Research Paper

Understanding young peoples' and family members' views of treatment for first episode psychosis in a randomised controlled trial (MAPS)

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1. Introduction

Adolescence is a time of vulnerability for the onset of mental health problems, with most conditions, including psychosis, emerging at this age [1,2]. Early Intervention for psychosis services have developed to address this critical stage [3]. However, the evidence that is base for treatments for first episode psychosis (FEP) in adolescents is extremely limited and current treatment guidance is largely extrapolated from the adult literature [4]. Given that adolescents may present with differing clinical needs, and may experience benefits and harms of treatments differently to adults, there is an urgent need for more youth-specific treatment research.

NICE Guidelines for treatment of psychosis in children and young people (CYP) [5] specifically call for research to test the comparative efficacy and safety of antipsychotic medication and psychological intervention in CYP. The Managing Adolescent first episode Psychosis (MAPS) study addressed this call by examining the feasibility of such a trial [6]. Sixty-one adolescents aged 14–18 with FEP were randomised to one of three treatment allocations: antipsychotics only (AP), psychological intervention only (PI), or a combination of both. MAPS is the first trial of this type, and findings are reported elsewhere [7].

The Lancet Psychiatry Commission regarding the development and evaluation of psychological therapies recommends nested qualitative studies to inform interpretation of clinical trials [8]. In the

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context of MAPS, investigations of the treatment views of participants and their family members would improve understanding of treatment acceptability and impact. Most treatment–specific qualitative studies however examine adult experiences of AP, generally reporting mixed views of benefits weighed against costs of AP use [9,10]. One study has examined young people’s (YP) views of AP, with benefits of AP commonly being offset by adverse effects [11]. Adult studies examining both CBT and FI for psychosis have identified the importance of therapeutic alliance in the process of psychological therapy, and improved understanding as a key outcome [12–15]. No qualitative studies exist of either adolescent or family perspectives. Consequently, a nested qualitative study was conducted within the MAPS trial to evaluate the perspectives of trial participants and family members regarding acceptability and experience of treatments.

2. Method

2.1. Participants

Participants comprised thirteen YP who took part in MAPS and eighteen family members (sixteen interviews) at three study sites: North West, Oxfordshire, Sussex (see Table 1 for participant characteristics). MAPS participants were YP aged 14–18 years experiencing FEP (full inclusion and exclusion criteria are reported elsewhere [6]). YP were eligible to take part in the qualitative study if they had already given consent to be audio-recorded, and family members were only approached if their young person agreed. A purposive participant sampling approach was taken with the aim of identifying a sufficiently diverse range of trial participants and family members (treatment allocation and engagement, age, gender, ethnicity).

The option of attending interviews was highlighted to YP during their 6-month trial assessment, and those interested were approached unless there were concerns about their capacity or current risk. Thirteen of twenty-three YP invited to interviews participated (56%), as did eighteen of twenty-four family members (75%). In-person interviews were conducted at a time and location of consenting participants’ preference, usually at home, school, college, or NHS premises. This study was approved by the North West - Greater Manchester East NHS Research Ethics Committee (16/NW/0893). All participants provided written informed consent to participate.

| Table 1  | Participant characteristics. |
|----------|-----------------------------|
|          | Young people N = 13         | Family members N = 18 [16] |
| Age (years), mean (range[SD]) | 16 (15–19[1*19*24]) | 49 (37–71[8*03]) |
| Gender, n (%)                           |                          |
| - Female                                 | 10 (77%)                 | 14 (78%)              |
| - Male                                   | 3 (23%)                  | 4 (22%)               |
| Ethnicity, n (%)                         |                          |
| - White British                          | 8 (62%)                  | 18 (100%)             |
| - Other                                  | 2 (15%)                  | –                     |
| Treatment allocation, n (%)             |                          |
| - Antipsychotic medication only          | 3 (23%)                  | 2 (13%)               |
| - Psychological intervention only        | 5 (38%)                  | 7 (31%)               |
| - Combined treatment                    | 5 (38%)                  | 7 (31%)               |
| Treatment received, n (%)               |                          |
| - Antipsychotic medication only          | 3 (23%)                  | 2 (13%)               |
| - Psychological intervention only        | 6 (46%)                  | 5 (31%)               |
| - Combined treatment                    | 4 (31%)                  | 9 (50%)               |
| Treatment quantity (across allocations) |                          |
| - AP, duration, weeks (range)           | 34 (19–52)               | –                     |
| - CBT, sessions (range)                 | 17 (2–24)                | –                     |
| - FI, sessions (range)                  | 3 (1–5)                  | 4 (1–7)               |
| Family relationship, n (%)              |                          |
| - Mother                                 | –                        | 13 (72%)              |
| - Father                                 | –                        | 4 (22%)               |
| - Grandmother                            | –                        | 1 (6%)                |

