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RESEARCH ARTICLE

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Family and informal carers' views and experiences of antipsychotic reduction and discontinuation within a medication reduction research trial

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ABSTRACT

Background: Family/informal carers play important roles in supporting or monitoring medicine-taking for people with recurrent psychosis, but their views on antipsychotic medication are under-researched.

Aim: To explore family/informal carers' views and experiences of antipsychotic reduction and discontinuation within a medication reduction research trial (Research into Antipsychotic Discontinuation And Reduction [RADAR]).

Method: Semi-structured interviews with 15 family/informal carers of participants in the antipsychotic reduction/discontinuation arm of RADAR who had completed the trial up to one year previously. Data were analysed using thematic analysis.

Results: Most carers observed improvements in social engagement, daily functioning or identity, and challenges related to mental health over the 24-month reduction period. Carers described a general state of vigilance that was heightened during the trial, and often felt they were better at detecting warning signs of deterioration than clinicians. Carers' views did not necessarily reflect their loved ones' relapse status. Many wished they had been more involved in the trial. Some expressed cautious optimism for future reductions, although complete discontinuation was generally deemed less viable.

Conclusions: Carers' perspectives on antipsychotic reductions within the RADAR trial complement main trial findings and explorations of service users' experiences. Clinicians should endeavour to include carers in decisions about, monitoring and support of changes or reductions to antipsychotics.

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1. Introduction

Schizophrenia and related psychotic disorders affect up to 1% of the global population and can be highly debilitating (McGrath et al., 2008; Palumbo et al., 2015). Ongoing maintenance treatment with antipsychotic medication is recommended for people with recurrent conditions (Lally & MacCabe, 2015; National Institute for Health and Care Excellence, 2014). Studies on service user perspectives of antipsychotics have found that while short-term use is usually perceived as beneficial for symptom management and relapse prevention (Mills et al., 2011), for many, side effects can significantly impair quality of life (Thompson et al., 2020) and there is wariness regarding long-term use (Bjornestad et al., 2019). Viewing antipsychotics as the "least worst option" and "lesser of two evils", some service users feel resigned to this situation or feel their choices are limited due to their illness or pressure from others (Morant et al., 2018; Murphy et al., 2015), including medical professionals and family members who fear the consequences of potential relapse (Lewins et al., 2024; Watts et al., 2021).

Many people with recurrent psychosis rely on family or friends (informal carers) for emotional, social, and

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economic support (Caqueo-Urízar & Gutiérrez-Maldonado, 2006). Family/informal carers can facilitate access to services, improve treatment engagement, and reduce admission and relapse rates (Jansen et al., 2015; Norman et al., 2005; Ramírez García et al., 2006). However, their role is often under-recognised and they frequently experience high levels of burden and mental distress (Magliano et al., 2005; Onwumere, Sirykaite, et al., 2018) or feel unsupported by services (Onwumere et al., 2016). As those closest to service users, family members are often the first to notice changes in mental health or impacts of medication (Onwumere, Shiers, et al., 2018). Family carers' views on medication can influence service users, for example in shaping their attitudes or encouraging or discouraging consistent medication use (Deane et al., 2018; Wade et al., 2017). When carers' and service users' views differ this may be a barrier to family involvement or support (Landeweer et al., 2017). Research on family members' perspectives on antipsychotic medication is scarce, but existing studies identify carer concerns about adverse effects, relapse, being excluded from prescribing decisions, and feeling undervalued by professionals (Harris et al., 2017; Morrison & Stomski, 2017). Like service users, family/informal carers typically hold ambivalent views about antipsychotics (concerns over adverse effects while valuing medication for preventing relapse), but often perceive medication to be necessary for providing stability, and find reduction or discontinuation difficult to contemplate (Lewins et al., 2024).

