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RESEARCH

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What does taking olanzapine mean to young people with anorexia nervosa and their families? Findings from the OPEN feasibility trial

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Abstract

Background Olanzapine is a second-generation antipsychotic medication often prescribed for young people with Anorexia Nervosa (AN), though supporting evidence is limited. The OPEN feasibility trial of olanzapine for young people (12–24 years) with AN, explored the feasibility of a future definitive trial on olanzapine in young people. Qualitative interviews examined the acceptability of olanzapine and trial design among young people with AN and their families. Here, we explore: what does taking olanzapine mean to young people with AN and their families, specifically regarding decisions to take or decline it?

Methods Twelve young people who agreed to take olanzapine, two who declined, and four parents took part in semi-structured qualitative interviews, which were conducted and analysed by lived-experience researchers using reflexive thematic analysis. Four young people who agreed to take olanzapine also took part in follow-up interviews, totalling 23 interviews with 16 participants. Of the interviewed parents, three had a child who consented to olanzapine and one had a child who declined. Lived-experience-led analysis, influenced by the survivor research tradition, is novel as applied to this topic.

Results We constructed four themes: (1) Moving away from illness in contexts of desperation, moving towards recovery as broader life goals; (2) Parents and young people critically evaluate multiple information sources on olanzapine; (3) Consent versus coercion in olanzapine decision-making are determined by treatment history and clinical power dynamics; (4) Ambivalence around recovery can be heightened regarding medication. Across themes, young people and parents showed their decision-making to be careful and context-bound, factoring in: concerns around treatment delays; trusting or mistrustful relationships to clinicians or the broader system; peer experiences; and fears around recovery alongside goals for improved quality-of-life. Reported clinical conversations about weight

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gain did not always reflect olanzapine's evidence base. Important risks included unsupervised olanzapine cessation where wishes to stop were not accommodated clinically, and increased food restriction on starting olanzapine.

Conclusions Views and experiences of olanzapine are inseparable from young people's clinical and social contexts. Clinicians should consider discussing these contexts alongside medication, bearing in mind clinical encounters' complex power dynamics, and should be clear about olanzapine's association with weight gain.

Trial registration ISRCTN80075010.

Plain English summary

Olanzapine is a drug that is often prescribed for treating anorexia nervosa (AN) in young people, yet there is limited evidence to support its use. We conducted a feasibility study with young people aged 12–24 with AN to explore whether it would be possible to conduct a larger trial that would test the effectiveness and safety of olanzapine in this group. We interviewed 14 young people that either agreed or declined to take part in the feasibility study and four parents. We found that young people who took olanzapine wanted it to support an overall improved quality-of-life, including changes in mental and physical health. Many had mixed views on how far these hopes were met but reported a range of improvements. Decisions to take olanzapine were based on carefully evaluated information from clinicians, peers, academic literature, and previous positive or negative experiences of treatment. For many, a willingness to take part depended on the belief that they could withdraw their consent at any time, which in turn was influenced by wider feelings of trust (or distrust) in clinicians. The prospect of olanzapine prompting a sudden recovery could be frightening and caused some participants to restrict their food intake further.

Keywords Olanzapine, Anorexia nervosa, Lived experience, Qualitative, Thematic analysis

Background

Anorexia nervosa (AN) is characterised by restriction of nutrition relative to requirements leading to low body weight; fear of weight gain or maintenance; and a strong relationship between low weight and self-worth, or disturbance at one's weight [1]. It is prevalent among women [2] with peak onset in developmentally-sensitive adolescence and emerging adulthood (<25 years) [3]. AN's severe quality-of-life impact increases with illness duration, with a mortality risk higher than asthma or diabetes in 15–24-year-olds, and high carer impacts [4]. Despite this, there is a 2.5-year average gap between onset and treatment [3]. Those with atypical AN (AAN), featuring identical symptomatology except low weight, wait longer [5]. Against the background of long waits, young AN patients experience relatively high levels of compulsory treatment, although some consider this necessary retrospectively [6]. Negative compulsory treatment impacts are moderated by family and therapeutic relationships [7].

Evidence-based treatments are typically family-focused therapeutic interventions for adolescents (<18) and individual psychotherapies for adults. Across ages, talking therapies and nutritional management are first-line treatments and pharmacological interventions have hitherto played a relatively minor role [4]. Despite treatment, recovery is challenging; eating-disordered thoughts persist beyond weight restoration, demanding significant energy to manage [8].

Olanzapine, a second-generation antipsychotic (SGA), is currently recommended in AN for obsessional thinking by Australian, German, US and Dutch guidelines

[9]. World Federation of Societies of Biological Psychiatry guidelines see limited evidence for olanzapine as a weight gain aid in AN and none for effects on eating disorder (ED) symptoms. However, UK psychiatrists report olanzapine as the most common off-label prescription for young people with AN [10]. Reviews highlight mixed expectations regarding action mechanisms, from harnessing side effects (i.e. appetite stimulation and weight gain) to affecting psychosis-like beliefs around food, weight, and body image. Primary trial outcomes of olanzapine in AN have been weight-focused, though some measure rumination, anxiety, sleep, or body dysmorphism [11–13].

Survey data suggests AN patients and carers want medications to target psychological symptoms (e.g. anxiety, anorexic thoughts), with most patients concerned about medication-induced weight gain and metabolic change [14]. Weight restoration in AN is complex: focusing exclusively on weight gain can maintain illness [15] and AAN patients report treatment-related weight stigma [16]. Taken together, this evidence shows that effective, timely treatment is currently urgent but rare and that there is a gap between existing quantitative pharmacological research and patient priorities. The research also highlights that family and therapeutic relationships and power dynamics are likely to be key to decision-making around medication.

Qualitative research can explore these complexities and ambivalences to provide nuanced context for quantitative data. As such this study aims to explore the lived experiences of young people with AN and their families in the UK regarding the decision to take or decline olanzapine,

focusing on perceptions of its acceptability, impact on symptoms, and relationship to other available treatment. We believe this study is unique in examining the decision-making process from the perspective of those who have consented and declined to take olanzapine and their parents, and hope that it will provide clinicians with an enhanced understanding of patients' and carers' varied, context-bound priorities in medication-related discussions and decisions.

Methods

Study design

We report qualitative findings from Olanzapine for young PEople with aNorexia nervosa (OPEN) an open-label single-arm feasibility trial of olanzapine for AN in young people (12–24 years) [17]. 39 young people under ED services were approached: 20 consented to olanzapine following screening; 10 declined; 9 were excluded (already on olanzapine or needed to start it urgently ($n=2$); clinical team deemed olanzapine unsuitable ($n=1$); did not meet inclusion criteria ($n=1$); reason not recorded ($n=5$)). 13 (65%) completed 16-week follow-up [18]. The trial stopped early due to recruitment difficulties [18], making qualitative exploration of olanzapine-related decisions important for future research.

The study was approved by Health and Social Care Research Ethics Committee B (reference 22/NI/0010) and the Health Research Authority (HRA) on 11 April 2022.

