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## A qualitative exploration of family members' perspectives on reducing and discontinuing antipsychotic medication

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### ABSTRACT

**Background:** Antipsychotics are routinely prescribed to people diagnosed with schizophrenia or psychosis on a long-term basis. Considerable literature explores service users' opinions and experiences of antipsychotics, but studies investigating family members' views are lacking.

**Aims:** To explore family members' perspectives on antipsychotics, particularly their views on long-term use, reduction and discontinuation of antipsychotics.

**Methods:** Semi-structured interviews were conducted with 11 family members of people experiencing psychosis. Participants were recruited through community support groups and mental health teams. Interviews were analysed thematically.

**Results:** The majority of family members valued antipsychotic medication primarily in supporting what they saw as a fragile stability in the person they cared for. Their views of medication were ambivalent, combining concerns about adverse effects with a belief in the importance of medication due to fears of relapse. They described a need for constant vigilance in relation to medication to ensure it was taken consistently, and often found changes, particularly reduction in medication difficult to contemplate.

**Conclusions:** Findings highlight that family members' attitudes to medication sometimes conflict with those of the people they care for, impacting on their health and the caring relationship. Family members may need more support and could be usefully involved in medication decision-making.

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## Introduction

Psychotic disorders, including schizophrenia, are potentially severe conditions with an incidence of 31.7 per 100,000 person-years (Kirkbride et al., 2012). For some, these are long-term conditions, although at 20-year follow-up, around a third of people with psychotic illnesses are likely to be fully recovered, and two thirds showed a significant reduction in symptoms (O'Keeffe et al., 2019). Drugs, commonly referred to as antipsychotics are recommended as the foremost treatment option both acutely and on a long-term basis (NICE, 2014). Compared to placebo, they are effective in reducing acute symptoms and can prevent relapse, though this is not true for all (Leucht et al., 2012; Smith, Leucht & Davis, 2019).

Qualitative studies have demonstrated that whilst many users value antipsychotics for symptom management and relapse prevention, some find side-effects such as weight gain, physical pain, lethargy, mental clouding and demotivation difficult to tolerate (Gray & Deane, 2016; Morant

et al., 2018; Thompson et al., 2020). Therefore some researchers have long advocated a more cautious approach to the long-term use of antipsychotics (Rappaport, Hopkins, Hall, Belleza & Silverman, 1978; Chouinard & Jones, 1980; Morrison et al., 2012; Murray et al., 2016).

Family members play a pivotal role for many people, including those with psychosis and schizophrenia. They may provide caring roles including practical help, emotional support, and support with pharmacological and psychological interventions. Estimates indicate that family members of people with schizophrenia save the UK public £1.25 billion per annum (Onwumere et al., 2016). The stress of this role and increased rates of depression, burnout, insomnia and physical illness amongst family members is widely reported (Smith et al., 2014; Gupta et al., 2015; Onwumere et al., 2016; Smith et al., 2019). Relapse places substantial strain on family members who often have little support themselves (Gutiérrez-Maldonado et al., 2005). In addition, service users identify maintaining family relationships as a significant reason for adhering to their medication (Wade et al.,

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2017). A survey found that family members' attitudes towards medication, as described by participants, play a stronger role in predicting medication adherence than the attitudes of the service user themselves (Deane et al., 2018).

Family members play a crucial role in encouraging people to take medication as prescribed, fostering commitment to psychological therapies as well as supporting safe medication withdrawal for some (Landolt et al., 2016). Therefore, family members often seek medication-specific advice and support (Wallace, 1994). Despite this there is a paucity of research into their views and experiences of the use of antipsychotics (Morrison & Stomski, 2017), despite the increasing body of research exploring service users' views, including on reducing or discontinuing antipsychotic medication (Geyt et al., 2016; Larsen-Barr et al., 2018).

### Aim

The current study is a qualitative investigation of the experiences and perspectives of family members who provide care for people with psychosis and schizophrenia about antipsychotic medication, focusing particularly on views about long-term use, reduction and discontinuation.

