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Personal preferences for treatment and care during and after a First Episode Psychosis: A qualitative study

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Abstract

Aim: A first episode of psychosis (FEP) is a stressful, often life-changing experience. Scarce information is available about personal preferences regarding their care needs during and after a FEP. Whereas a more thorough understanding of these preferences is essential to aid shared decision-making during treatment and improve treatment satisfaction.

Methods: Face-to-face interviews with participants in remission of a FEP were set up, addressing personal preferences and needs for care during and after a FEP. The interviews were conducted by a female and a male researcher, the latter being an expert with lived experience.

Results: Twenty individuals in remission of a FEP were interviewed, of which 16 had been hospitalized. The distinguished themes based on personal preferences were tranquillity, peace and quietness, information, being understood, support from significant others, and practical guidance in rebuilding one's life. Our findings revealed that the need for information and the need to be heard were often not sufficiently met. For 16/20 participants, the tranquillity of inpatient treatment of the FEP was predominantly perceived as a welcome safe haven. The presence and support of family and close friends were mentioned as an important factor in the process of achieving remission.

Conclusions: The current exploratory study showed that patients were able to indicate their personal needs. Important findings are the need for information and the need to be heard. Interestingly, hospitalization was mostly seen as an opportunity to achieve tranquillity. More lived experience expertise is needed to elucidate the needs of individuals in the early phase of a FEP to aid people who are recovering from their first psychosis in rebuilding their lives again.

KEYWORDS

First Episode Psychosis, personal needs, personal preferences, remission

1 | INTRODUCTION

A first episode of psychosis (FEP) is a stressful, often life-changing experience, not only for the people who experience it but also for their significant others. Psychoses can vary largely with regard to symptoms, comorbidity, and severity (Ahmed et al., 2018). Therefore, treatment should include careful consideration of the individual needs and preferences, of patients as well as those of their significant others (Fusar-Poli et al., 2017). These preferences can be met by professionals, in a shared decision-making process (SDM). Duncan et al. (2010) suggest that interventions that increase SDM in individuals with mental health conditions may increase treatment satisfaction. However, during a FEP, most individuals are not familiar with the concept of psychosis and the available treatment options. The impact of going through a FEP should not be underestimated and may even be sufficiently traumatic to develop PTSD symptoms, which could have a profound negative impact on a person's outcomes (Rodrigues & Anderson, 2017). Educating individuals on their diagnosis and potential treatment options as soon as possible can aid the SDM process, including the use of (web-based) tools to gain insight. It may be necessary to put more emphasis on educating individuals on their medical condition. Being well-informed enhances the ability to take part in SDM, for example by using (web-based) tools to gain more insight into the diagnosis and available treatment options (van der Krieke et al., 2013). After experiencing a FEP, individuals face a new and unfamiliar situation as a person recovering from psychosis, while challenged by various additional factors, including residual psychotic symptoms, cognitive deficits, impaired metacognition, and sometimes a continued limited insight into the illness (Leonhardt et al., 2020). The unfamiliar situation might restrict their capacity to make optimal decisions.

Research has shown that a person's consent to engage in a collaboratively chosen treatment strategy predicts both treatment adherence and better long-term outcomes (Guinaudie et al., 2020; Simmons et al., 2021). Both individuals with lived psychoses and clinicians bring different, but equally important, knowledge to the decision-making process (Fiorillo et al., 2020). If the provided care is better suited to the needs of the individual involved, this might increase successful treatment. Indeed, a comprehensive literature review showed that poor therapeutic alliance was associated with non-adherence to antipsychotic medication in patients with schizophrenia (Lacro et al., 2002).

Some studies have investigated personal preferences in FEP treatment approaches, yet this type of research is significantly under-represented given the importance of this topic. Ramsay et al. (2011) revealed that answers to open-ended questions in FEP yielded employment, education, relationships, housing, health, and transportation as the most frequently stated life goals. Furthermore, Bak et al. (2003) showed that the severity of psychotic experiences, the average level of control over symptoms, and coping strategies determine whether people have a specific need for care.