Qualitative interviews aimed to examine acceptability of olanzapine and trial design among young people with AN and carers, and views on a potential future randomised controlled trial (RCT). Here, we explore: what does taking olanzapine mean to young people with AN and their families, specifically regarding decisions to take or decline it?

Recruitment and participants

Service users with AN or AAN who could read and write in English, aged 12–24 years, under inpatient, day patient, or outpatient care at ten English sites, who had not gained 2 kg or more in a month of treatment as usual were included.

Exclusion criteria were: suicidality and serious self-harm, substance misuse, serious AN medical complications, use of opioids or medication interacting with olanzapine, recently starting or changing other psychopharmacological medication (<4 weeks on stable dose), and participation in other AN pharmacological trials. For full details see the trial protocol [17].

All young people approached for trial participation were invited to interview. Parents of participants still in the trial at 16 weeks, and of young people that declined to take part ("decliners") were invited to interview if

the young person consented. Some agreed to trial participation but not interview, and relatively few decliners wanted to be interviewed, leading to interviews with: 12 of 20 trial participants prescribed olanzapine ("consenters"); two of 10 decliners; three parents of consenters; one parent whose child declined. While interviews with participants were planned at baseline and 16 weeks, participants' schedules meant that most baseline interviews were conducted shortly after starting olanzapine and in one case, only the 16-week interview was feasible.

All interviewees but one were female, with one non-binary interviewee, and all were white. Under 16-year-olds were asked if they were comfortable to be interviewed with a parent on the advice of the ethics committee. Most participants started olanzapine before their first interview; four had second interviews, of whom two had stopped olanzapine. All interviewees but one (Lucy) who was hospitalised between interviews, were outpatients at time of interview.

Table 1 contains further interviewee details.

Data collection

Interviews were conducted by a researcher with lived experience of AAN, VK. Following screening, participants were invited to interviews at baseline and 16-weeks. Decliners were invited to speak about their decision-making. Upon agreement, participants were contacted with a Participant Information Sheet (see Appendix A / Supplementary Materials 1-6) and consent form. Interviews were conducted and recorded online via Microsoft Teams, using semi-structured topic guides developed by the wider research team, including a Patient and Public Involvement (PPI) group. Different guides were used for consenters, decliners, and carers (see Appendix B / Supplementary Materials 7-10). Interview guidance was used flexibly, following the interviewer's judgement. Data were transcribed verbatim by a UK service and stored according to the Data Protection Act 2018 [19]. Participants received a £10–20 Love2Shop voucher per interview.

Interviews ranged from 24 to 56 min, with a mean length of 43 min.

Analysis

Anonymised transcripts were analysed using NVIVO 14 for coding organisation [20]. Originally, framework analysis was planned due to interviews' multiple time points and perspectives. In practice we saw complex relationships between codes across interviewee groups, so swapped to reflexive thematic analysis (RTA) [21, 22]. We also felt RTA's interpretive lens, centring the analyst's role in theme development, fit better with a lived-experience-led approach (see below). RTA enabled us to fully integrate data from parents, consenters, and decliners to directly compare factors and contexts which

Table 1 Interviewee details

Pseudonym	Age	Olanzapine status at interview 1	Olanzapine status at interview 2 (approx. 16 weeks)
Trial participants ("consenters") (n = 12)			
Amelia	17	Taking (4 months)	No second interview (interview 1 held at 16 weeks)
Angela (interviewed with her mother due to age)	13	Taking (time unclear)	No second interview (did not respond to invite)
Camila	21	Stopped	Stopped
Daisy (interviewed with her mother due to age)	15	Taking (1 month)	No second interview (did not respond to invite)
Emma	18	Taking (time unclear)	No second interview (withdrew from trial)
Farah	16	Not yet started	No second interview (did not respond to invite)
Hannah (interviewed with her mother due to age)	12	Taking (5 weeks)	Stopped
Lily	19	Taking (time unclear)	Taking
Lisa	23	Taking (3 months)	No second interview (did not respond to invite)
Lucy	22	Taking (2 weeks)	Taking
Megan	18	Taking (time unclear)	No second interview (withdrew from trial)
Sophia	23	Taking (2 weeks)	No second interview (did not respond to invite)
Decliners (n = 2)			
Grace	22	Declined	n/a
Scarlett	24	Declined	n/a
Parents (n = 4)			
Maria (Lucy's mother)	n/a	n/a	n/a
George (Lucy's father)	n/a	n/a	n/a
Ava (Lily's mother)	n/a	n/a	n/a
Maya (parent, child not interviewed)	n/a	Declined	n/a

led to different decisions on olanzapine. As this change occurred early in the analysis process (towards the start of initial coding) it did not change our data handling significantly.

We also elected not to separate out or exclude data from those with co-occurring psychiatric conditions, instead discussing co-morbidities where they formed part of decision-making. In this we were following the main trial protocol, but also felt it would increase the real-world relevance of the results, as psychiatric and other comorbidities are common in AN [2].

RTA is flexible in theoretical approach [21]. We grounded analysis in social constructionism: coding inductively, examining interviewees' language as both

constructing their individual experiences and relating to wider discourses shaping experiences of AN care. Practically, themes combined semantic, descriptive analysis with more interpretive ideas latent in interviews' language, guided pragmatically by the research question and the medical trial context.

We moved iteratively through RTA's six stages: familiarisation, coding, initial theme generation (conducted by RRO and VK), reviewing themes, refining and naming themes, and write-up. This process is illustrated in Fig. 1: diagram of theme development, which shows how initial codes and themes were shifted, merged, and finally split into the final four themes. We have also included a supplementary table containing quotes which support these themes but were too lengthy to include in the main manuscript (see Appendix C / Supplementary Material 11).

RRO, VK, and VL discussed all stages as they progressed. On discussion, data which initially appeared contradictory could typically be integrated into an interpretive narrative for a single theme.

Lived experience, reflexivity, and trustworthiness

We were guided by literature on quality in RTA and endeavoured to satisfy the key questions outlined by Braun and Clarke in reporting our methods [23]. PPI in OPEN's design is described in its protocol [17]. Both first authors had lived experience of EDs and/or off-label antipsychotics. Analysis was influenced by survivor research: a collection of approaches guided by experiential knowledge and patients' lived social and political contexts which reflexively draws on similarities and differences in experience between participant and researcher [24]. There is tension between this approach and psychopharmacological research, and caution within survivor research around collapsing intersectional differences between those with lived experience of a particular diagnosis or service [25]. However, there is also a tradition of applying survivor knowledge to medical treatments: interviewees may reflect differently on these with lived-experience-interviewers than clinicians, despite intersectional differences [26]. Research within and beyond EDs highlights how lived experience can improve results' validity, decrease power imbalances within research, enhance ethical practice, and create increasingly empathic environments [27, 28]. Our lived experiences of power dynamics between patients and clinicians, and among patient groups, sensitised our analysis to power relations and contexts in medication-related decision-making.