While many service users attempt to reduce or stop their antipsychotics, this may result in relapse or withdrawal symptoms, particularly if done abruptly and without clinically-guided supervision or support (Larsen-Barr & Seymour, 2021; Salomon et al., 2014). Antipsychotic reduction that is gradual and clinically guided may have relatively lower relapse risks (Horowitz et al., 2021) and encourage a greater sense of agency and involvement in service users (Mølgaard et al., 2024). Building on previous work (Leucht et al., 2012; Wunderink et al., 2007, 2013), Research into Antipsychotic Discontinuation And Reduction ("RADAR") was the first randomised controlled trial (RCT) to investigate gradual, clinically-guided antipsychotic reduction and possible discontinuation compared to maintenance treatment over 24 months in people with a diagnosis of schizophrenia or recurrent psychosis (Moncrieff et al., 2019). The trial found no differences in its primary outcome of social functioning at trial end in the antipsychotic reduction group compared to the maintenance group, and more relapses in the reduction group (Moncrieff et al., 2023). A complementary qualitative investigation of service users' experiences (Morant et al., 2023) has also been reported. To our knowledge, no previous studies have explored informal carers' perspectives on antipsychotic reductions that are clinically guided. This study aims to explore the views and experiences of family/informal carers of people who were randomised to the antipsychotic reduction/discontinuation arm of the RADAR trial.

2. Methods

2.1. Setting

This study was embedded within the RADAR trial, a multicentre RCT conducted in England (2016–2022) (Moncrieff et al., 2019). Participants were randomised to antipsychotic reduction/discontinuation or maintenance antipsychotic medication over 24 months. In the intervention arm, psychiatrists were asked to see their patients every 2 months and offer a flexible reduction schedule provided by the trial team. Carers were not specifically invited to attend appointments but could be involved in participants' treatment, as is standard practice.

2.2. Participants and recruitment

Participants were family members/informal carers of people randomised to the reduction/discontinuation arm of RADAR who had completed the trial up to one year previously. They were recruited from research sites in London. People under 18 or who lacked capacity to consent or had insufficient command of English for an interview were excluded. Participants were purposively recruited to obtain a sample that included variations in age, gender, ethnicity, and relationship with person they cared for. Service users' experiences in the trial were not included in the purposive sampling approach.

Permission to contact a family member/informal carer was sought from service users as they concluded the RADAR trial (Figure 1). Once granted, carers were called to discuss the study and check eligibility. Due to pandemic restrictions, participants were interviewed via telephone or Skype and they received £15 for their time. Ethical approval, including for minor pandemic-related amendments, was granted by the London – Brent Research Ethics Committee [ref:16/LO/1507].

2.3. Research team positionality and reflexivity

Our team consisted of researchers working in the larger RADAR trial, including its principal investigator (JM), qualitative lead (NM), trial manager (JS), and research assistants (ML, JAR, ZH). First author