* 16 interviews; 2 included two parents.

b 18 years old at trial entry; 19 at interview.

c details about ethnicity and site removed to ensure participant anonymity.
2.2. Procedure

Semi-structured interview schedules were developed to explore views of MAPS treatments. The bounds of confidentiality, anonymity, and data security were discussed prior to each interview. Interviews were conducted by RB, SR, and JB, and audio-recorded; recordings were transcribed verbatim, at which point identifying information was removed.

2.3. Data analysis

Data analysis followed Braun and Clarke’s approach to Thematic Analysis [16]. Analysis was conducted inductively at the manifest level, to accurately represent participants’ immediate meaning, and to elicit accessible thematic representations of interviewees’ views.

All authors were involved in the analysis and read all or a sample of the transcripts. WJ initially coded all transcripts within NVivo qualitative data analysis software (Version 11 [17]). RB and WJ reviewed and developed this initial coding, which sought to identify all sections of data that informed the research question. The emerging coding framework was regularly discussed and refined under supervision with SP. These analysis discussions also identified new questions to ‘ask’ of the data, prompting further refined coding and interpretation until thematic sufficiency was achieved [18,19]. The core analysis team (RB, WJ, and SP) periodically met with the wider central team (DS, MP, TM) to further develop the analysis and establish consensus of the emerging thematic ‘maps’ representing both commonalities and variations within the dataset. Over time, this mapping process elevated or reduced the prominence of key candidate themes in order to produce a final model of participants’ perspectives. JB and SR provided remote review of structured findings.

Study design, data generation, and analysis were conducted with the involvement of individuals with personal or parental experience of psychosis-spectrum difficulties. The multidisciplinary analysis team included service user, parent caregiver, general practitioner (GP), clinical psychology, and health psychology perspectives. These are both recognised steps to increase trustworthiness in the final analysis [20].

2.4. Role of funding

This study was funded by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme following a commissioned call (15/31/04). The call specified the interventions, population, setting, comparator, study design, and important outcomes. The funder of the study had no role in data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

3. Results

There was a single superordinate theme of ‘Any help was better than nothing’, where participants weighed the perceived benefits and costs of each treatment against the urgent need to seek help regardless of treatment type (see Fig. 1). Subordinate thematic categories expand on these in relation to each intervention and are described and illustrated below with data. Where young people had experienced combined treatment, analysis sought to identify explicitly treatment-specific views. Additional supporting quotes are shown in the Appendix to provide further detail and increase transparency of analysis.

3.1. ‘Any help is better than nothing’

For both YP and family members, treatment acceptability was primarily characterised by acceptance of any treatment that may help:

didn’t know what was like going on with me and stuff like I didn’t understand why I heard stuff so I thought if it’d help then I wouldn’t mind any of them (YP12, AP+PI)

YP and family members expressed urgency in needing help for distressing experiences and valued timely access to the treatments offered in the trial, particularly psychological therapy, as this was seen to be limited within NHS services. Family members in particular felt that “any help was better than nothing” (F04) and had wanted to “throw everything at it” (F08), perceiving that more treatment, regardless of type, increased the likelihood of benefit. The priority of accessing support as quickly as possible was weighed to varying degrees against concerns around the safety of treatments, particularly medication side effects.

3.2. Views of treatments

There were a range of views around each treatment type, and where YP had received combined treatments, YP and family members often reflected upon interactions between treatments, along
with degrees of uncertainty when attributing effects or changes to any one treatment.

3.3. Antipsychotic medication

Informed both by perceived effectiveness and potential side effects, most YP and all family members reported that they did or would have accepted AP:

if it helps then I’ll take it (YP03, AP+PI)

One YP explicitly stated they would not have accepted AP if it had been allocated, though several YP and family members preferred AP over CBT as it was seen to more effectively reduce distress or extreme behaviour, and three family members suggested intervening if AP had not been prescribed:

I would have considered that him not taking antipsychotics would have put his [siblings] at risk. I’d have said sorry no that’s not happening (F06, AP)

3.3.1. Valued changes

All participants who took AP (n = 7) reported benefits, including psychosis-specific and general wellbeing improvements. The most common psychosis-specific improvements were reductions in auditory and visual hallucinations:

the aripiprazole’s reducing the level of voices I hear so they’re quite, the volume isn’t as loud, they’re quite reduced now, so it’s a lot easier to manage (YP11, AP)

Additional psychological benefits included reductions in social anxiety, paranoia, or unwanted cognitive intrusions, which contributed to improved social functioning:

when you’ve got like medication that’s making you more stable, then you’re more like logical about leaving the house and stuff (YP03, AP+PI)

Most family members identified similar benefits they attributed to AP, and had observed deteriorating symptoms where AP were temporarily absent. Perceived benefits were psychosis-specific and more general (e.g. improved sleep and functioning).