In the tradition of survivor researcher reflexivity, lived experience of recovery and ongoing struggle(s) shaped this analysis. Like most participating patients, both first authors are white women with experience of (A)AN during adolescence and/or young adulthood, although

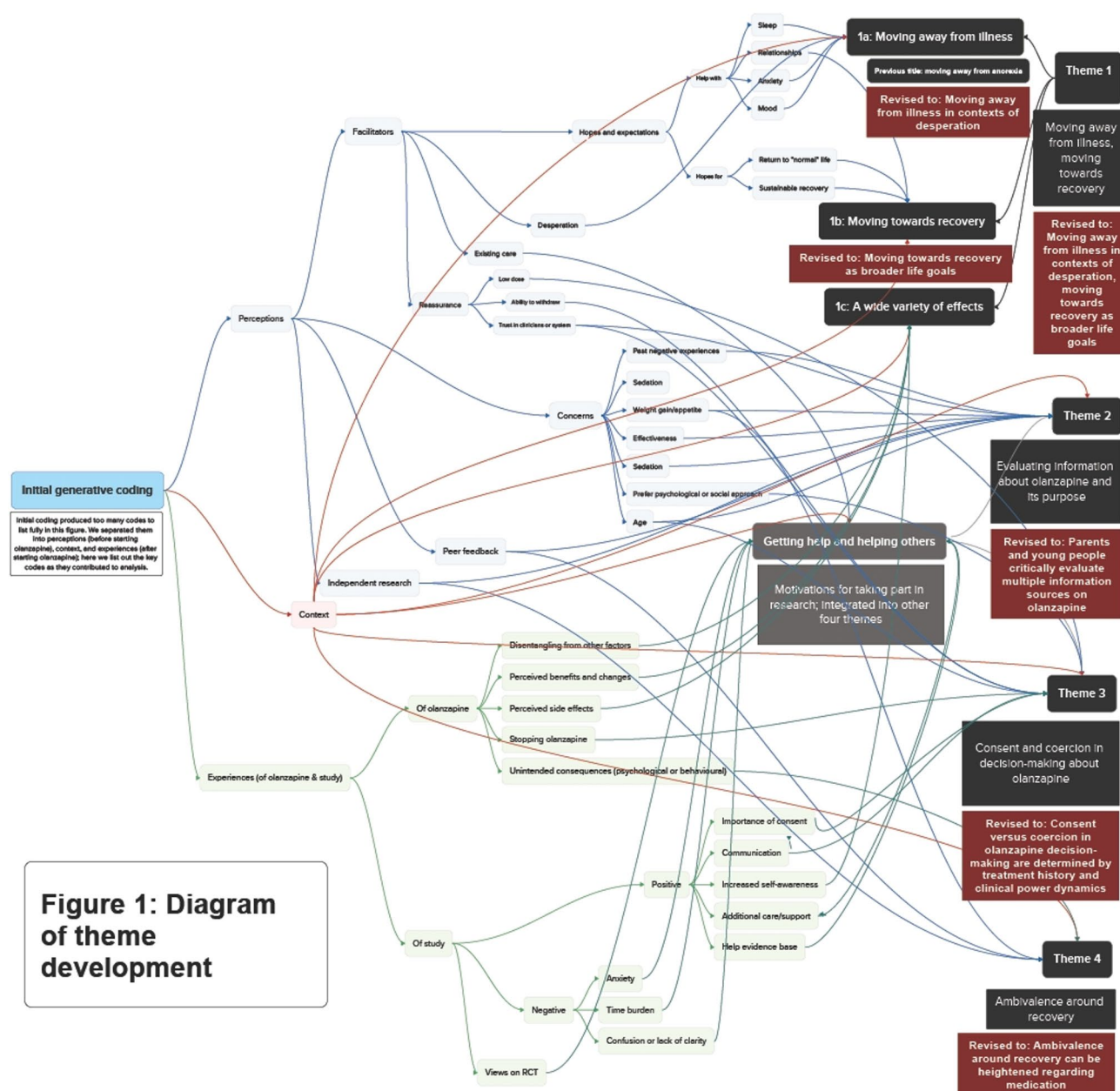


Fig. 1 Diagram of theme development

we recognise that adolescents today inhabit a different world to our teenage one. We drew on our experiences of both help and harm from austerity-wracked psychiatric services. First and last themes (Moving away from illness in contexts of desperation, moving towards recovery as broader life goals; Ambivalence around recovery can be heightened regarding medication) reflect this tension between recovery and ongoing struggle, alongside challenges with seeking holistic care in an overstretched system. Experiences of help and harm, and related reflections around trust in clinicians and healthcare systems, shaped the middle themes (Parents and young people

critically evaluate multiple information sources on olanzapine; Consent versus coercion in olanzapine decision-making are determined by treatment history and clinical power dynamics). During the first five stages of analysis, RRO kept reflexive notes detailing points of contact and divergence between her own experiences and participants; these shaped the reflections above and fed into group discussion with VK and VL where we tempered the risk of over imposing authors' perspectives on participants' accounts.

Results

Moving away from illness in contexts of desperation; moving towards recovery as broader life goals

Moving away from illness in contexts of desperation

Decisions to take olanzapine could be constructed as a desire to move away from anorexia and other co- or pre-existing mental health conditions; and/or a move towards life goals incompatible with illness. In between were hopes and expectations for quality-of-life improvements, such as improved sleep and anxiety. Young people and parents commonly described starting olanzapine out of desperation to move away from illness, sometimes exacerbated by significant waits for help and deterioration:

If you're kind of, you're kind of drowning, you know, somebody throws you a lifeline; you don't sort of, you grab it, you know what I mean. (George, Lucy's father)

I struggled with my mood for so long I was desperate to find something that could potentially help. So being put on olanzapine was a bit of a, I was really, it was a bit of a blessing really. I was really grateful for that. (Lisa)

We came out of hospital in October to no support again because we were on the end of long waiting lists [...] So, bless her, the eating disorder then took hold again. (Angela's mother)

This decision could be significant symbolically, easing stress on family relationships:

I think for my dad it was like he didn't really care if it did anything, but I think for him the fact that I just said yes to taking it, he was like, "She's trying. She put the effort in," and I think that meant a lot to him. (Camila, second interview)

However, most hoped for concrete improvements in food-related distress or wider difficulties. Lisa, also diagnosed as bipolar, linked her desperation to mood; Megan wanted help with:

Sleep... maybe, like my OCD is very bad at the moment. So that to get better. And to stop worrying as much. Maybe, like countering my anxiety a bit, yeah. That's it. (Megan)

Just to be able to eat food easily, not like, I know it wasn't going to cure it, but to be able to just think this is just food. Like if you need it to help you. And if it would hopefully just like quieten the anxiety down and not make me think so much about it. Or not think so long about it. (Hannah, first interview)

While OPEN focused on AN, participants also wanted olanzapine to help them move away from other difficulties—poor sleep, intense anxiety, mood disorders.