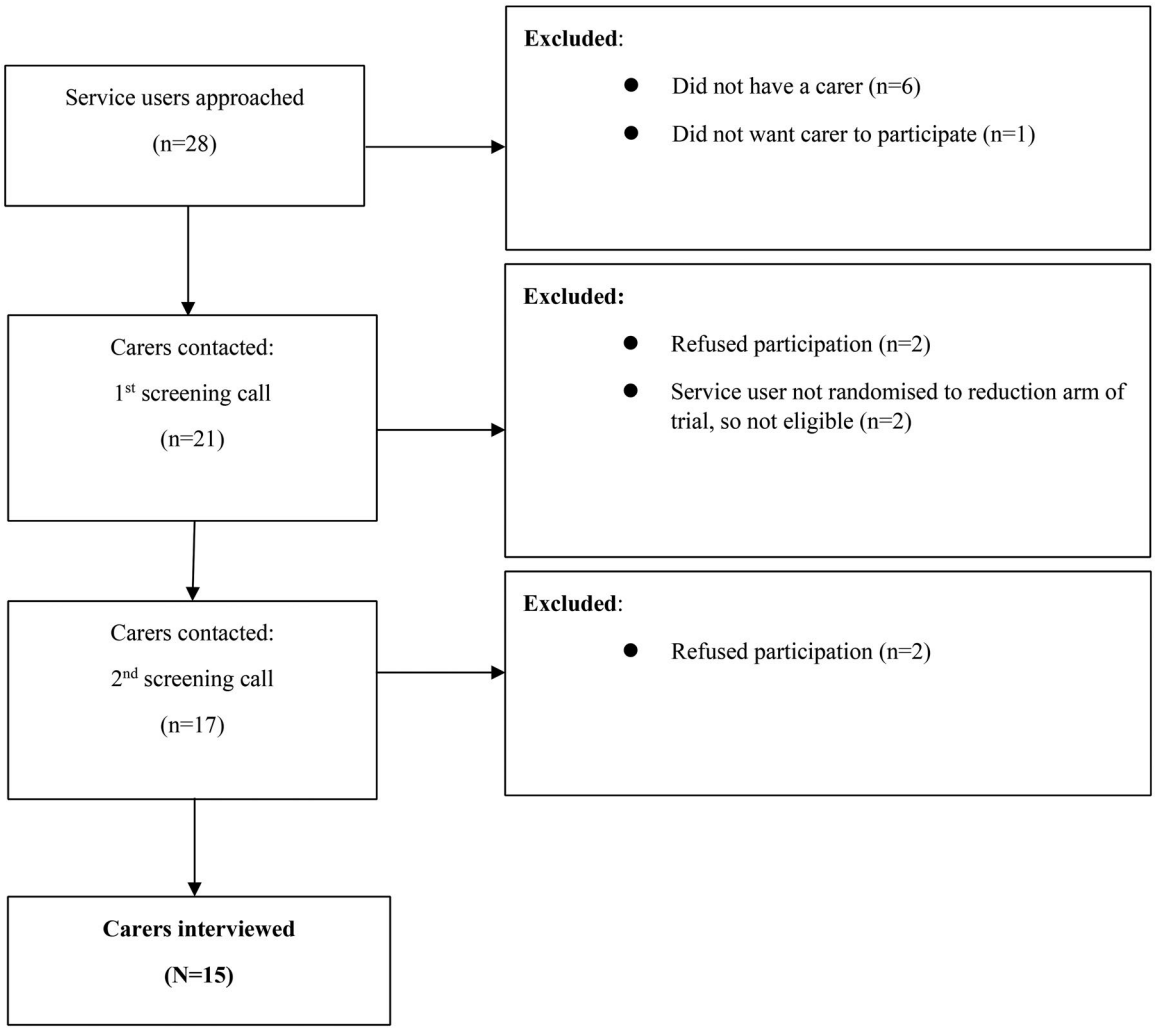

Figure 1. Flow diagram showing participant recruitment process.

SO was independent of the trial and RS was a consultant with lived experience of family caring. Throughout the study, we reflected critically on these positions in team discussions with the aim of ensuring we maintained a position of openness to carers' own views and experiences regardless of our own. Reflexivity was enhanced by Patient and Public Involvement activities and collaborative analytic processes (see below) that encouraged us to consider diverse perspectives and interpretations throughout.

2.4. Data collection

Data were collected via semi-structured interviews. Questions were organised temporally and covered: loved ones' experiences with antipsychotics before the RADAR trial; hopes and fears regarding the trial; views and experiences of reduction/discontinuation during the trial (e.g. improvements/negative effects observed, benefits/challenges for carers); and recommendations for other informal carers regarding reduction/discontinuation. Questions were adapted to prioritise participants' voices, with additional probes used to elicit more information where appropriate. Interviews were conducted by SO, ML, and JAR, none of whom were already known to interviewees. Participants were made aware of interviewers' positionality as described above. Interviews lasted 45–90 min (except for one, lasting 23 min) and were audio-recorded with participants' permission.

2.5. Patient and public involvement

The interview topic guide was developed initially by the research team and revised following discussion by RADAR's Lived Experience Advisory Panel (LEAP). This consisted of 10 people with experience of antipsychotic medication through personal use or as carers. A family carer LEAP member (RS) provided feedback on a later draft, reviewing question wording and relevance.