Torrecilla-Olavarrieta et al. (2021) concluded that the perception of being part of the decision-making process regarding their treatment, together with a higher age of onset, led to higher satisfaction scores. Furthermore, Nordon et al. (2012) stated that more recent use of antipsychotic agents and psychosocial therapy was related to

higher treatment satisfaction. In sum, perceived participation in the decision-making process concerning treatment was associated with higher treatment satisfaction (Cruz et al., 2017).

Wiersma et al. (1998) highlighted the relevance of considering both objective and subjective assessments of personal needs. They pointed out that it is important to learn more about the subjective needs in the early stage of psychotic disorders. Currently, little is known about the personal preferences and needs of people during and after recovering from a FEP. More insight into the needs of individuals experiencing a FEP may inform clinical teams and give indications of how to best address these needs and enhance treatment satisfaction and outcomes. Considering the above, a deeper understanding of personal needs and preferences of care during the first months of treatment of people with a FEP is critical.

In the current study, we aim to gain more insight into the personal perspective on received care and the needs of people with a FEP regarding their treatment during the acute phase and the subsequent recovery period thereafter (3–6 months after psychosis) using an interpretative phenomenological approach.

Too little is currently known about the personal needs of individuals that are going through such a stressful phase in their young lives. We hypothesize that a better understanding of personal needs would aid a better and quicker recovery trajectory, due to an improved match of the treatment to the needs of the individual recovering from a FEP. A more tailored treatment trajectory would allow individuals to get back on track with the lives that were put on hold. To maximize our ability to capture issues relevant to the first phase of illness during and directly subsequent to a FEP, we opted for a qualitative assessment in the present study.

2 | METHODS

2.1 | Research design

The current study used a descriptive, interpretative phenomenological approach to gain insight into the personal needs of individuals recovering from a FEP. Matua and Van Der Wal (2015) employed a phenomenological methodology to investigate subjective experiences, aiming to uncover the concealed elements within these subjective experiences. This major philosophy has become increasingly important in interpreting these subjective experiences. An in-depth understanding of subjective experiences allows healthcare professionals to better meet the personal needs of people recovering from a FEP. Other research used a descriptive phenomenological approach for their study to help them provide unique, personal insights and subjective experiences of humans with lived experiences, not an objective situation nor the clinicians' perspective (Huurman et al., 2023).

To better understand the personal needs during and after a FEP of the participants in the present study the same approach was chosen. A guideline was written to discuss all possible relevant topics, while a semi-structured interview approach allowed to explore other subjects if so, prompted by the participants. The interview started with open-ended questions to elicit spontaneous recollection of

topics that played a role during the process of recovery. When no more spontaneous items could be recollected, several predefined topics were discussed. These predefined themes followed the EBRO module of Psychiatry standards, in the Netherlands (Netwerk kwaliteitsontwikkeling GGZ, 2017; Veling et al., 2012). This EBRO module is the Dutch Guideline for 'Early Psychosis' care. By using this phenomenological approach, we aimed to retrieve underlying, deeper experiences and thoughts. By using the Dutch Guidelines for Early Psychosis (EBRO Module), we followed the approach of these guidelines, involving individuals as much as possible in the approach to their treatment. The current study followed the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007), except for audio/visual recording (item no. 19, COREQ). At the time of constructing the interview, researchers were unaware that recording was proposed to do so.

2.2 | Population

We invited individuals in remission for 3–6 months after a FEP for participation in our study. Individuals were selected from the ongoing HAMLETT trial (Begemann et al., 2020; Medical ethical registration number-number: 2017-343; EudraCT no. 2017-002406-12), investigating the effects of early discontinuation versus maintenance treatment on long-term clinical outcome. The number of participants depended on data saturation. Researchers of the HAMLETT trial (Central Inclusion Team—CIT) asked potential candidates about their interest to engage in the current study during the baseline study visit when they were 3–6 months in remission of FEP. Upon informed consent, IHH approached the participants to schedule an appointment to conduct the interview. The setting of the interview was initially planned to be a face-to-face set-up at a location according to the participants' preference (home, hospital, and public place). Due to the constraints during the COVID-19 pandemic, a digital set-up was in place. Potential participants were invited to take part consecutively until data saturation was reached. Participation in this sub-study was not mandatory for participation in the HAMLETT trial. Of the 42 individuals who were invited to participate, 22 individuals refused. Participants were not asked to provide reasons for refusal.