Moving towards recovery as broader life goals

Longer term, participants hoped that olanzapine would help them move towards a recovery represented by life goals that were incompatible with acute illness. Education featured prominently as a clear comparator with others of similar age, alongside improved relationships via reduced food-related distress. Farah's construction of anorexia as something one actively *does*—rather than has—highlights recovery's incompatibility with active AN:

[Doing] something as intensive as A levels and an eating disorder, you need to pick one or the other because doing both is just so much. You can't concentrate at all. (Farah)

My hope is that it will improve like my relationship with food and then in turn that will probably help my relationships with my family and friends, like everyone around me. Um, just because when I have a better relationship with food, I'll be able to invest more of my time and like emotions into other people, relationships with them. (Lily)

A wide variety of effects

Our dataset contained more information on starting than sustained experiences of taking olanzapine. However, most interviewees had started olanzapine for at least one interview, so we could begin to examine how far these hopes were fulfilled. Angela reported olanzapine "dialled down the voice in [her] head a little"; Sophia described being able to hold tension between anorexic thoughts and recovery goals more easily. However, Lucy felt her AN's grip had not loosened.

I've felt myself feel less hateful towards myself and I felt more able to, I don't know, just kind of think about the bigger picture and think, "Okay, yes, I have an eating disorder. Yes, I want to be thin. But I also want to finish my master's". And that for so long was something that I was really struggling to do. I just kept putting off and put it off and put it off. But the olanzapine was kind of a quite a nice like mediating factor I think because it was basically like, "Okay, we know that you hate yourself and we know that you hate your body, but you just need to get this done. So just eat and then get it done, and then we'll see what happens". So that's kind of, I don't know, it's quite like a neutralising force. (Sophia)

I'm still as anorexic as ever, psychologically. Even if I put on weight. (Lucy, second interview)

Mixed experiences were also evident regarding various other effects. While sedation benefited some, it was unmanageable for others:

I'm actually sleeping sometimes a good amount a day, that bit's like, oh, I'm hungry now because my body's used up all the energy to go to sleep. (Emma)
She was finding that she was more tired during the day and it was having a bit of a knock-on effect that she would be coming home and go to bed, but you know, we weren't too sure if it was the olanzapine, I mean, she spoke to the doctor at [hospital], but by that point, she just...I'm afraid to say she took herself off them. (Hannah's mother, second interview)

Interviewees considered the difficulty of disentangling olanzapine's impact from other treatment, learnt capacity to manage distress, or simply time passing:

At the beginning when I was eating better, obviously the guilt was still very much there and very impeding [...] I still feel it now. Not as much because I think I'm more used to it and I've more learned to like block it out. I'm not sure, maybe that was partly due to the medication. I'm not really sure. (Megan)

Overall, interviewees' hopes around olanzapine related to AN recovery and broader quality-of-life. Short-term, this could mean relief from psychological symptoms, and a desire to move away from desperation. Longer-term, some saw taking olanzapine as part of a move towards recovered life, with repaired social relationships and a return to education. Those able to reflect on experiences of taking olanzapine reported mixed views on whether it met those hopes.

Parents and young people critically evaluate multiple information sources on olanzapine

When deciding to start or decline olanzapine, interviewees discussed multiple information sources, usually starting with clinical conversations. Reducing anxiety, insomnia, or the "anorexic voice" were common primary aims.

[My psychiatrist] says that it helps with the anorexic voice, you know? That part of you which is not encouraging you to eat. (Farah)

I've not been sleeping, and they were telling me ways I could try, but nothing seemed to be working. And then [clinician] turned around and said, "I feel like we maybe should try you on olanzapine to help you

get drowsy and help you to sleep," [...] And I knew straight away, like it was kind of like a light-bulb moment. (Emma)

Weight gain was part of these conversations, but not typically the first outcome listed. Those who agreed to olanzapine described being reassured that this was only common at higher doses, via appetite increase rather than metabolic change, or that it would not cause weight gain:

They did also say about that some of the symptoms of taking olanzapine were weight gain, which I thought was quite scary, but then they explained that it was more if you take high doses of it and also it doesn't make you gain weight, it just makes you hungrier, I think. (Daisy)

At first, my eating disorder was quite worried about if the olanzapine would make me put on weight. But it got explained to me many, many times that it would not make me put on any weight. (Angela)

Yet, extra-clinical information sources such as others' lived experiences (family members, fellow patients, online discussion) and independent research could confirm weight gain concerns:

From when I read scientific articles, I just think from my point of view it does, it just does look a bit like a weight gain drug and it just looks like to me, it just makes you bit sleepy and doesn't actually improve any kind of thought process. (Scarlett, decliner)

Environments where access to external information was tightly controlled—i.e., hospital—could generate the most severe anxieties, due to the concentration of fears around weight. However, Grace highlighted that weight gain concerns were not unique to AN:

In hospital a lot of people talked about olanzapine in a really scary way, I would say. Like it would scare the eating disorder because everyone used to be like, "Oh it makes you hungry," and stuff. (Camila, first interview)

I've read in different forums and stuff [...] I always want to find other people's opinions, and not just medical professionals as well. But even people without eating disorders, they do flag up weight gain as a concern. (Grace, decliner)

Some described information received and their reactions through personification of their AN. Farah spoke about the anorexic voice: the definite article and rhetorical "you know?" constructing this as a reference to an existing

concept, introduced by her psychiatrist, opened up to the interviewer via Farah's clarifying definition. Angela constructed her AN as capable of worrying; Camila hers as being scared. These references personify the ED as an entity or self-part somewhat outwith conscious control, but also create a degree of separation between them and AN while evaluating olanzapine.

While they could introduce anxiety, extra-clinical information sources could encourage and reassure. Young people were thoughtful about risks and benefits of information from different sources, including peers in person and online; parents also evaluated multiple information sources, sometimes with opposite outcomes:

I heard from someone, an acquaintance that also had anorexia and started taking olanzapine and is in a much better place now. (Lucy, first interview)

There's like an anorexia community where they do just, there's a lot of spread of irrational ideas about medications or what doctors, like meal plans or anything like that [...] it depends who you're with. Luckily, a lot of my friends who have anorexia are very positive and doing very well. So, I'm not surrounded by that anymore. (Camila, first interview)

So, I know it's an antipsychotic, although it was on a low dose, I didn't want her to be started on antipsychotics at a young age. I know about the side effects. (Maya—parent, decliner; working as a GP)

I researched and saw that there was very little problematic side effects. (Ava, Lily's mother).

Parents and young people critically weighed up multiple information sources before consenting or declining.

Consent versus coercion in olanzapine decision-making are determined by treatment history and clinical power dynamics

Among interviewees who started olanzapine, a common finding was the ability to withdraw from OPEN and olanzapine as key to consenting. This remained important throughout, improving the experience of research and medication even for those committed to both, highlighting the importance of consent as an ongoing process.

