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Olanzapine for young PEople with aNorexia nervosa: An open-label feasibility study – Qualitative study

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BACKGROUND

- There is a lack of direct involvement of people with lived experience in research processes, specifically in eating disorders (1).
- Lived experience perspectives are required by major funding bodies and improve quality, relevance, and acceptability of research (2).
- Qualitative data highlights individual perspectives and offers an in-depth examination of the studied phenomenon (3,4).

AIMS

- The **primary aim** of the qualitative study is to examine the **acceptability of the intervention** and study design from the perspective of young people with Anorexia Nervosa (AN) who either decline or agree to participate in the OPEN feasibility study.
- The **secondary aim** is to explore the perspectives of health care professionals (HCPs) to understand capacity, barriers and facilitators, and effectiveness of olanzapine in treatment.
- With consent of participants, interviews with families and carers or closed loved ones will explore additional perspectives and gain insight into potential changes within home dynamics, differences in perceptions, and perceived changes in the effectiveness of olanzapine.

METHODS

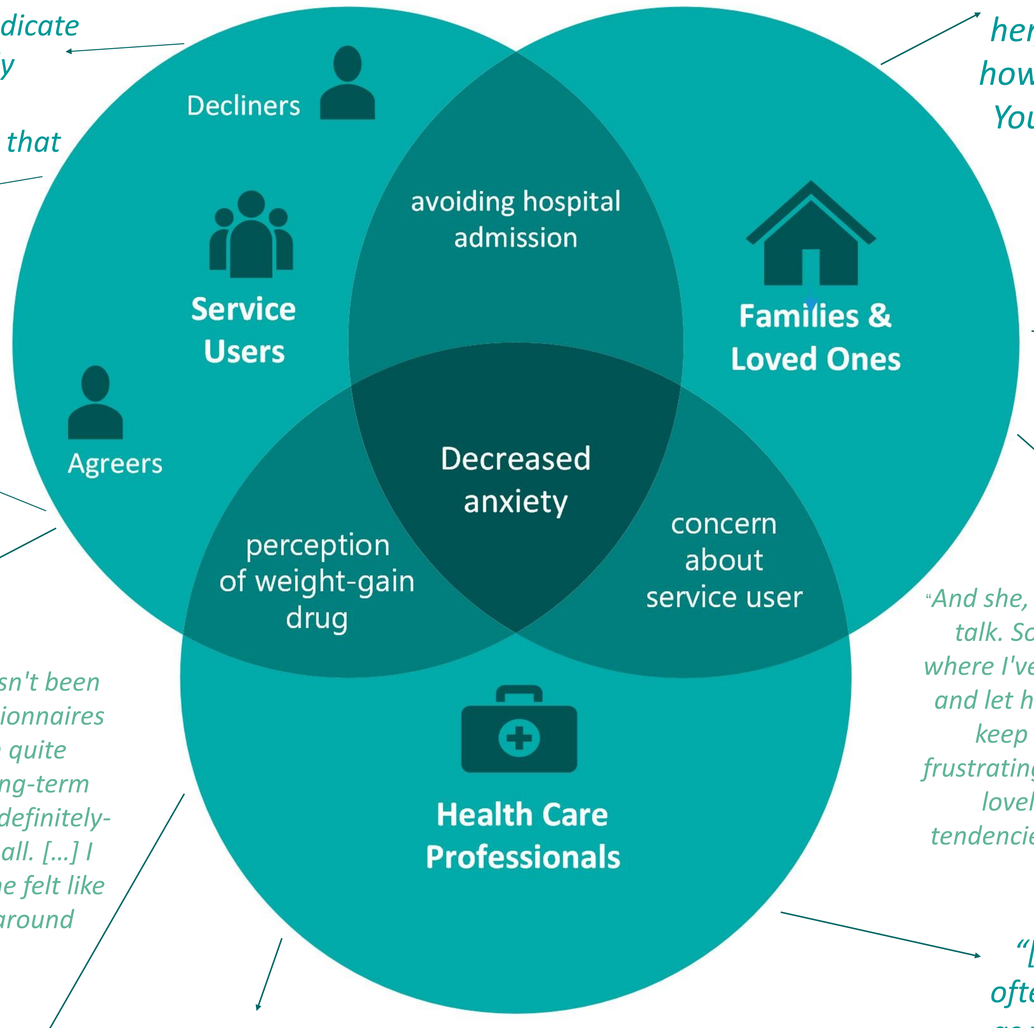
Participant experience of recruitment and treatment, acceptability, and reasons for adherence and non-adherence will be explored in semi-structured qualitative interviews conducted by a researcher with lived experience of AN. Service users will be interviewed at baseline and discuss why they agreed or refused to take part in the study. Interviews will examine the decision-making process and the perceived risks and advantages of taking olanzapine. At the 16-week follow-up, the interview will ascertain how participants experience the olanzapine treatment, study design, and their involvement in the study, including perceived challenges, benefits, and attitudes towards a future randomized controlled trial. Upon the young person's consent, families or carers will be invited to contribute their views after the 16-week assessment. Additional interviews with HCPs will explore the perceived barriers and facilitators to recruitment and retention. Data analysis will incorporate framework analysis conducted by two qualitative researchers.