## Materials and methods

### Procedure and topic guide

A semi-structured interview topic guide was adapted from a focus group guide designed for mental health professionals that was developed in collaboration with service users and family members (Cooper et al., 2019). Interviews were piloted with mental health researchers, including a researcher who is a family member of someone with psychosis. Interviews began with broad questions about long-term use of antipsychotics and later focused on opinions about and experiences of loved ones reducing or discontinuing medication. A flexible interviewing style with probing of responses allowed family members to raise issues they considered relevant. Prior to the interview, written informed consent was obtained and capacity assessed. Interviews lasted between 45–60 minutes and were audio-recorded with permission. Participants were reimbursed £10 to cover their travel and time. Audio recordings were transcribed verbatim and anonymized. Ethical approval was obtained from the London-Brent Research Ethics Committee (ref:16/LO/1507).

### Research team and reflexivity

Interviews were conducted by AL, JAR and JS. Authors were part of a research team working on an ongoing randomized trial of antipsychotic reduction in the UK (RADAR; Moncrieff et al., 2019). The first author was independent of the trial, and participants, and their loved ones were not involved in the trial. A reflexive stance was adopted regarding how these positioning may shape the research process, with team discussions about this throughout the design, analysis and write-up phases.

**Table 1.** Demographic characteristics of the sample.

	N (%)
Gender	
Female	8
Male	3
Gender of Service User	
Female	2
Male	7
Employment	
Retired	8
Part Time Employment	1
Unemployed	2
Ethnicity	
White British	10
British Indian	1
Current method of antipsychotic delivery	
Depot Injection	5
Oral tablets	6
Diagnosis of the person they care for	
Paranoid Schizophrenia	8
Schizoaffective Disorder	1
Acute Schizophrenia and Drug-Induced Psychosis	1
Schizophrenia with Catatonic Features	1
Relation to the person they care for	
Parent	10
Spouse/Partner	1
Living with the service user	
Yes	7
No	4
Number of years caring for service user	
<5 years	1
>5 years	10

### Setting

Data were collected in London. Interviews were conducted at health service premises or in participants' homes, depending on their preference.

### Participants

Participants were identified and recruited through a local carer support group and from the clinical caseloads of community mental health services. Participants either volunteered themselves after support group meetings, or were approached by their usual clinician. Eligible participants were: (a) aged 18 or over; (b) a parent, relative or friend who identifies with the term 'carer' of someone with an ICD-10 diagnosis of: schizophrenia, schizoaffective disorder, delusional disorder or another non-affective psychosis who is currently taking antipsychotic medication.

### Data analysis

Data were analysed using thematic analysis, with the aim to identify common themes in the family members' experiences and opinions, as well as variations and patterns of themes across the data set. The six phases of thematic analysis described by Braun and Clarke (2006) were used as guidance. Themes were identified and then clustered into broader and more abstract over-arching themes, using qualitative analysis software (NVivo 11, 2015). A primarily inductive approach was adopted. The initial analysis was conducted by AL. Other members of the team reviewed sub-samples of data to inform the development of an initial coding frame. All authors participated in discussions about developing higher-order themes throughout analysis.

## Results

### Context and overview

Participants included ten parents and one spouse. Two sets of husbands and wives were included (interviewed separately), thus interviews related to nine service users (7 male service users, 2 female). All were long-term carers of people who had used mental health services for 5 years or more, with the exception of one parent of a 25-year old man (P09). Family members had a high degree of involvement in the lives of the people they cared for, the majority of whom had long, complex mental health backgrounds with histories of numerous episodes. Five service users received antipsychotic medication by long-acting ‘depot’ injections. Many also had complex physical health needs (Table 1).

Overall, participants’ perspectives on antipsychotic medication fell on a broad spectrum. In general, P09 disliked antipsychotic medication and wished her son could discontinue immediately. At the other end of the spectrum, P11 believed the benefits of the medication far outweighed any negative effects. The remaining nine participants acknowledged both positive and negative effects of antipsychotics, with many describing a journey over the course of their relative’s condition in which they grew to view medication as the only available option. Table 2 summarises the themes and sub-themes identified in our analysis that are elaborated in detail below.