I thought I'd give it a try, anyway, because if it was too much for me, with everything that was going on, I didn't have to stay. (Amelia)

It definitely makes me feel more comfortable that I can just withdraw whenever I want to. Not that I'm thinking of withdrawing, but I like that the option is there. (Daisy)

Further confidence in olanzapine came from trust in prescribing clinicians. This relationship held in reverse: past

iatrogenic (treatment-related) trauma and/or coercion eroding trust was a reason to decline.

I took it as a given that they wouldn't, if there was a risk, they wouldn't prescribe it as such. (George, Lucy's father)

I had the Mental Health Act used not only to feed me against my will, but also to medicate me against my will, which felt like it was completely disabling and felt like all of my freedoms had been completely removed and stuff. And the medication that they prescribed me was olanzapine [...] my consultant there basically said to me, "I want to sedate you so that you can't move," [...] It just felt completely disabling and I felt like a zombie constantly. I couldn't participate in any of the therapeutic activities on the ward because I was just too tired. And yeah, it was just, it was really scary and I did anything I could to avoid taking the medication and eventually the way that I got off it was I was given a week's leave at home or something. And I just, when I went home, I just didn't take it. (Grace, decliner)

Between these extremes, some described subtle difficulties providing free, ongoing consent. Hannah, the youngest participant, took herself off olanzapine after expressing her wish to do so several times; Camila described consent as the outcome of repeated offers of olanzapine during previous treatment:

I know you went a couple of times, didn't you, to [name], like her doctor, and then because she was, like, "I don't want to take them anymore," and then she spoke to the doctor, and they kind of agreed that she would carry on for a bit longer, but I think she felt that, you know, that she wasn't...I'm not saying wasn't being listened to, but it was a bit like, "You're not giving it a try," kind of thing, "Give it a bit longer." (Hannah's mother, second interview)

I was like, this is... this is like, what, fourth or fifth time I've been offered this drug. It must be helpful [...] they caught me at the time I was quite desperate. (Camila, first interview)

At first interview Camila had stopped olanzapine; being "caught" in desperation suggests less than enthusiastic consent. Hannah and Grace stopped olanzapine without medical supervision when they felt that supervision explicitly or implicitly did not consider their views.

For Sophia, the trial represented additional support in the face of discharge from secondary services, but also anxiety about withdrawing because of "the hard work people have done for the study":

I was going to be discharged from [service], but by taking part in the study, I was kind of able to touch base more than I would have been if I just got discharged and that was it. (Sophia)

For others, participating in OPEN represented an altruistic opportunity; this also came up in discussions of a potential RCT. However, blinding participants could be distressing for this population:

I think anorexics like control, so I think not knowing what it is that they're, I don't know, ingesting is... that's scary. I'd find it scary. But yeah, I think it would take a bit of control away from an anorexic, which could be difficult. (Camila)

I liked the idea of potentially helping people in the future. Like I like the fact that me giving a bit of my time now might help someone who's struggling further down the line if it does prove to be successful. And if it doesn't, then we know that it's not a thing. (Lisa)

Decisions to take olanzapine within OPEN involved contextual influences beyond clinical consent conversations. Interviewees described olanzapine representing a spectrum of experiences around consent to treatment: from informed consent as ongoing process, withdrawable at any time; through clinical or other contexts complicating the ability to freely consent; to forced treatment. Choices around olanzapine, and the freedom to make them, were inseparable from treatment and trial contexts and related clinical power imbalances.

Ambivalence around recovery can be heightened regarding medication

Olanzapine's association with recovery meant it could represent a frightening loss exacerbated by a potentially rapid pharmacologically-induced change:

Part of me was like okay, if I'm taking part in a study for medical intervention for an eating disorder instead of therapy intervention then what if it worked and what if I suddenly don't have an eating disorder anymore, which is like quite terrifying for me. (Sophia)

Lisa described this loss as frightening for peers and herself:

Is [medication] just putting like a plaster on something but not letting it actually heal properly? [...] Some people might not want to have less symptoms of anorexia because people don't want to lose their eating disorders because it's a part of all of our iden-

ties. And has been for a long time. So actually, it's a scary thought being put on medication that might potentially take that away. (Lisa)

This may link to Camila's "anorexia community" and peer experiences described by Lucy above regarding information sources on olanzapine. Lisa spoke earlier about a long struggle with anorexia; sticking-plaster solutions are a common metaphor for quick fixes to complex and/or long-term problems.

At interview Sophia and Lisa were taking olanzapine, so this fear was at least initially surmountable for them. However, Camila's experience was different:

I was so paranoid that [olanzapine] was making me gain weight that I ended up actually restricting more for the two weeks that I was on it, which I was straight with myself about because I seem to not be able to let these things help me. [...] So, yeah, that's pretty much why I ended up going off it. (Camila, first interview)

In her second interview Camila described feeling like a "monster comes out" when "challenging the anorexia, taking the medication". This, alongside being *unable* to allow medication to help, suggested particularly strong felt powerlessness regarding her AN.

While elements of the conversation around olanzapine were medication-specific, experiences of taking and stopping olanzapine were inseparable from the complex relationships participants had to their AN, peers, clinicians, and themselves.

Discussion

Results in context

These findings illustrate complex influences on decisions regarding olanzapine and research participation. Participants described hopes for olanzapine improving their quality-of-life. We operationalised improved quality-of-life as changes beyond AN-specific symptom reduction: i.e., reductions in non-AN-specific symptoms such as poor sleep and general anxiety, and a life beyond illness with equivalent educational and relational opportunities to others of similar age. This reflects other findings around goals for AN treatment more broadly which conceive of recovery as broader than weight restoration and highlight clear life goals as motivators in treatment [29, 30]. For some this was against a background of desperation with psychological distress which, again, was not limited to AN symptoms. Treatment delays fed into this desperation, mirroring findings from a meta-synthesis of qualitative research with parents of young people with AN, which highlight such delays as a core concern [31]. Our study population spans the age of transition

from child to adult mental health services which can be a challenging treatment context [32]: surprisingly this was largely undiscussed, perhaps as a function of the topic guides' specific focus on medication or because it did not represent an immediate concern.

Where data were available on olanzapine's effects, participants reported a range of improvements, but some struggled with side effects or increased anxiety around weight gain which in one case led to increased restriction. Two of four young people who took part in follow up interviews had stopped taking olanzapine. As such we had little data on how far hoped-for improvements were sustained. Making decisions around olanzapine, young people and parents integrated and critically evaluated information from clinicians alongside direct and indirect lived experiences, peer conversations, and independent research. In discussing this, some young people partially or fully personified their ED, reflecting a well-documented discourse around an ED "voice" or sub-self: a critical internal commentary (metaphorical or literal) on food, weight, and self-worth to which people variably related [33]. This may also reflect clinicians' discourses which commonly externalise EDs and/or family therapy, which explicitly aims to do so [34].