3.3.2. Adverse effects and challenges of antipsychotics

All YP who took AP reported side effects, as did almost all family members. Sedative effects were the most common (e.g. “I felt really really tired” YP02, AP; “it is quite strong and it does knock you out” F16, AP), though sedation and increased sleep were also viewed by some in positive terms. YP reported other notable side effects including worsening mood and physical symptoms such as pain, headaches and unwanted weight gain, and one YP described the potentially stigmatising impact of taking AP. Additional adverse effects observed by family members included tremors, anger, agitation, pacing, headaches, and nausea. Family members also described short-term deteriorations while YP were adhering to AP, in some cases attributing these deteriorations to AP, and several family members had intervened when concerned about adverse effects of AP:

the dose that she was originally put on was too high so I tried that for two days and I just went back and said this isn’t my child… she was like a walking zombie… I actually got a phone call from school to collect her from school because she was not fit for anything that day (F04, AP+PI)

There was also some concern about long-term AP use amongst both YP and family members (“if that can be avoided I don’t think it’s a bad thing”, F05, PI), and several challenges that arose in relation to the sourcing or maintenance of AP prescriptions. One mother personally administered daily doses in case her son forgot, and another posted AP to her son while he was away from home to ensure continued adherence.

3.4. Psychological intervention

Overall, YP and family members expressed a clearer preference for psychological therapy, informed both by positive beliefs about therapy (having someone to talk to, addressing historic issues), and concerns about AP (side effects, long-term dependence). Some were initially cautious (“I don’t like speaking to anyone. It would have been difficult”, YP05, AP); one mother worried that attending CBT might have been harmful for her daughter, following a negative experience of counselling. Some parents viewed CBT positively but doubted it would help as much or as quickly as it might if combined with AP. Family members consistently viewed FI in positive terms, and several were disappointed that they had not been involved in FI. However some YP were clear that they had or would have declined FI from the outset.

3.5. Cognitive behavioural therapy

3.5.1. Interpersonal engagement and activity

Most YP who attended CBT sessions valued having regular opportunities to speak about their difficulties with therapists they found trustworthy and understanding:

I could never talk to anyone, and cos it’s kind of hard to talk to people about things that they’re never gonna understand but with [therapist] I felt like I can talk to her about anything (YP13, PI)

YP valued practical flexibility, especially therapists’ capacity to visit them at home and to rearrange sessions when requested. CBT was experienced as a more active and interactive therapeutic approach than YP had expected or experienced previously, with most YP describing aspects of collaborative working, goal-setting, therapists’ use of written materials, and homework tasks.

3.5.2. Valued changes

Many YP who undertook CBT described benefits. The most common benefit identified by both YP and family members was YP gaining improved understanding of themselves and their psychological experiences:

[therapist] would ask me ok ‘so when you’re really anxious kind of what’s going on, like what happens’ and then we found ok, when I’m really anxious then I’ll start like hearing things and I’ll start to see things (YP08, PI)

YP’s understanding was seen to have improved especially by gaining new ways of thinking about and responding to distressing thoughts, emotions, and psychotic experiences:

like I will feel something and then I’ll end up going in the same circle of my actions, whereas when someone’s offering you a new way it might change how you do it (YP03, AP+PI)

YP and several family members identified the normalising of psychotic phenomena as particularly helpful:

I think it’s really good that there was somebody out there who could say actually you know what this is normal, and there’s lots of people who experience it (F12, AP+PI)
Some YP and family members attributed full or partial reductions in auditory or visual hallucinations to engagement with CBT, and many identified additional improvements in mood-related domains such as confidence, motivation, stress, anger, and anxiety. YP who found CBT beneficial also identified improvements in their social and occupational functioning, and this was commonly echoed in family interviews (“she’s going out with her friends more now”, F10, PI; “he’s doing well at college”, F14, PI). YP also described feeling more able to open up to others, enabling further social support.