2.6. Data analysis

Interviews were transcribed by study team members and anonymised. Data were analysed using thematic analysis within NVivo software. This followed the staged guidelines of Braun and Clarke (2006). Data familiarisation involved detailed reading of transcripts and cross-checking against audio-recordings and summary notes written after each interview. Early stages analysis developed primarily descriptive codes specific to pieces of data (phrases or paragraphs of transcript). From this, a hierarchical thematic framework was progressively developed by integrating and organising initial coding into overarching themes to capture broad concepts, issues or underlying meanings. This involved a recurrent process of reading transcripts, coding and exploring the content of coded data (Nowell et al., 2017). Later stage analysis involved exploring variations and patterns of participant positions. Analysis was approached collaboratively, with the lead analyst (SO) discussing analytic ideas with study team members at intervals through the analytic process. These discussions enhanced reliability, reflexivity, and provided opportunities to extend analytic ideas and consider alternative perspectives or interpretations of data (Barry et al., 1999).

3. Results

3.1. Participant characteristics

Between May 2020 and 2021, fifteen carer participants ("CP") were interviewed. The sample included several ethnic groups (9 White, 4 Black, 1 Pakistani, and 1 Other Mixed Background) and captured a variety of relationships (4 spouses, 3 parents, 3 children, 2 siblings, 2 friends, and 1 cousin). Nine lived with the person they cared for (Table 1). Five had loved ones who relapsed during the trial, of whom three were hospitalised (severe relapse) while two had "non-severe"

Table 1. Sociodemographic characteristics of participants (N = 15).

Characteristics	Category	Frequency (N)
Gender	Female	8
	Male	7
Ethnic group	White British	7
	Other White Background	2
	African	3
	Other Black Background	1
	Pakistani	1
	Other Mixed Background	1
Marital status	Married/civil partnership	8
	Single/unmarried	4
	Divorced	2
	Separated	1
Employment status	Full-time employed	5
	On unemployment/sickness benefits	3
	Full-time carer	2
	Unemployed	2
	Retired	2
	Housewife	1
Living situation	Living with spouse (+/- children)	7
	Living alone (+/- children)	4
	Living with friends	2
	Living with parents	1
	Other (living with parents, wife, & siblings)	1
Relationship with person being cared for	Spouse	4
	Parent	3
	Child	3
	Sibling	2
	Friend	2
	(First) Cousin	1
Age of informal carer	56–65	7
	46–55	4
	36–45	2
	25–35	2
Age of person being cared for	75–85	2
	56–65	4
	46–55	3
	36–45	2
	25–35	4
Living with person being cared for	Yes	9
	No	5
	Occasionally	1
Diagnosis of person being cared for	Schizophrenia	13
	Schizoaffective disorder	2

Table 2. Service user relapse and antipsychotic discontinuation during the trial.

Family/informal carer ID	Service user relapse during the trial*	Service user discontinued antipsychotics completely at some point in the trial
CP1	None	Yes
CP2	None	No
CP3	Severe relapse	No
CP4	Non-severe relapse	Yes
CP5	Severe relapse	Yes
CP6	None	Yes
CP7	None	No
CP8	None	No
CP9	None	No
CP10	Non-severe relapse	No
CP11	None	No
CP12	Severe relapse	No
CP13	None	Yes
CP14	None	No
CP15	None	Yes

*Relapse as defined by RADAR trial expert endpoint committee: severe relapse = requiring acute psychiatric hospitalisation; non-severe relapse = managed by community services.

Table 3. Thematic analysis.

Main themes	Sub-themes
Starting points: pre-trial views and experiences	Views of antipsychotic medication
	Apprehension about antipsychotic reduction/discontinuation
Perceived impacts of antipsychotic reduction/discontinuation	Positive effects: Engagement, motivation, identity
	Negative effects: "Going backwards"
Family/informal carer challenges during the trial	Carer as 'lookout'
	Carer knows best
Recommendations about carer support for antipsychotic reduction/discontinuation	Importance of monitoring and partnerships
	"Cautiously optimistic": Thoughts on further reduction

relapses that were managed by community services. Six service users discontinued their medication completely at some point during the trial, two of whom were among those who relapsed (CP4, CP5) (Table 2).

