having the, um ... depression side of it. (Participant 3: 37-year-old female)

Therefore, problems of withdrawal on a previous occasion could become a conscious key driver for continuing to take medication and could forestall attempts to discontinue.

LR: Is there anything else that ... makes you keep taking the drugs?

P: ... the major factor is the side effects of coming off them .... I don’t think I take them to sustain my mood but purely just to stop the side effects. I’ll maybe be just have to grin and bear it. (Participant 4: 28-year-old female)

Patient reports highlighted the importance of GP contact to help manage the stopping process and minimize patient trauma during their attempts to stop.

The importance of the GP’s role in facilitating cessation

As with decisions to start antidepressants, GPs were seen as playing an important role in helping patients to reach a decision to stop. Those who described themselves as ‘well monitored’ referred to the benefit of sharing decisions about treatment.

I was monitored very closely by my doctor. I saw her ... every week, and then every two weeks and then throughout the whole time ... to chat with her to see how I felt really. So between the two of us we could decide ... if it was right (to stop) or not right really. (Participant 1: 47-year-old female)

One man spoke explicitly about their fears of the consequences of stopping without the support of an expert.

The reason why I don’t do it off my own back is pure fear. (Participant 16: 64-year-old male)

And, one of the longest users of SSRIs (and the most severely depressed of the interviewees) described wanting to try discontinuing but reported feeling that there had been a lack of opportunities to discuss doing so.

I don’t know if they’re any good to me anymore but they’re certainly not letting me come off them. And I want to come off them and no-one will help me, and I don’t know what the effects will be if I come off them myself cause nobody will tell me. (Participant 13: 43-year-old female)

Seven of the 17 participants reported receiving advice on tapering their dose to minimize discontinuation symptoms. One participant reported that she gained a sense of security because her GP had informed her that she could always return to a higher dose if tapering her dose proved too difficult. In this way, she was merely ‘testing the waters’, rather than making an irreversible decision.

I didn’t have to worry because I didn’t have to feel bad because I could just up the tablets slightly so I had that, which was a bit of a cushion I suppose. (Participant 7: 41-year-old female)

Overall, 14 of the 17 participants had received their SSRI on a repeat prescription (without being reviewed by the GP). A few said that they had seen their GP once or twice a year while taking their SSRI. Two interviewees mentioned that GP visits occurred only on receipt of a review date at the bottom of their repeat prescription.

LR: How often would you see your GP about it?

P: I haven’t seen him for ... my review date is ... was last November, so I, I, they keep lining up, I must make an appointment to go and see him so that is down to me ... They keep signing the form so I keep on doing it. (Participant 6: 39-year-old male)

Discussion

Initial attitudes towards SSRIs revealed a sense of conflict regarding decisions to start the medication.
GPs played an important role in resolving patient dilemmas about starting SSRIs, by providing reassurance and support. This correlates with findings from related studies discussed above.

Several factors influenced patient decisions about long-term use. Of great importance was the uncertainty that surrounded the benefit of taking an SSRI. Or, where improvement had occurred participants were unsure whether continued use was necessary. Continuing despite a perceived lack of benefit and fearing the consequences of stopping has been noted elsewhere.

Discontinuation symptoms (whether experienced or anticipated) and a fear of relapse were identified by patients as strong barriers to discontinuation. These were relevant regardless of prior experience of stopping. Anxieties about stopping affected even some who reported no tangible benefit from SSRIs. Verbeek-Heida and Mathot in their qualitative study of the views of 16 SSRI users in the Netherlands noted a similar rationale for continuing. The risks of discontinuation were more immediately feared than continuing long term, described as, ‘better safe than sorry’.

Interviewee accounts clearly highlighted that GP involvement is crucial. In the absence of explicit discussion, patients may conclude that continued use is recommended. Moreover, fear and uncertainty meant most patients were reticent to initiate discussions about discontinuing with their GP. As Pollock and Grime suggest, ‘Whether and when to seek medical advice are judgements that are particularly difficult for people experiencing psychological distress’.

Attempts to discontinue without seeking medical advice led some to experience potentially avoidable discontinuation symptoms. Van Geffen et al.’s survey of 66 patients in the Netherlands also found that individuals deciding to discontinue their SSRI unsupervised often did so abruptly, which led to needless withdrawal effects.

In the Introduction, it was noted that there is increasing anecdotal concern that some patients may continue SSRI use for longer than is indicated and encounter problems when trying to discontinue. This small interview study provides evidence that this may be the case with some patients.

Strengths and limitations
Little previous research has tackled the issue of discontinuing SSRI medication from the patient perspective. This paper contributes novel information to a relatively unexplored area. The sample was limited to one group practice, but encompassed a good age and gender mix. The practice was above the national average for prescribing of SSRIs, but anecdotal evidence suggests it is not unusual in allowing repeat prescriptions to be issued without seeing the patient.

No information on non-responders was available and hence it is not possible to assess the representativeness of the responders. GP invitations to participate may select participants who are more influenced by their GP and more likely to report a need for GP involvement in decisions to stop. However, research highlights the importance of GP contact when deciding to start treatment and it is likely that the same holds true when deciding to stop.

Interview data can only provide accounts rather than direct evidence of the issues discussed and it is possible that some interviewees reported wanting to stop medication for reasons of social acceptability. However, interviews were analysed with sensitivity to this discourse.

Limitations aside, these findings highlight the fear and uncertainty experienced by some long-term users and suggests some implications for the GP management of long-term users.

Implications for practice
Patients want regular review. They need GPs to initiate discussion about the possibilities of stopping (when appropriate) throughout the course of their SSRI use. Relying on patients to seek a consultation when they feel it is necessary is not appropriate for patients who may not have the energy or motivation to consult. GPs need also to be aware that the use of repeat prescriptions in this group may have an alienating effect, leaving patients unsupported and dissuaded from stopping or with no advice on minimizing the effects of withdrawal. Stopping SSRIs, like starting, can be a momentous occasion for patients and a difficult and uncertain transition. Patients’ accounts indicate that proactive GP support is vital to this process.

Acknowledgements
We thank the GPs, practice staff and patients who participated in the study.

Contributors: LR undertook data collection. The qualitative analysis was planned and carried out by LR, GML and TK. All authors wrote the paper and approved the final version.

Guarantor: GML

Declaration
Funding: School of Medicine Year 4 Study in Depth Programme, University of Southampton.

Ethical approval: The study received ethics approval from the Local Research Ethics Committee.

Conflicts of interest: TK has received fees for speaking at educational events and/or funds for research from Lilly, Lundbeck, Pfizer, Servier and Wyeth pharmaceuticals.
References

11 Verbeek-Heida PM, Mathot EF. Better safe than sorry—why patients prefer to stop using selective serotonin reuptake inhibitor (SSRI) antidepressants but are afraid to do so: results of a qualitative study. Chronic Illn 2006; 2: 133–142.