### Fragile stability

With the exception of one respondent, family members’ opinions about long-term antipsychotic medication were dominated by a pervasive fear of relapse. Periods of stability were described by family members as precious but fragile. They expressed fear and uncertainty at the prospect of disturbing this fragile stability by reducing or discontinuing medication. Many family members described feeling exhausted by their caring role, which ran alongside other responsibilities in their lives, and viewing medication as a tangible tool that could increase stability and prevent relapses and the consequent chaos this caused.

*I know they think that some people can come off the medication. But with clozapine... It’s a dangerous one to mess around with. My opinion is: once you’ve stabilised something, you can’t play about with it - that’s it. From my experience with changing the medication, it can go very wrong - P11*

Many respondents described past experiences in which the person they cared for had altered their medication in an unsupervised way, resulting in relapse. The traumatic consequences of relapses, including hospitalization, service user-initiated violence and family incidents were described at numerous points throughout the interviews, often unprompted, indicating how significant these memories were for participants:

*[son’s name] was violent just before, umm... he pinned myself and my partner in the kitchen. And he got very aggressive... So that would really scare me if [son’s name] returned to that state. - P08*

Several respondents described a long journey through many difficult situations and phases to a state of relative stability. This had often involved the use of various antipsychotics in different doses and forms over many years. When asked about support provided during reduction or withdrawal attempts some spoke highly of support from psychiatrists and/or care coordinators who helped with medication changes. Several more respondents, however, felt they didn’t have any other supports or that any support they did receive was quickly taken away. Overall family members described feeling exhausted by this journey of “experimentation” to find an antipsychotic regime for their loved ones that controlled symptoms without inducing intolerable adverse effects, and some were still engaged in this process:

*This has all taken place over 30 years. When she was on the tablets first of all, the pills, it knocked her out and she got very fat: put on stones and stones, and then when she went on the injections, that didn’t make her put on weight but she was still the same [experiencing psychosis]. And now the new psychiatrist that we’ve got, he started giving her different pills to counteract the side effects.... It all takes time, with this medication, and we’re having to watch her all that time. - P03*

Overall, participants’ concerns to maintain a degree of stability resulted in the vast majority expressing cautiousness around medication changes, particularly reductions or discontinuation. Many indicated that they would rather not “rock the boat” after years of trial and error with medication, reflecting the severity of their relative’s condition and the fragile nature of their recovery. When asked how they would feel about their child reducing medication, one parent responded:

*She’s been on it for so long. She’d have to come off it very, very, very slow. It would be worrying the life out of me. - P01*

One participant (P09) who cared for the youngest service user in the sample, did not share this view. She was concerned that taking antipsychotics stifled her son’s true self and potential and would reduce the likelihood of him leading a fulfilling life in the future. She described his academic excellence and autonomy before experiencing psychosis and emphasised her desire for him to return to that version of himself, which she felt his medication impeded. She explicitly stated that she no longer feared relapse and that, in her view, one or two relapses would be preferable to lifelong dependency on medication. She expressed an active interest in the possibility that he might be supported to reduce and eventually discontinue his antipsychotics, because the adverse effects were too devastating to justify continuation.

*He put on a lot of weight; he used to shiver; he couldn’t stand or sit properly; there was inflammation in his liver; and he became diabetic [...]. By giving him that high dosage originally, he’s lost his sense of being... It’s like the medicine controls his life. And he’s very young, he has a long way to go still. - P09*

### Ambivalence

A second overall feature of interview narratives was that family members felt deeply ambivalent about antipsychotic medication. Although most believed medication was

**Table 2.** Thematic Analysis.

Main Themes	Sub-Themes
Fragile Stability	Trauma of relapse Fear of altering medication Length of time on medication Fear of the unknown
Ambivalence	No alternative Good therapeutic effect Negative side effects Losing and gaining a part of the person they loved
Constant Vigilance vs Autonomy	Constant worry Practical issues with giving medication Coercing service user to take medication Responsibility for the distribution of medication Distrust that service user will take medication Perceiving the depot injection as a “safe guarantee”

effective and necessary to prevent relapse and associated problems, they were also concerned about adverse effects of medication. A tension was apparent between valuing the stabilising properties of medication, and anxiety about the harm it might be doing.