3.2. Qualitative findings overview

A broad range of views was expressed in our data. Of 15 respondents, two conveyed strongly negative views about antipsychotics reductions within the RADAR trial, three were generally positive, whilst the majority described a mixture of positive and negative effects in their loved ones and had mixed views of reduction/discontinuation overall. However, these positions did not map clearly onto the relapse or medication discontinuation status of the person they cared for. For example, CP4 and CP10 had primarily positive views of their loved ones' reduction experiences despite their (non-severe) relapses during the trial. Conversely, though CP1's child did not relapse, their views of the trial were broadly negative. For other carers whose loved ones relapsed, only one (CP12) reported overall negative views of the trial; one (CP3) did not mention their spouse's relapse, while another (CP5) attributed their spouse's relapse to "anxiety" related to a life transition.

Results are presented below, providing a chronological overview of carers' views and experiences of antipsychotic reduction/discontinuation: Section 1 ("starting points") describes carers' retrospectively reported views and expectations before the trial; Sections 2 and 3 cover views, challenges and reported experiences during the 2-year trial; and Section 4 describes recommendations and thoughts about potential future antipsychotic reduction/discontinuation (Table 3).

3.2.1. Starting points: Pre-trial views and experiences

3.2.2.1. Views of antipsychotic medication. Opinions of antipsychotic medication before the trial varied. Some appreciated that antipsychotics allowed service users to be stable and balanced:

> I was just grateful that they managed to find the cocktail of drugs that had him balanced… He was having what looked like almost demonic episodes, it was the world's greatest nightmare… So when they finally managed to get [him] the medication and he was able to leave hospital… I was just so grateful. CP8

Others felt medication did more harm than good, citing side effects including weight gain, drowsiness, and lack of motivation. CP10 described his friend as "zombified" and said "it felt as if he was getting worse" with clozapine. These views shaped respondents' expectations of the reduction trial: those who reported positive experiences of antipsychotics were more sceptical about reduction/discontinuation (e.g. CP1, CP12), compared to those who reported seeing more negative side effects in their loved ones (e.g. CP4, CP10).

3.2.2.2. Apprehension about antipsychotic reduction/discontinuation. Many carers hoped that gradual reduction/discontinuation in the trial would yield benefits for their loved ones, especially in lessening side effects. However, most were also apprehensive:

> I thought it was a really good idea, because I could see the negative impacts that her medication was having on her… But at the same time I was a bit anxious about whether or not she would be able to cope – would she relapse, or…would she be OK. CP4

In several cases, this related to previous negative experiences with reduction/discontinuation, both supported and unsupported. Some carers were concerned about negative consequences (i.e. mental health deterioration/relapse) not only for their loved ones, but also for themselves:

> I get a bit frightened… I don't want him to start acting up, misbehaving and things like that, it's too much for me. CP11

3.2.2. Perceived impacts of antipsychotic reduction/discontinuation

3.2.2.1. Positive effects: Engagement, motivation, identity. The majority of respondents saw improvements in their loved ones' mood, behaviour, or general wellbeing at some point during the trial. Most commonly reported was increased willingness to engage socially, described as becoming more talkative, helpful or spending more time with family or friends:

> I noticed that when she was on the trial, she was more willing to come to me and speak to me about things and … share jokes, and things like that. CP4

> Since she's been off of them [antipsychotics] she's got a lot more bubbly… Her way of looking at things is changing, the way she thinks is changing, the way she speaks to people is changing. Once upon a time, you could say a load of stuff to X, and she'd look at you, and go, 'OK, it isn't my problem.' Now she'll try and help out, she'll try and do what she can to make a difference. CP6

Carers noticed increased motivation, independence and ability to engage in activities, e.g. helping with housework. CP13 noted that his loved one "started to look after herself a little bit better", by planning future trips, eating healthily, and socialising with others:

> Whereas there'd been periods when she'd been locked inside her flat, with cardboard on the windows and curtains shut, she was getting a bit more sunshine, a bit more fresh air, and I'd say that was probably…if I look back over the last 7 or 8 years, that's probably the best time, those 2 years. When she was under some sort of supervision, but reducing her medication. CP13

Several also felt that reduction positively impacted service user identity or agency. CP10 stated that, when his friend was on antipsychotics, "he just wasn't right. It wasn't the same person that I knew." Some described their loved one gaining confidence, returning to their "old self", or being better able to lead a "normal" life with medication reductions:

> He was able to be more present with other people… he wasn't so sluggish and withdrawn. It enabled him to become more like somebody without a mental health problem. He's able to cope with less sleep… he's able to watch a film, he's doing a Masters, he's leading a pretty normal life, now. CP14

3.2.2.2. Negative effects: "going backwards". Additionally, most respondents also described negative impacts in the person they cared for. The temporal sequencing of these in relation to positive effects varied in ways that paralleled the diversity of service users' responses to medication reductions. Reported negative impacts included sleep difficulties, mood swings, and increased psychotic symptoms. Two respondents (CP15, CP3), were unsure whether to attribute these to the reduction itself, or to other factors (e.g. physical health issues or the pandemic). Two respondents had primarily negative experiences of medication reductions: CP1, whose relative was not recorded as relapsing during the trial described them as "going backwards" as their auditory and visual hallucinations and associated distress worsened in their view, in comparison to a prior 3-year period of stability when taking medication by depot injections. CP12 reported that their relative had previously been stable for 15 years but had started to be non-adherent with their medication regime after being enrolled in the trial. This led to deterioration and two hospital admissions:

> Obviously that little decrease that's happened has made her think, 'Well I don't need to take them at all now'. That's when I started finding tablets and that's never happened in years. So that's what I mean, [RADAR] started something. CP12

Some respondents expressed concerns around the pace and timing of medication reductions. For example, CP7 thought their partner might be "cutting the tablets too quick", and CP4 worried that their relative stopping medication "at that time was a bit too early". These concerns were also described in the context of challenges faced by carers.

3.2.3. Family/informal carer challenges during the trial

3.2.3.1. Carer as "lookout". Four respondents described being "on guard" for warning signs that their loved ones might be deteriorating, or on the verge of another psychotic episode. While this feeling of constant vigilance was central to respondents' general caring experiences, some viewed this as particularly stressful and challenging during the trial:

> The only challenge is being on the lookout, always observing him closely, and just having at the back of my mind that it could go terribly wrong at any

minute… cause I know that once his medication is touched, it tends to have an effect on him. So it was like… when is it going to happen? CP8

Conversely, CP9 felt that with medication reductions they did not have to "follow her every move" (e.g. when cooking/eating with a knife) as their loved one's mood had improved so they were less concerned about possible self-harm.

3.2.3.2. Carer knows best. Many respondents described having specific insights into their loved ones' illness and greater ability to detect "warning signs" than others, particularly amongst parent/child and spouse pairings. This was helpful in the context of reduction/discontinuation, with carers sometimes notifying doctors/trial staff of signs of deterioration. However, some respondents reported that – due to previous negative experiences with healthcare services, or dislike of medication – their loved ones would "mask" symptoms in front of healthcare professionals, which was frustrating for carers:

Doctors will say to him, 'How are you? Are you hearing any voices?', 'No I'm fine.' But in our private life, he will let me know everything – you can see his illness quite actively, but if the doctor asked him certain questions, he can fool them, up to a certain point. CP11

CP1 said they started noticing signs of deterioration three weeks into the reduction period but their adult child only told clinicians about the return of hallucinations nine months after stopping medication. The sense that carers often had greater awareness of their loved ones' state of mind than clinicians and sometimes the person themselves, but that this was insufficiently considered, was conveyed particularly strongly by the two respondents with overall negative experiences of the trial (CP1, CP12). CP11 felt that the trial was encouraging their partner not to be on any medication but that "as his spouse, I know him better than anybody else, and I know that he couldn't function on no medication." CP12 felt that concerns they and another family member expressed were not given enough weight: "I've been born into this… you do not need to start messing about with her". These sentiments were echoed in participants' recommendations, specifically, the need for proper monitoring and partnerships between carers and medical professionals.