3.5.3. Adverse experiences and challenges

Although neither YP nor family members described CBT as harmful, participants did experience difficulties while undertaking CBT. In particular YP identified the initial difficulty of ‘opening up’ with their therapist, or feeling upset by revisiting distressing experiences:

I think that it was good that I did that cos I kind of came to terms with all of it… but yeah while I was talking and stuff and, it was upsetting (YP12, AP+PI)

Additional idiosyncratic adverse experiences related to goal setting, being spoken to by a therapist as if by a teacher, fatigue following sessions, and short-term stress in relation to behavioural experiments.

Several family members described difficulties for their YP engaging in CBT, in one case attributed to sedative effects of AP, and for another due to a learning difficulty. Some YP and family members were uncertain about the durability of benefits attributed to CBT (“it doesn’t really stop things from happening again”, YP03, AP+PI), and several family members expressed disappointment around CBT ending.

3.6. Family intervention

There was more variability in YP’s engagement with FI than with CBT, and wide variance in family members’ involvement in FI. However feedback from both groups was broadly positive.

3.6.1. ‘A chance to tell them what I’m going through’

FI was seen to facilitate a safe space for YP and family to express concerns in a contained way. Although YP may have discussed their difficulties to some degree with family members prior to FI, several had not, and family sessions were valued for enabling such discussions and the development of a shared perspective:

the family session was a chance for me to tell them what I’m going through and a chance for them to tell me what I’ve been doing wrong, and what I’ve been doing right (YP06, PI)

3.6.2. Improved understanding amongst family members

The most consistent change associated with FI by both groups was improvement in family members’ understanding of the YP’s difficulties, which was in turn seen to facilitate improved communication and support:

now [YP] will talk to me so the positive is if she’s on a low she will, she knows that I am here and I will talk with her (F04, AP+PI)

3.6.3. Difficulties of family intervention

Along with outright reluctance to involve family members in FI, several YP recalled that it had initially been difficult to undertake FI sessions, feeling that discussions could be embarrassing or even ‘scary’:

I think to actually get that conversation started of like I hear people that aren’t there… it’s really really hard to put that into words and especially to someone that you love because what you don’t want them to do is turn around and be like you’re crazy… that’s your immediate fear (YP10, AP+PI)

Experiences of substantial distress in FI were more often described by family members than YP, who felt upset by some of the YPs’ disclosures. Importantly, family members specified that they accepted such distress in order to help their YP:

it was probably one of the hardest things I’ve had to do sitting listening and I didn’t want to, I didn’t want to listen, but she didn’t want to have to go through it… it never crossed my mind to stop anything because I knew it was for her (F02, PI)

Several practical challenges of FI were identified by family members, such as finding time to attend sessions or undertake between-session family activity, and several family interviewees expressed disappointment because they had not been involved in FI.

3.7. Combined treatment

3.7.1. ‘Best of both’

Some YP and a majority of family members voiced a first preference for combined treatment, and all YP who engaged with both treatments described the combination as helpful. They suggested that as each treatment could help in different ways, a combination offered the optimal range of short and long-term benefits. A consistent view was that AP enabled YP to be sufficiently well to engage with the demands of therapy:

Yes I do think they worked well together, I think the fact that the medication calmed her mind, helped her focus on her CBT sessions and put in to practice what she’d been, what [therapist] was teaching her (F02, PI)

4. Discussion

This is the first qualitative study to investigate in-depth the views of both young people and family members in relation to treatments for FEP. Findings illustrate complex views of treatment acceptability and experience; amongst family members in particular, there was a strong endorsement for early commencement of treatment for FEP irrespective of treatment type. AP were valued for reducing symptoms of psychosis, but also elicited strong concern around unwanted side effects and long-term use. However the strongest concern was voiced by family members worried about AP not being prescribed in cases of serious risk and severe distress. CBT was broadly viewed as a more benign and therefore acceptable intervention, and was seen to help YP understand and cope with their experiences, although several YP and family members were concerned that CBT alone would not sufficiently alleviate serious distress or risk. The clearest difference between participant groups was evident in views of FI: while FI was acceptable to all family members interviewed, several YP explicitly opposed family involvement. Combined treatment was well accepted, particularly amongst family members; there was common recognition that treatments work in different ways, and that a combination may interact to bring about greater change.