Conversations about olanzapine were a window on how young people conceptualised recovery and potential anxiety around losing this self. This supports research highlighting AN's enmeshment with identity and impact on various value systems as a factor in treatment-related decision-making [35, 36]. It also aligns with anxieties expressed regarding other medications such as antidepressants among this group [37]. Participants' desire for broad quality-of-life improvement supports research suggesting this is a priority for pharmacological outcomes among AN patients [14]. Given the intense anxiety associated with AN-specific recovery, quality-of-life and/or educational goals may be less frightening foci than weight gain.

Implications for research and practice

Our analysis highlights the clinical and social contexts in which young people and parents make decisions about olanzapine, and the significant power clinicians have in these conversations. Given the desperation motivating some to take medication, deterioration on lengthy waiting lists, and desire for increased care and support, it is difficult to separate these decisions from the UK's under-resourced mental health services [38, 39]. This leads us to wonder how full consent can be when choosing from very limited options.

Concerning randomised controlled trials in AN, anxieties around trial blinding could be key due to specific anxieties around control in AN patients. Participants accentuated informed consent as an ongoing process,

supported by consistent reassurance on the ability to withdraw, which should be/is critical in research with young people [40]. While participants in any trial have this right, the challenging treatment context and particular anxieties described above suggests this needs careful scaffolding for this patient group.

Weight gain concerned participants but seemed to be handled ambiguously in clinical conversations, with Angela reporting being reassured that olanzapine would not cause weight gain. This caused some concern within the research team and is difficult to interpret without the full context of the relevant clinical conversation: weight gain is a treatment outcome for all underweight AN, and some interviewees described reassurance that olanzapine-associated weight gain is via increased appetite rather than metabolic change. However, the tension between publicly-available information on weight gain, of which many participants were aware, and Angela's reported clinical conversations, highlights the need for clinicians to be extra careful when discussing this medication that service users fully understand the potential effects and mechanisms.

While it is unsurprising that AN patients would worry about pharmacologically-induced weight gain, others prescribed SGAs also commonly consider stopping them due to this [41]. Clinicians should not assume all concern in this area relates directly or exclusively to AN cognitions.

Clinicians should be aware that behind medication-related decision-making is likely a detailed evaluation of significant information, potentially including previous iatrogenic trauma, peer accounts, and academic research. OPEN's clinician interviewees understood the drive to research medication independently but also considered it a potential recruitment barrier [42].

These findings could help multidisciplinary teams involved in shared decision-making around medication understand patients' decision-making processes. Shared decision-making can be challenging in AN due to the relative paucity of specific pharmacological guidance [43]; it may therefore be useful to develop a decision-making tool or guide for conversations around olanzapine collaboratively with young people. We have highlighted potential points for inclusion below.

As discussed under theme three (consent and coercion), those who no longer wish to take medication may stop with or without medical supervision: this is particularly common with antipsychotics due to side effects, although off-label doses are under-researched [44]. Unsupervised medication cessations can be difficult for patients, who report a lack of safety advice on this [45]. Adequate continuation support was a concern for clinicians in OPEN who expressed hesitancy prescribing

olanzapine due to follow-up difficulties when unable to see patients continuously [42].

Finally, clinicians should consider the strength of some young people's fear of recovery and potential unintended consequences of starting olanzapine, notably increased food restriction.

Bearing in mind all the above, and aiming for trauma-informed, autonomy-focused care [46, 47], we recommend that clinicians consider overtly discussing the following points when proposing olanzapine. Trauma-informed care as conceptualised in survivor literature requires clinicians to engage with the power imbalances between clinicians and patients across the system [46]; this contextualises the power imbalances in AN care for young people as a specific—perhaps particularly acute [48]—manifestation of a broader phenomenon. We recognise that this dynamic is complex where patients feel such deep ambivalence and fear around recovery.

Our recommendations are guided by the principle that trusting therapeutic relationships curb iatrogenic trauma and are fostered by open discussion and understanding of patient perspectives and fears. This should be combined with clinicians' judgement and knowledge of their specific patients, and an understanding of the significant power they hold within young people's lives in particular. As such they should consider proactively discussing:

- The impact of delays and waiting lists on young people's and parents' treatment experiences and decisions (where applicable);
- What sources of information young people and parents are using to evaluate olanzapine, respecting that they may critically evaluate both clinical and extra-clinical information sources, including information from peers. This should include discussion of what olanzapine does and how, without concealing its association with weight gain;
- Previous experiences of coercion and iatrogenic trauma, although these conversations must be handled carefully, respecting where young people may not feel safe to disclose this;
- Anxieties and ambivalence about recovery.

Strengths and limitations

This paper represents a first step in exploring young people's and carers' perspectives on olanzapine prescribing and future research in AN. These are under-represented in AN research despite olanzapine being commonly prescribed. Another strength is the lived-experience-led analysis: survivor research, with its explicit commitment to reflexivity and focus on social contexts and power dynamics, is novel as applied to this topic. Interviewing decliners and carers captured perspectives underrepresented in AN research [27].

Those under 16 were interviewed with a parent present. This was both a strength and a limitation: it helped some less confident young people take part who many not otherwise have done, and provided additional context. However, it may also have made it harder for participants to be open about some aspects of their care and how relationships with their carers affected their treatment decisions.

The inclusive sample—all those approached for the feasibility trial who consented to interview—captured the widest range of perspectives possible. We feel we achieved information power [49] defined as rich and in-depth insights, particularly for the consenters group. It would have been helpful to interview more decliners, as their inclusion is a unique feature of this study. Two decliners plus one parent provided vital insights and rich personal experiences, but are unlikely to be sufficient to explore decliners' experiences fully. Such groups may require more targeted recruitment efforts: Grace's experience suggests those declining medication may be less trustful of, or have more experiences of coercion within, the healthcare system. This may make some less inclined to trust researchers who approach them via their clinicians.

The small number of second interviews is a limitation: the dataset focuses on early olanzapine-related decisions and experiences. It is difficult to know precisely why participants did not take up follow-up interviews, but this may be due to communication channels used (the trial protocol specified email communication, which may not be the most effective way to reach young people) and/or reduced engagement with OPEN overall over time.

Participants were all white; no male patients were interviewed, and data on sexual orientation were not collected within this trial. This is common in AN research and risks reinforcing exclusion of those at the sharpest end of forced treatment, since racialised groups are more likely to be compulsorily admitted [50]. The qualitative study also did not systematically collect comorbid diagnoses or olanzapine doses.

Future research could explore experiences not represented here: adults > 25, racialised groups, and those taking olanzapine longer-term.

Conclusions

Our study is novel in its application of survivor research methodology to young people's and parents' decision-making regarding olanzapine for AN, and integrating perspectives of consenters and decliners. This provides readily translatable insights into how young people and their parents make decisions relating to olanzapine in the UK context specifically, and more broadly as these relate to navigating power relationships between patients and clinicians. These insights are summarised by our

interpretive theme names: 'Moving away from illness in contexts of desperation, moving towards recovery as broader life goals'; 'Parents and young people critically evaluate multiple information sources on olanzapine'; 'Consent versus coercion in olanzapine decision-making are determined by treatment history and clinical power dynamics'; 'Ambivalence around recovery can be heightened regarding medication'.