*[My son often says] ‘I wish I could get rid of the weight’. I just say, well [son’s name] it’s doing one thing good, it’s helping stabilise things, and helps you to lead quite a normal life. – P06*

Medication was valued for its ability to help manage the symptoms of an acute episode, restoring the individual to their former self.

*When he takes the meds, he’s back ... he comes back. “Mum give me a hug”, all those things. It’s kind of shocking to begin with, it’s very difficult to deal with. Because he goes away and this person comes back every time. – P02*

On the other hand, much time during the same interviews was spent discussing the adverse effects of medication that clearly troubled participants. A range of effects were discussed, including weight gain, movement problems, decreased motivation, cognitive effects, personality changes and suicidality. Although a minority of participants felt medication could restore their loved one’s personality by effectively managing symptoms of psychosis, the majority thought it changed or stifled their personality. General lethargy and sedation were the most frequently mentioned negative effects, with service users described as passive, child-like or dependent.

*He was just like a zombie – sitting in the chair dribbling and dribbling. It wasn’t a quality of life. And I thought, oh I wonder if he’ll always be like this – P06*

For ten participants, these themes of both the benefits and costs of antipsychotics ran alongside each other, resulting in an overriding sense of ambivalence. Family members’ concerns about the burden of adverse effects and consequent impairment on life quality made many participants particularly upset as they perceived no viable alternatives to medication. Overall, participants seemed to reach a resigned conclusion that medication represented the only tangible hope for stability, and therefore adverse effects had to remain an unpleasant part of service users’ lives.

*But what else is there? There’s nothing else for him to take. Umm ... So he’s got to stay on it really. There is no alternative. So I’m not happy about it, but that’s all there is. – P04*

P09 expressed a different view that the harms outweighed the benefits of long-term medication, and felt that stopping medication was the only chance her son had to recover and live a fulfilling life.

*The medication has weakened him mentally and physically. He’s living in his own world now – like a bubble. So basically he’s just like a small child. So what do small children do? Eat drink, sleep, watch TV. That’s it. – P09*

### **Constant vigilance versus autonomy**

Many of our participants described feeling considerable responsibility for ensuring medication was adhered to consistently, and for monitoring service users’ reactions to medication. Participants described constantly looking out for early signs of mental health relapse and they highlighted constantly worrying that their relative might discontinue medication privately and abruptly. This led some family members to keep possession of the medication themselves, or to closely monitor or supervise medicine-taking. For most of the parent participants, this sense of both responsibility and the need to maintain detailed involvement provided a sense of control, but also represented a regression in the relationship dynamic, that at times resembled caring for a younger child. It also led parents to worry about what would happen to their child when they passed away. This view was similarly shared by the participant who was a spouse, who describes worrying about who will care for his wife once he dies and explains the change in their relationship dynamic from romantic to “reciprocal caring”:

*I have trouble getting her to take them sometimes ... So I keep reminding her that the doctor said she’s got to do it. I have to say to her “come on, take them”. And what I’ve got her to do, is I get her to remind me to take mine. She’s my carer as much as I am hers- P05*

*Sometimes [son’s name] will say “oh I’ll take it later”. But I’ll keep on at him. It’s really important to me that he takes it and that he has the quality of life – the best quality of life that he can have, and I think that’s what medication gives him. – P04*

*We keep a good eye on him – but I can’t do much for him now, cause I’m getting old and I’ve got this condition. But it’s just the future ... who’s going to look after him? – P11*

There was a strong sense that many participants wished the person they cared for could be more autonomous, in



terms of both medication and independent living. However, this was often mentioned in passing, and was generally given less weight than more pervasive concerns about ensuring regular medicine-taking.