PROGRESS/RESULTS

Recruitment began in June 2022 across several NHS sites and will run until May 2023. Out of 16 participants recruited, 7 service users who participated, 3 service users who declined to take part, 3 carers, and 3 HCPs were interviewed by the 20.04.23.

"I was on and off section a lot of the time. And one time that I was under section 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 […]."

"I remember in the beginning it seemed to calm her, very quickly actually, I was quite surprised how quickly […] it felt like a successful few days. You know, she just seemed a lot calmer or in a better place."



So, I think for me personally it was this kind of like weight gain drug, and my parents were also very apprehensive because they read around Olanzapine. It wasn't approved. They didn't really want to put me on it at this age when there's no long-term evidence, there are no long-term results. And I guess it was also because it was my first inpatient stay, […]

"[I] got to a place now that I feel a lot less anxious around foods."

"[…] the motivation was the olanzapine basically. It was kind of basically pragmatic, you know, "Would it work?" you know, in terms of that. Because we got to the stage with the home recovery where it wasn't working […] we were kind of, we were probably in quite a desperate situation where nothing was working and so it felt like a lifeline, you know."

"I think I'm glad […] I decided to take part. I think it hasn't been too stressful. I haven't found the meetings or the questionnaires or the bloods to be too overwhelming. I found them quite manageable. And this was my first time […] on any long-term medication. So, I was a bit hesitant to begin with, but I definitely- I've got used to it now. I haven't skipped any doses at all. […] I think I would recommend this study actually, if someone felt like they wanted some help with managing the anxiety around anorexia and recovery."

"And she, I guess she doesn't want to talk as much as I'd like to talk. So, we're kind of like in a weird stage at the moment where I've been […] encouraged by the [hospital] to stand back and let her find her way, or what's the right amount to eat to keep her weight the right level. […] at the moment it's frustrating, exasperating, slightly depressing. But equally, she's lovely and kind and sweet and exhibiting none of the tendencies that you would normally associate with somebody with anorexia. So, it's kind of weird."

"I think this is probably related to the pandemic, but we've been getting […] people on assessment that are more unwell than they were before, or […] they get to the service when they're really unwell, whereas before they weren't as unwell. And that is why we've had this kind of constant issue because then I've prescribed olanzapine on assessment a few times already, which never used to happen."

"I guess for some people there is the issue that they might only see, "Oh, weight gain," and then not really think about other potential benefits so that they end up not really having a very balanced view of that. But I would think that any doctor worth their salt prescribing something like this would want to give a very balanced view of why this medication is being prescribed."

"[…] some people are willing to try it but I think very often the real struggle is to get people to eat a bit more as well and to make a bit of a commitment to that. And olanzapine may or may not help with that[…] And so, I'm open about the olanzapine, but I have a sort of question mark about it and I think I see it very much as an adjunct to other things, not as a standalone treatment."

CONCLUSIONS/DISCUSSION

The qualitative study will provide insight into barriers of inclusion to the study, ways in which trial procedures, recruitment and retention could be optimised, and outline the value and expectations that service users, families and HCPs place on olanzapine as a treatment for AN. The unique perspective of the qualitative researcher will enable a trustworthy environment for inclusive knowledge co-production, improving ethical practice and data validity (1, 3).

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