The main inclusion criteria of the HAMLETT study are experience of a FEP and current antipsychotic medication use. Eligibility criteria for our interview were 3–6 months remission, as it was for the overarching HAMLETT study, of psychotic symptoms and an age range of 16–55 years. Participants with a history of dangerous or harmful behaviour or coercive antipsychotic medication treatment based on a judicial ruling were excluded from our study.

2.2.1 | Data collection

Semi-structured interviews were conducted by two researchers; IHH is a female researcher by training; BSR is a male researcher with lived experience of psychosis. The main topics addressed in the interview were personal preferences on the need for care during FEP and the

subsequent recovery period after remission, covering at least the following topics: (1) perceived needs, (2) evaluation of received treatment and care, (3) met and unmet personal needs, and (4) persons or activities that played a decisive or significant role.

2.2.2 | Quality assessment

The criteria for qualitative research include trustworthiness, credibility, transferability, dependability, and confirmability (Bryman, 2012; Lincoln & Guba, 1985). Ensuring the credibility of retrieved findings involves exerting utmost effort to conduct research in accordance with established standards of good practice, and, where appropriate, submitting the research results to the patients who were studied for confirmation that the researcher had understood them correctly. This technique is referred to as respondent validation (Bryman, 2012). Therefore, during each interview, the feedback loop was built in to check whether interpretations were in line with what the participant shared during the interview. Transferability was strengthened by comparing the revealed data with the existing literature on this subject to confirm the findings or establish the opposite. To strengthen dependability, the researchers ensured complete records and kept audit trails of the research process (Bryman, 2012). Researchers were challenged by the supervisor of the study with regard to their personal values or ideological inclinations that might have influenced the findings (Bryman, 2012). Both researchers brought their own perspectives on how the interviews were interpreted. The fact that one of the researchers was an expert with lived experience brought a valuable dimension to the study. Due to his own experience, questions touched upon themes that might otherwise have remained undiscussed.

The interviews were conducted in a semi-structured manner. To reveal topics in a deductive as well as in an inductive way, participants were first asked to spontaneously recollect the most important personal needs during their FEP. This open-ended question was repeated until no additional spontaneous needs were mentioned. After these spontaneous recollections, we included a range of predefined topics. Participants were asked whether there was a need to discuss the topic and if so, whether information on the topic was met or not met during the treatment of their FEP. Subsequently, we asked participants how they think the specific topic could have been better addressed. The predefined topics included: psychoeducation, approach of the healthcare professionals (doctor/nurse), why hospitalization was needed (if applicable), information on pharmacotherapy, offered psychosocial interventions, intimate relationships, and financial matters. By using the phenomenological approach, we tried to retrieve underlying, deeper constructs of personal needs. All Interviews were planned to be conducted by two interviewers (BSR and IHH) together, one of whom has lived experience with psychosis. As both interviewers were complementary to each other, this set-up enabled us to touch upon different aspects and constructs. This approach allows one to delve deeply into matters, relevant to the participant (Dicicco-Bloom & Crabtree, 2006). Moreover, it aids with monitoring the process on the one hand and digging into underlying constructs of the personal needs

of participants on the other hand. Revealed constructs were noted by both researchers and combined to form a complete answer.