Abbreviations

AN	Anorexia nervosa
AAN	Atypical anorexia nervosa
ED	Eating disorder
OPEN	Olanzapine for young PEople with aNorexia nervosa
SGA	Second generation antipsychotic

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40337-025-01401-z>.

Supplementary Material 1.
Supplementary Material 2.
Supplementary Material 3.
Supplementary Material 4.
Supplementary Material 5.
Supplementary Material 6.
Supplementary Material 7.
Supplementary Material 8.
Supplementary Material 9.
Supplementary Material 10.
Supplementary Material 11.

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Author contributions

All co-applicants (HH, JT, VL, MS, DN, US) of OPEN contributed to the study design. VK conducted the data collection. RRO and VK analysed the data. RRO drafted the manuscript with support from VK and VL. JK contributed to recruitment of OPEN and the reviewing of this paper. All authors read and approved the final manuscript prior to submission.

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Data availability

Research data are not shared to protect study participant privacy.

Declarations

Ethics approval and consent to participate

The study was approved by Health and Social Care Research Ethics Committee B (Reference 22/NI/0010) and the Health Research Authority (HRA) on 11 April 2022.

Consent for publication

Not applicable.

Competing interests

HH will receive funding from the UK Medical Research Council (MRC) for a double-blinded randomised controlled feasibility trial to test oral ketamine in people with anorexia nervosa and depression; the trial will start in 2025. HH is the principal investigator of a phase 2 clinical trial investigating the efficacy and safety of investigational COMP360 psilocybin treatment in anorexia nervosa.

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References

1. Feeding and Eating Disorders. In: Diagnostic and statistical manual of mental disorders. American Psychiatric Association Publishing; 2022. (DSM Library). https://doi.org/10.1176/appi.books.9780890425787.x10_Feeding_and_Eating_Disorders.
2. Keski-Rahkonen A, Mustelin L. Epidemiology of eating disorders in Europe: prevalence, incidence, comorbidity, course, consequences, and risk factors. *Curr Opin Psychiatry*. 2016;29(6):340–5.
3. Allen KL, Mountford VA, Elwyn R, Flynn M, Fursland A, Obeid N, et al. A framework for conceptualising early intervention for eating disorders. *Eur Eat Disord Rev*. 2023;31(2):320–34. <https://doi.org/10.1002/erv.2959>.
4. Schmidt U, Adan R, Böhm I, Campbell IC, Dingemans A, Ehrlich S, et al. Eating disorders: the big issue. *Lancet Psychiatry*. 2016;3(4):313–5.
5. Harrop EN. 3201 Patient perceptions of healthcare provider interactions among higher-weight women with eating disorders: opportunities for earlier screening, improved referral, and increased clinician rapport. *J Clin Transl Sci*. 2019;3(S1):151–151.
6. Guarda AS, Pinto AM, Coughlin JW, Hussain S, Psych MRC, Haug NA, et al. Perceived coercion and change in perceived need for admission in patients hospitalized for eating disorders. *Am J Psychiatry*. 2007.
7. Tan JOA, Stewart A, Fitzpatrick R, Hope T. Attitudes of patients with anorexia nervosa to compulsory treatment and coercion. *Int J Law Psychiatry*. 2010;33(1):13–9.
8. McCombie C, Ouzzane H, Schmidt U, Lawrence V. 'Physically it was fine, I'd eat what normal people do. But it's never like this in my head': A qualitative diary study of daily experiences of life in recovery from an eating disorder. *Eur Eat Disord Rev*. 2024;32(1):46–55. <https://doi.org/10.1002/erv.3018>.