3.2.4. Recommendations about carer support for antipsychotic reduction/discontinuation

3.2.4.1. Importance of monitoring and partnerships. Despite challenges, most respondents thought that people looking to reduce their medication should "give it a try", and emphasised gradual, clinically guided and supported reductions. This included those with negative personal experiences of the trial, although with caution. For example, CP1 felt that reduction/discontinuation:

> should be tried with everybody […] because some people might not come crashing down like X did, and it would be 100% worth it.

CP4 felt that their parent's reductions in the trial were "more beneficial" than a previous attempt to stop medication without clinical support because of the gradual pace and regular clinical monitoring. Several respondents felt reassured that their loved ones were closely monitored throughout the trial, and most were satisfied with support they received. However, many respondents wished they had been better informed in advance of, and more involved during the trial. CP12 in particular found it "ridiculous" that her parent had been invited to participate and felt strongly that she should have been consulted first.

> I would have said no, and if they were asking for a reason I would have told them you need to go looking back and see what her record's like and see how settled she's been in the last 15 years. She does not need to be messed about with, she's still ill […] but we know it's not going to get better by you taking the medication away that's made her settled. CP12

Similarly, CP1 wanted opportunities to provide input about their child's medication and thought this might have improved outcomes.

3.2.4.2. "Cautiously optimistic": thoughts on further reduction. When asked whether they would support future medication reduction attempts, some respondents adopted a cautious attitude:

> I don't know what effect it could have if she tries to reduce the tablets more than what she has done already… I'm cautiously optimistic – it can help, but I don't know. CP7

This wariness revolved around uncertainty about side effects and potential return of psychotic symptoms. In general, reduction seemed to be more acceptable to carers than complete discontinuation:

> I think it's great, any steps towards one day perhaps not taking medication at all have to be good – it has made him more alert, more present, and, you know,

> he can function better. But this seems to be the limit, the level that he can cope with at the moment. CP14

Similarly, CP11 felt that while their partner could never completely discontinue medication due to the severity and duration of their illness, a "newly diagnosed person" could potentially benefit from reduction and/or discontinuation. One respondent was optimistic about their child reducing medication in the future and wanted them to take part in a similar reduction programme again. Others recognised tensions between their hopes for their loved ones to be medication free and a "reality" of them needing medication.

4. Discussion

This study of carers was conducted within the "RADAR" trial of clinically guided antipsychotic reduction/discontinuation for people with recurrent psychosis (Moncrieff et al., 2023), which found no differences in social functioning between the antipsychotic reduction and maintenance group, and an increased risk of relapse in the reduction group (Moncrieff et al., 2023). Data was collected before main trial findings were published, so carers were not aware of these at time of interview. The focus on family/informal carers' experiences during the 24-month trial complements a similar qualitative study of service users who received the reduction intervention (Morant et al., 2023). Like service users, carers reported complex, dynamic, and variable combinations of experiences of antipsychotic reductions. Many reported noticing and valuing positive effects of dose reductions that included increased social engagement, improved daily functioning, and changes in identity. This mirrors both users' trial experiences (Morant et al., 2023) and broader research on what is important to users in relation to taking antipsychotics (Thompson et al., 2020). However, this was set against negative experiences and challenges reported by some carers relating to mental health deteriorations and relapses, concerns that were shared by the service user participants and that have been reported in other studies (Gopal et al., 2017; Suzuki et al., 2014). For carers in the current sample, medication reductions increased the need for constant vigilance, which has been noted in similar populations (Lewins et al., 2024), and which created a heightened sense of precariousness. This was also reflected in concerns about the pace and timing of reductions.