2.3 | Analysis

A content analysis was conducted of the constructs, revealed through the phenomenological of personal needs of individuals recovering from a FEP. Thematic analysis is an appropriate method of analysis for seeking to reveal and understand experiences, thoughts, or behaviours across a data set (Kiger & Varpio, 2020). All captured information was transcribed by one of the interviewers and supplemented with additional information from the other interviewer, if any. After transcribing all interviews, the transcripts were thoroughly read and reread by both interviewers (BSR and IHH). BSR and IHH then actively constructed themes, following the coding of the set of data (BSR and IHH). At an intermediate stage, the coding and analyses of the data were presented to a third researcher (NB) until consensus was reached. They identified the main themes that emerged from the transcripts. This was done first with the spontaneously recalled personal needs, followed by the provided set of topics. No software (item no. 27, COREQ; Tong et al., 2007) was used to code the data.

2.4 | Ethical approval

Ethical approval was obtained for the HAMLETT study from the research and ethics committee of the University Medical Center Groningen, The Netherlands, protocol number NL 62202.042.17. On average, an interview lasted 1.5 h. Participants were offered EUR 20 in gift vouchers at the end of the interview, as a token of appreciation for their invested time. To reduce potential response bias, the gift vouchers were not mentioned prior to the interview when appointments were made.

3 | RESULTS

3.1 | Participant characteristics

In total, 20 interviews were conducted. The mean duration of an interview was 1.5 h. Table 1 shows an overview of the participant demographics and main characteristics. Due to the constraints during the COVID-19 pandemic, 5 out of 20 interviews were conducted via an online video call platform. Eleven out of 20 participants were female. Of all participants, $n = 16$ participants (80%) had been hospitalized sometime during their FEP, with the length of hospitalization varying from 2 to 24 weeks, with a mean duration of 5.7 weeks (SD = 5.6 weeks).

Five themes could be distinguished according to personal preferences on the need for care during their first psychotic episode and the first 3–6 months of the recovery period: (1) Tranquillity, peace, and

quietness; (2) Need for information; (3) Feeling of being understood; (4) Support from loved ones; and (5) Practical guidance in picking up one's life. The themes are described in more detail below.

3.2 | Tranquillity, peace, and quietness

Participants mentioned that tranquillity and feeling safe were one of the most important needs during the psychotic episode. Participants indicated that sometimes they did not manage to achieve tranquillity themselves. Some participants reported several factors that helped in this regard, including hospital admission, support from relatives and medication. Nine participants ranked peace and quietness as their most important need during the phase towards remission. They achieved tranquillity with a quiet room to sleep during hospitalization (*'During the first week of my admission I only slept to recover'*, part. #17). One participant experienced this tranquillity at home with family (*'I needed as few stimuli as possible'*, part. #7). Besides peace, the hospitalization also helped to provide a sense of security.

3.3 | Need for information

Participants reported that they needed more information about the psychotic experiences, as well as about potential treatment options (*'I wanted to understand what was happening but did not receive any explanation'*, part. #13). Participants stated that more explanation on the diverse topics would have led to better understanding of the situation and less anxiety (*'I was so scared; I did not trust anyone. Being in solitary confinement was also very frightening; nothing was explained to me. I did not understand what was going on'*, part. #4).

Participants also reported that the term psychosis was not explained to them, or that they could not relate to the explanation that was given. Participants would have liked to talk more often about their experiences, causes, and meanings so that they could get a better understanding (*'I did not know what a psychosis was and did not receive any information on the psychosis in the beginning'*, part. #17).

A clear need for information about the received medication was also mentioned, this was an unmet need for half of the participants: (*'I would have liked to have information about the medication—I got an injection, but no one told me why and what it was for'*, part. #4). Furthermore, participants missed clear information about the effects and side-effects of antipsychotics. More information might have helped them to be more motivated to take the medication (*'I needed more information on the medication: of one type of medication, I got very sedated, the other type of medication made me eat more so I gained weight'*, part. #8) (*'I was very suspicious of the medication, so I did not want to take it. When a friend motivated me to take the medication, this distrust was quickly lessened by taking the medication'*, part. #9).

TABLE 1 Demographic characteristics of the participants.