Most treatment-specific studies with which to compare these findings are derived from adult populations, which focus predominantly on aspects of antipsychotic prescribing, and this includes studies comparing patient and professional views of treatment for psychosis, none of which discuss adolescent treatment [21,22]. One previous study of YP views of AP identified ambivalence, and benefits of AP being tempered by adverse effects, although this study sample was not psychosis- or adolescent-specific [11]. Both YP and family
members in this study reported benefits, adverse effects, and concerns about long-term use of AP, and this accords well with existing research. A recent major review of thirty-two studies concluded that although service users hold largely positive views about short-term use of AP to address acute difficulty, they are more sceptical or concerned about long-term use due to negative impacts of AP on functional and social recovery [10].

Participant accounts of CBT in this study highlight largely positive views of interpersonal engagement with therapists, commonly valued improvements in understanding psychosis, self, and coping, along with symptom reductions, and these aspects have previously been identified in qualitative adult studies of CBT [11–13]. Challenges of CBT are also reported in the present study, particularly the difficulty of ‘opening up’ about distressing thoughts and emotions, reliving past experiences, and finding the process cognitively difficult, and these have also previously been identified [12,13]. No notable concerns about long-term adverse effects of CBT (or FI) were described by participants, nor have such concerns been reported in existing qualitative literature [11–13].

Our findings identify the perceived value of sharing concerns and enhancing support in FI amongst both YP and family members, and similarly this accords with a substantial body of literature exploring family and carer experiences of family involvement in adult psychosis treatment [23,24]. A review of 22 qualitative studies identified the key elements of FI as therapeutic alliance, support, and the opportunity for sharing, along with the provision of psychoeducation around psychosis [14], and each of these factors is evident in our findings.

A comparison of YP and family views with those of clinicians consulted for the MAPS trial [25] shows general agreement between groups, with several discernible differences. While YP and family viewed AP as helpful, the majority did not emphasise AP as a first-line treatment to the same degree as clinicians; rather they accepted it as one treatment option amongst others, and sometimes the only treatment available due to lack of psychotherapeutic resource within NHS services. Some family members and clinicians felt that CBT alone would not address acute distress or risk as effectively as AP, a specific concern not voiced by YP. A preference for combined treatment was shared by a majority of both family members and clinicians, but was explicitly stated by fewer YP.

Exploring the views of YP and family members about multiple treatment types may limit the ability to inform any one topic. While we sought to capture a diverse range of views to reflect the full variance of the trial sample, participant sampling was not systematically conducted in line with variance within quantitative outcome data (i.e. a quantifiably representative range of treatment experiences). There was some inevitable sampling bias due to the lower rate of contact YP and family members had with trial staff if allocated to receive AP only (AP-only allocations accounted for the fewest YP and family participants in this study; 23% and 13% respectively). Moreover, as all participants had consented to a trial where both AP and CBT/FI were delivered, findings may not reflect the complete range of concerns held by those who fully reject AP or therapy. Although YP and family dyads were included in five cases (i.e. YP and their family member/s attended interviews), our methodology did not directly compare related participants’ accounts, and this would be an interesting avenue for further research. Interviews were cross-sectional, so may not have captured valuable views of changes over time.

Given the broad acceptability of both main treatment types, along with individual differences in treatment preferences, further definitive trial evidence is warranted to establish the relative treatment targets, effects, and negative impacts of each treatment type to help inform and improve treatment choice for YP with FEP and their family members. This might be achieved by ordering the delivery of interventions in line with individual outcome priorities and preferences. Researchers are increasingly exploring the value of targeting treatments to specific difficulties based on patient preference [26,27], and future qualitative research can enhance this approach by exploring and informing treatment for specific aspects of psychosis [28].

Declaration of Competing Interest

RB reports personal fees from CBT for psychosis (CBTp) Training at Oxford Cognitive Therapy Centre (OCTC), Oxford Health NHS Foundation Trust. JB reports personal fees and fees paid for clinical supervision of CBTp training at OCTC, Oxford Health NHS Foundation Trust. DS reports personal fees from the National Clinical Audit of Psychosis, personal fees from Wiley Blackwell publication “Promoting Recovery in Early Psychosis” 2010, ISBN 978-1-4051-4894-8, outside the submitted work; and is an expert advisor to the NICE centre for guidelines, member of the current NICE guideline development group for Rehabilitation in adults with complex psychosis and related severe mental health conditions, and board member of the National Collaborating Centre for Mental Health (NCCMH), outside the submitted work; the submitted work represents personal views and not those of NICE, NCCMH or NACP. APM reports personal fees from CBT for Psychosis training, and personal fees from Book publishing, outside the submitted work. MP reports personal fees and fees paid to the Psychosis Research Unit from CBT Training at Greater Manchester Mental Health NHS Foundation Trust. All other authors report no conflict of interests.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.eclinm.2020.100417.

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