Respondents' views of medication and expectations regarding antipsychotic reduction/discontinuation before the trial were consistent with previous work on family/informal carers who typically value medication in providing stability, so can be reluctant to make medication changes often despite awareness of adverse effects (Lewins et al., 2024; Morrison & Stomski, 2017). Several had been apprehensive about medication reductions but valued the clinical guidance and monitoring of dose reductions and were generally supportive of others trying this following their experiences. However, as has been found in research with clinicians (Cooper et al., 2019) there was less support for complete discontinuation, even from those who were generally positive about medication reduction. This was based on concerns about relapse and concurs with previous findings that avoidance of relapse is a key motivator of medication-taking amongst both informal carers and people with recurrent psychoses (Bjornestad et al., 2019; Drapalski et al., 2009; Lewins et al., 2024; Morant et al., 2018).

4.1. Strengths and limitations

This study adds to the relatively small corpus of literature on informal/family carers' views of antipsychotic medication. It is the first study exploring these people's experiences of antipsychotic reduction/discontinuation done in a gradual and clinically guided way as part of a UK-based research trial. This ensured we accessed views specifically about medication reductions done as part of clinical care over a consistent 24-month period. In previous research on this topic (e.g. Lewins et al., 2024) carers' views have been based on a greater diversity of experiences including abrupt discontinuations or medication reductions done without the knowledge of clinicians.

Our sample was demographically diverse and captured a variety of relationships between carers and service users and trial outcomes, including a similar proportion with relapse outcomes as in the main trial. However, within a relatively small sample we were not able to compare the experiences of people at specific intersections of this diversity. Most eligible people invited to take part (n = 19) agreed to do so, with only four declining participation. Participants may have had more positive views of the trial than those who declined, though we aimed to include carers whose loved ones had negative experiences with reduction/discontinuation during the trial. We were only able to invite carers of service users who consented to this, so may have missed carers whose opinions on medication and treatment differed from those of the person they cared for. However, only one trial participant we approached for this study did not consent to their carer being contacted. Finally, as carers were reporting on their experiences retrospectively, recall bias may be present.

4.2. Implications

A key feature of many carers' experiences of the trial was feeling insufficiently included in medication reduction processes. Some felt that relapses or other negative outcomes might have been avoided if they had been able to share their knowledge of the service user's history and current mental state with clinicians. This mirrors previous findings (Harris et al., 2017; Onwumere, Shiers, et al., 2018; Stomski & Morrison, 2018) that carers often want to be more involved in medication decisions.

There are important clinical implications, suggesting the value of "triangles of care" that combine the views and needs of clinicians, service users, and their families (Bradley & Green, 2018; Hannan, 2013; Morant et al., 2016). Carers often provide support for medicine-taking and have also been found to play a key role in supporting service users with antipsychotic reduction/discontinuation, specifically (Katz et al., 2019; Larsen-Barr & Seymour, 2021). However, tasks linked to medication management can contribute to carer burnout (Onwumere et al., 2016; Wainwright et al., 2015), and clinicians should be mindful that antipsychotic reductions may add to already considerable carer burdens (Gutiérrez-Maldonado et al., 2005; Magliano et al., 2005; Onwumere, Sirykaite, et al., 2018). Clinicians supporting or guiding antipsychotic reduction/discontinuation should aim to develop collaborative partnerships with carers and consider their views. They should also be aware that family/informal carers' views about medication may differ from those of the people they care for (Lewins et al., 2024), and that service user privacy and confidentiality should also be considered (Brennan et al., 2016; Landeweer et al., 2017). Engaging with informal carers whilst respecting patient wishes, and providing information about antipsychotic reduction processes, benefits, and risks can enhance support for both service users and carers.

4.3. Future directions

Future studies could usefully explore possible cultural barriers or facilitators to antipsychotic reduction/discontinuation which are yet to be identified. Given the importance of family/informal carer involvement in medication use, further research is needed on the interpersonal dynamics that may shape service user and carer experiences of antipsychotic reduction/discontinuation, and potential strategies for facilitating these processes where appropriate.

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Data availability statement

Data are available upon reasonable request.

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