Part #	Gender	Age group	Adm during FEP	Dur. adm. (weeks)	Expected duration of AP use (yr ^b)	Residential status	Educational level	Occupancy
1	Male	26–30	Yes	6	<1	With parents	Senior General Ed. ^c	Volunteer
2	Male	21–25	Yes	2	1	Students home	Senior General Ed.	Studying
3	Male	21–25	Yes	8	1	Sheltered home	Unknown	Volunteer
4	Female	41–45	Yes	3	2	With partner & family	University	Employed
5	Female	36–40	Yes	9	>2	With partner & family	Practical & Prevocational	Employed
6	Male	21–25	Yes	4	1	With parents	Senior General Ed.	Expert by experience
7	Female	56–60	No	n/a	2	With partner	Higher prof. ^d & Pre-University	None
8	Female	46–50	No	n/a	>2	Single	Unknown	Employed
9	Female	26–30	Yes	2	1	Single	Practical & Prevocational	Employed
10	Male	21–25	No	n/a	<1	Not known	Higher prof. & Pre-University	Trainee
11	Male	36–40	Yes	2	<1	Single	Higher prof. & Pre-University	Employed
12	Male	26–30	Yes	6	1	Not known	Senior General Ed.	Employed
13	Female	≤20	Yes	? ^a	>2	Single	Senior General Ed.	None
14	Male	21–25	Yes	24	2	With parents	Practical & Prevocational	Employed
15	Female	21–25	Yes	3	>2	With parents	Practical & Prevocational	Employed
16	Male	21–25	Yes	3	2	With parents	Higher prof. & Pre-University	Employed
17	Female	26–30	Yes	3	1	Single	University	Studying
18	Female	≤20	Yes	8	1	Single	Senior General Ed.	Employed
19	Female	31–35	Yes	2	<1	With partner	Higher prof. & Pre-University	Employed
20	Female	31–35	Yes	n/a	1	Single	University	Employed

^aDuration of hospitalization was unknown.

^bYear.

^cEducation.

^dProfessional.

3.4 | The feeling of being understood

Participants mentioned that being understood was important to them ('I wanted my request for help to be listened to', part. #7); ('From GP to specialized Care: there was a no-judgment space. I was heard', part. #10). Participants appreciated this feeling of being understood.

Participants indicated that it felt good to always have someone around to talk to and who understood their situation ('It felt good to talk to the same nurse (case manager) every time', part. #10). Participants described that they met with many different staff members, which complicated contact with care providers in some cases. They also indicated that telephone contact by a healthcare provider with a restricted number was difficult ('Follow-up phone calls were made with

unknown telephone numbers; therefore, I wasn't able to recognize my healthcare provider', part. #2). Feeling understood by health care providers helped them to understand themselves ('I realized that I need medication and using cannabis is not good for me', part. #10).

3.5 | Support from loved ones

Some participants who were admitted during a FEP would have appreciated more contact with significant others (family members) during their hospital stay, but this option was not always offered ('I would have liked to have my dad with me during my admission, but he was not allowed to visit me', part. #15). One participant described

feelings of loneliness during hospitalization (*'I was left alone when I needed loved ones around me'*, part. #5). Others described the support of significant others as very helpful, also for making important choices in treatment (*'A friend persuaded me to take my medication, not my physician'*, part. #9). Furthermore, the support of family members, like parents, was mentioned as being beneficial in preventing admission and working towards recovery (*'Involving my parents when I got sick, we were able to avoid hospitalization. Hence, living in with my parents again was a necessity'*, part. #10).

3.6 | Practical guidance in rebuilding one's life

Participants said that it was important to have a spokesperson to turn to. Having a primary, acquainted point of contact, somebody to talk to was preferred. This practical help could consist of a fellow patient or a caregiver to help in rebuilding the day structure again (*'There always was someone with whom I could have a conversation, with fellow patients as well as caregivers'*, part. #18; *'I was guided into a clear daily structure, and that was helpful'*, part #11; and *'Everything was arranged for me at that time and that was very welcome'*, part. #19).