*I haven't got round to letting him do it himself on his own. I've not felt confident enough yet. I'm worried he'll not do them and end up not taking them. So I'm not ready yet to leave them alone. – P07*

The day-to-day responsibility family members felt for this, alongside their fears about relapse, meant that participants found it difficult to contemplate questions about the possibility of reducing or discontinuing antipsychotic medication. This sense of responsibility was such a central focus of their relationship with their relative, and indeed of their lives generally, that for most, it appeared to trump concerns about the negative effects of medication or lack of autonomy. When participants were asked how they would feel if their relative wanted to reduce their medication, many responded with fear or apprehension, or seemed unable to seriously contemplate this. Some were wary because they anticipated the need for even more intensive monitoring.

*I'd be frightened to change it. Because it might become less effective as time goes on... But to reduce it would just be... just be a car crash – P02*

*If she's more on a level, I won't change it because I don't want to muck it about, you know what I mean? I don't know, it's just... You just got to watch 'em all the time, when you bring it down or whatever. Cause you don't know how they're gunna react. – P01*

## Discussion

This study is the first qualitative investigation into family members' perspectives on antipsychotic medication, with a particular focus on attitudes towards reducing or stopping such medication. Family members welcomed what they perceived as the ability of antipsychotics to reduce relapse risks and help maintain a fragile and precious stability but expressed concerns about pervasive and debilitating adverse effects: weight gain, lethargy, and physical illness. They regretted their loved one's loss of autonomy and agency that they linked to both adverse effects, and a concern to closely monitor medication taking. For some, these relationship dynamics were experienced as a regression to earlier parent-child roles. Overall, this constituted a long-term compromise to achieve recovery, but left family members with ambivalent feelings towards medication and their caring role. Most participants accepted medication as a 'necessary evil,' to which there was no realistic alternative.

### Theme one: fragile stability

Most of our sample found the prospect of reducing or stopping medication difficult to contemplate, having experienced many years of exhausting and sometimes frightening experiences relating to their loved one's mental health problems. The one family member who was positive about reducing or

stopping medication, cared for a younger person with a shorter history of mental health problems and also believed medication was impeding her son from making a full recovery. Her view is consistent with some evidence that long-term antipsychotic use may result in poorer outcomes for some people (Harrow et al., 2012; Wunderink et al., 2013). Cautiousness and fear about reducing or discontinuing antipsychotic medication in most of our participants concords with clinicians' perspectives, who are also wary of relapse and loss of stability and tend to discourage service users from making significant medication reductions (Cooper et al., 2019). Both clinicians and family members may feel a sense of responsibility for maintaining wellness and avoiding relapses, and both may fear having to manage the consequences of deterioration in mental health provoked by reducing or stopping medication.

### Theme two: ambivalence

Findings resemble those of other research on attitudes towards antipsychotic medication among family members (Morrison & Stomski, 2017) and service users who, on the whole, also value relapse prevention, but many find the debilitating nature of adverse effects and loss of autonomy difficult to tolerate (Bjornestad et al., 2017; Morant et al., 2018; Thompson et al., 2020). Overall, this research suggests that defining recovery as a reduction in symptoms is oversimplistic and may be achieved at the expense of aspects of quality of life. However, in contrast to service users, who come to a variety of different conclusions about the value of antipsychotic medication (Bjornestad et al., 2017; Geyt et al., 2016; Morant et al., 2018), all but one of the family members in our sample thought that consistent medicine-taking was extremely important.

### Theme three: constant vigilance vs autonomy

The near-unanimous opinion that consistent medication adherence is important led many family members to a situation of constant vigilance about regular medication taking that came to dominate their lives and generated persistent anxiety. These findings may help explain why family members of people with psychosis report poorer life quality, more social isolation and greater incidence of psychiatric disorders compared with family members of those with other long-term illnesses (Magliano et al., 2005; Hayes et al., 2015). Findings could also support previous literature which has indicated that some service users experience family members' involvement in overseeing their medication use as overly coercive (Rogers et al., 1998), and report that they have low levels of social support when attempting medication withdrawal (Larsen-Barr et al., 2018). This is a concern given evidence suggesting the importance of social support for successful reduction or discontinuation of antipsychotics (Larsen-Barr & Seymour, 2021).