9. Hilbert A, Hoek HW, Schmidt R. Evidence-based clinical guidelines for eating disorders: international comparison. *Curr Opin Psychiatry*. 2017;30(6):423–37.
10. Beykloo YM, Nicholls D, Simic M, Brauer R, Mills E, Wong ICK. Survey on self-reported psychotropic drug prescribing practices of eating disorder psychiatrists for the treatment of young people with anorexia nervosa. *BMJ Open*. 2019;9(9):e031707. <https://doi.org/10.1136/bmjopen-2019-031707>.
11. Çöpür S, Çöpür M. Olanzapine in the treatment of anorexia nervosa: a systematic review. *Egypt J Neurol Psychiatry Neurosurg*. 2020;56(1):60. <https://doi.org/10.1186/s41983-020-00195-y>.
12. Han R, Bian Q, Chen H. Effectiveness of olanzapine in the treatment of anorexia nervosa: a systematic review and meta-analysis. *Brain Behav*. 2022;12(2):e2498. <https://doi.org/10.1002/brb3.2498>.
13. Thorey S, Blanchet C, Guessoum SB, Moro MR, Ludot M, Carretier E, et al. Efficacy and tolerance of second-generation antipsychotics in anorexia nervosa: a systematic scoping review. *PLoS ONE*. 2023;18(3):e0278189. <https://doi.org/10.1371/journal.pone.0278189>.
14. Dessain A, Bentley J, Treasure J, Schmidt U, Himmerich H. Patients' and carers' perspectives of psychopharmacological interventions targeting anorexia nervosa symptoms. In: Himmerich H, Jáuregui Lobera I, editors. *Anorexia and bulimia nervosa*. IntechOpen; 2019. Available from: <https://www.intechopen.com/books/anorexia-and-bulimia-nervosa/patients-and-carers-perspectives-of-psychopharmacological-interventions-targeting-anorexia-nervosa-s>.
15. Barko EB, Moorman SM. Weighing in: qualitative explorations of weight restoration as recovery in anorexia nervosa. *J Eat Disord*. 2023;11(1):14. <https://doi.org/10.1186/s40337-023-00736-9>.
16. Harrop EN, Hutcheson R, Harner V, Mensinger JL, Lindhorst T. "You Don't Look Anorexic": atypical anorexia patient experiences of weight stigma in medical care. *Body Image*. 2023;46:48–61.
17. Said O, Sengun Filiz E, Stringer D, Applewhite B, Kellermann V, Mutwalli H, et al. Olanzapine for young PEople with aNorexia nervosa (OPEN): a protocol for an open-label feasibility study. *Eur Eat Disord Rev*. 2024;32(3):532–46. <https://doi.org/10.1002/erv.3060>.
18. Said O, Stringer D, Sengun Filiz E, Mutwalli H, Bektas S, Akkese MN, et al. Olanzapine for young PEople with aNorexia nervosa (OPEN): results of a feasibility study. Submitted.
19. UK Government. Data Protection Act 2018. Statute Law Database; Available from: <https://www.legislation.gov.uk/ukpga/2018/12/contents>.
20. Lumivero. NVivo. Available from: <https://lumivero.com/products/nvivo/>.
21. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589–97. <https://doi.org/10.1080/2159676X.2019.1628806>.
22. Braun V, Clarke V. Conceptual and design thinking for thematic analysis. *Qual Psychol*. 2022;9(1):3–26. <https://doi.org/10.1037/qap0000196>.
23. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol*. 2021;18(3):328–52. <https://doi.org/10.1080/14780887.2020.1769238>.
24. Sweeney A, Beresford P, Faulkner A, Rose D, Nettle M, editors. *This is survivor research*. 1. publ. Ross-on-Wye: PCCS Books; 2009. pp. 200.
25. Voronka J. The politics of 'people with lived experience' experiential authority and the risks of strategic essentialism. *Philos Psychiatry Psychol*. 2016;23(3–4):189–201.
26. Rose D. Patients' perspectives on electroconvulsive therapy: systematic review. *BMJ*. 2003;326(7403):1363. <https://doi.org/10.1136/bmj.326.7403.1363>.
27. Musić S, Elwyn R, Fountas G, Gnatl I, Jenkins ZM, Malcolm A, et al. Valuing the voice of lived experience of eating disorders in the research process: benefits and considerations. *Aust N Z J Psychiatry*. 2022;56(3):216–8. <https://doi.org/10.1177/0004867421998794>.
28. Evans J, Papoulias S. Between funder requirements and 'jobbing scientists': the evolution of patient and public involvement in a mental health biomedical research centre—a qualitative study. *Res Involv Engagem*. 2020;6(1):12. <https://doi.org/10.1186/s40900-020-00185-7>.
29. Paulson-Karlsson G, Nevenon. Anorexia nervosa: treatment expectations; a qualitative study. *J Multidiscip Healthc*. 2012;169.
30. Karlsson S, Friberg W, Rask M, Tuveson H. Patients' experiences and perceptions of recovering from anorexia nervosa while having contact with psychiatric care: a literature review and narrative synthesis of qualitative studies. *Issues Ment Health Nurs*. 2021;42(8):709–19. <https://doi.org/10.1080/01612840.2020.1847222>.
31. Oketah NO, Hur JO, Talebloo J, Cheng CM, Nagata JM. Parents' perspectives of anorexia nervosa treatment in adolescents: a systematic review and metasynthesis of qualitative data. *J Eat Disord*. 2023;11(1):193. <https://doi.org/10.1186/s40337-023-00910-z>.
32. Lockertsen V, Holm LAW, Nilsen L, Rø Ø, Burger LM, Røssberg JI. The transition process between child and adolescent mental services and adult mental health services for patients with anorexia nervosa: a qualitative study of the parents' experiences. *J Eat Disord*. 2021;9(1):45. <https://doi.org/10.1186/s40337-021-00404-w>.
33. Pugh M. Understanding 'Ed': a theoretical and empirical review of the internal eating disorder 'voice'. *Psychother Sect Rev*. 2020;1(65):12–23. <https://doi.org/10.53841/bpspsr.2020.1.65.12>.
34. Kellermann V, Sengun Filiz E, Said O, Bentley J, Khor JWT, Simic M, et al. Clinicians' perspectives on the acceptability and feasibility of a clinical trial of olanzapine for young people with anorexia nervosa. Submitted.
35. Vincenzo C. Patient perspectives on premature termination of eating disorder treatment: a systematic review and qualitative synthesis. *J Eat Disord*. 2022. <https://doi.org/10.1186/s40337-022-00568-z>.
36. Tan J, Stewart A, Fitzpatrick R, Hope RA. Competence to make treatment decisions in anorexia nervosa: thinking processes and values. *Philos Psychiatry Psychol*. 2006;1(4):267–82.
37. Ludot-Grégoire M, David V, Carretier E, Lachal J, Moro MR, Blanchet C. Subjective experience of antidepressant prescription among adolescents with anorexia nervosa. *Front Psychiatry*. 2022;13:770903. <https://doi.org/10.3389/fpsyt.2022.770903/full>.
38. Iacobucci G. Community mental health services need support to improve patient satisfaction, says NHS leader. *BMJ*. 2024. <https://doi.org/10.1136/bmj.q908>.
39. Trades Union Congress. Breaking point: the crisis in mental health funding. 2018. Available from: https://www.tuc.org.uk/sites/default/files/Mentalhealthfundingreport2_0.pdf.
40. Gaining valid consent/assent from children and young people. In: *Psychology and Media Productions: Guidance for commissioners and producers*. British Psychological Society. 2019. <https://doi.org/10.53841/bpsrep.2019.rep163.10>.
41. Doane MJ, Sajatovic M, Weiden PJ, O'Sullivan AK, Maher S, Bjorner JB, et al. Antipsychotic treatment experiences of people with schizophrenia: patient perspectives from an online survey. *Patient Prefer Adherence*. 2020;14:2043–54.
42. Kellermann V, Sengun Filiz E, Said O, Bentley J, Khor JWT, Simic M, et al. A feasibility trial of olanzapine for young people with anorexia nervosa (OPEN): clinicians' perspectives. *J Eat Disord*. 2024;12(1):146. <https://doi.org/10.1186/s40337-024-01106-9>.
43. Himmerich H, Bentley J, Lichtblau N, Brennan C, Au K. Facets of shared decision-making on drug treatment for adults with an eating disorder. *Int Rev Psychiatry*. 2019;31(4):332–46. <https://doi.org/10.1080/09540261.2019.1571995>.
44. Larsen-Barr M, Seymour F, Read J, Gibson K. Attempting to discontinue antipsychotic medication: Withdrawal methods, relapse and success. *Psychiatry Res*. 2018;270:365–74.
45. Salomon C, Hamilton B, Elsom S. Experiencing antipsychotic discontinuation: results from a survey of Australian consumers. *J Psychiatr Ment Health Nurs*. 2014;21(10):917–23. <https://doi.org/10.1111/jpm.12178>.
46. Sweeney A, Taggart D. (Mis)understanding trauma-informed approaches in mental health. *J Ment Health*. 2018;27(5):383–7. <https://doi.org/10.1080/09638237.2018.1520973>.
47. Saunders KRK, McGuinness E, Barnett P, Foye U, Sears J, Carlisle S, et al. A scoping review of trauma informed approaches in acute, crisis, emergency, and residential mental health care. *BMC Psychiatry*. 2023;23(1):567. <https://doi.org/10.1186/s12888-023-05016-z>.
48. Atti AR, Mastellari T, Valente S, Speciani M, Panariello F, De Ronchi D. Compulsory treatments in eating disorders: a systematic review and meta-analysis. *Eat Weight Disord Stud Anorex Bulim Obes*. 2021;26(4):1037–48. <https://doi.org/10.1007/s40519-020-01031-1>.
49. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2016;26(13):1753–60. <https://doi.org/10.1177/1049732315617444>.

50. Barnett P, Mackay E, Matthews H, Gate R, Greenwood H, Ariyo K, et al. Ethnic variations in compulsory detention under the Mental Health Act: a systematic review and meta-analysis of international data. *Lancet Psychiatry*. 2019;6(4):305–17.

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