## Limitations

The principal limitation of this research was the sample size and constitution, made up primarily of parents, people with long histories of mental ill-health involving numerous relapses. Only one participant cared for someone with a less prolonged history, and only one was a spouse. This profile was partly a result of recruiting through a local carers support group whose attendees had particularly difficult caring experiences; and partly related to the clinical profile of users of community mental health services who typically have severe and persistent conditions. This likely also accounts for the fact that most family members were parents, since psychotic disorders often start in young adulthood. The sample was also reflected the research aim to explore the experiences of people who identify themselves as ‘carers’ and may not therefore represent the views of family members or other close associates who do not.

There was also little ethnic or cultural diversity in the sample, reflecting challenges in recruiting people from ethnic minority backgrounds to mental health research (Waheed et al., 2015). The prevalence in our sample of family members who were extremely cautious about medication changes made it difficult to explore views about reducing and stopping antipsychotic medication in detail. Nevertheless, the present sample represents an important group of people whose lives are severely impacted by a relative’s mental ill-health, and whose views on antipsychotic medication need to be understood. The validity of our analysis was enhanced by adopting a reflexive approach throughout and regular research team discussions about emerging themes and analytic processes. Furthermore, at all stages we consulted with a researcher with lived experience of caring for someone experiencing psychosis, which helped ensure the research was applicable and relevant to family members’ concerns.

## Implications for clinical practice and future research

Family members’ concerns and daily involvement in medication monitoring are likely to contribute to burnout and fatigue (Wainwright et al., 2015; Onwumere et al., 2016) and highlight the importance of considering the way that medication use impacts on family members as well as the service user themselves during clinical reviews. Providing medication information and emotional support for family members, including within existing support groups is also important. The trauma experienced by family members during their loved ones’ relapses also has implications for clinical practice. Interventions following relapse are often service user focused: services need to recognise the potential impact on family members and inter-familial relationships and consider offering trauma-informed support for family members.

The emphasis family members place on medication in maintaining stability and avoiding relapses may create difficulties for service users wishing to reduce or discontinue medication in a responsible manner because of concerns about side effects or life quality. Forming alliances and

finding friends or relatives, as well as professionals who can provide support during medication reduction is identified as a key facilitating factor by service users (Geyt et al., 2016; Katz, Goldblatt, Hasson-Ohayon & Roe, 2019), and empirical evidence suggests that support from family, friends or others increases the chances of successful medication discontinuation (Larsen-Barr et al., 2018). When family members are strongly convinced that medication is necessary or the only way of maintaining stability, it may be difficult for users to make decisions that conflict with this position, and this may be a significant barrier to making fully informed and autonomous healthcare decisions (Thompson et al., 2020). This suggests a need for greater consideration of the views of family members who report often feeling excluded from decision-making (Bradley & Green, 2018). Decision-making processes that take account of all relevant stakeholders’ views, and in which family members are involved can be part of positive ‘triangles of care’ that can support the choices and needs of individuals, and lead to courses of action that are sustainable and to which all are committed (Hannan, 2013; Morant et al., 2016).

Considering the limitations of the current study, future research should focus on capturing the opinions of a more diverse sample of family member that includes a range of caring relationships (e.g. siblings, children, partners of service users), family members of people with shorter histories of mental ill-health, and those from more diverse ethnic backgrounds.

## Conclusions

Family members’ attitudes to medication can often shape service users’ use of medication. This study illustrates why this is the case, and the emotional impacts of this on family members. Parents of people with psychosis have often experienced difficult and frightening episodes in their caring role that can generate high levels of anxiety and feelings of responsibility in maintaining their loved ones’ stability. The need that many family members feel to monitor regular medication use and remain constantly vigilant can be a source of tension and guilt, since their loved ones are adults with capacity, who they would like to be more autonomous. Findings highlight the importance of emotional support for family members, and suggests that family members’ attitudes to medication may sometimes conflict with those of the people they care for. In these circumstances it is important to consider family members’ views within collaborative care plans, and family members should be included in processes of shared decision making in relation to medication (Morrison & Stomski, 2017).

## Disclosure statement

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(CEP). She has written several books about psychiatric drugs, including one on antipsychotics, *The Bitterest Pills*.

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## Data availability statement

Data is available upon reasonable request.

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