One participant mentioned that she would have appreciated earlier intervention (*'Earlier intervention would have been better in my case'*, part. #8). She did not know what a psychosis entailed and became increasingly confused and anxious. Several participants appreciated that they received practical guidance from relatives who helped structure their daily schedules, remember appointments, or go somewhere.

Upon saturation of spontaneous recollection of personal needs, predefined topics revealed a need for psychoeducation, information about admission, and additional information about psychosis and its treatment. The need for psychoeducation was met by more than half of the participants, according to their opinion. The need for information about the hospitalization was met by half of the participants. Only a third of the participants felt that they would have needed additional information about medication.

3.7 | Advice from the participants

Participants were also asked what advice they would give to other people in psychosis care, regarding what to do and especially what not to do to get through the first months after a FEP remission. Participants mentioned the importance of ensuring rest, low stimuli, and good sleep (*'If you cannot manage this on your own, then ask assistance to help you with this'*, part. #11). Several participants also indicated that medication could help with this, as well as regaining control of their lives. They advised against cannabis. Participants also advised involving others, accepting, and not rejecting care providers, and actively involving loved ones (*'Gathering people around you who you can trust, who understand you and can support you is important. Staying in touch with people around you is sometimes difficult but important. Prefer to stay in touch with people outside the counseling service'*, part. #6).

Another respondent expressed advice to put society on pause just for a while (part. #14). Two participants advised focusing on other things and not just dealing with the psychosis. Several participants advised to remain active; and found sports and exercise to help feeling good and try to go back to work as soon as possible and use creative energy. A final advice was to avoid making major life decisions (about, e.g., work and study, part. #9) during the psychosis.

3.8 | Use of antipsychotic medication

All participants had received antipsychotic medication (AP) during their FEP. They were asked about their experiences with antipsychotics. The first question inquired about the expected duration of antipsychotic use. The recollection of this time frame is shown in Table 1 (column 6). Most respondents were told to take medication for the duration of 1 year.

Most participants remembered being given information about that medication. Most recollected information was about duration of antipsychotic treatment, mechanism of action and side-effects (*'My doctor told me that there is a possibility to gain some weight'*, part. #15) (*'I am very tired of the medication, and I tend to forget quite a lot. It is caused by the medication. I hope that I can stop as soon as possible'*, part. #18). Four participants mentioned that they did not receive sufficient information about antipsychotic options (*'I would have liked to have learned more on the duration of medication use and about the side effects'*, part. #2; *'I would have liked to have received more information in general'*, part. #7; *'... about the increased appetite and sedation'*, part. #16; *'... about the mode of action of antipsychotics'*, part. #20). Following the expected duration, participants were asked to think about medication use in the future: Almost half of the participants did not think they would still be using AP medication 2 years from now; in 5 years from now, none of the participants thought they would be using antipsychotic medication, whereas 50% thought they might be using AP medication and 50% stated they definitely would not be taking AP medication.

3.9 | Ontological authenticity

The ontological authenticity can be understood as a measure of the extent to which individuals and the inquirer have developed a more refined and comprehensive understanding of their own constructions, beliefs, and perspectives. It implies a continuous process of growth, learning, and self-awareness, where individuals evolve their initial understandings to encompass new information and insights (Amin et al., 2020). The ontological authenticity of this study was assessed upon completion. In this regard, an indication of the added value of this study was gained from the responses during the interviews: *'This was a really nice conversation'* (Part. #5), *'I felt heard'* (Part. #20), *'You had good questions'* (Part. #6), *'I liked to talk to an expert by experience'* (Part. #8). As such, the interview itself also seemed to be a form of intervention for the participants; the appreciation helped

them. People liked to communicate on an equal footing about their experiences, ‘without having to fill in all kinds of questionnaires’, as stated.

4 | DISCUSSION

To better understand the personal needs of people experiencing FEP, 20 participants in early remission of FEP were interviewed using a semi-structured open-ended interview by two researchers, one of whom was an expert with lived experience.

The five main themes regarding needs and personal preferences during FEP that were collected from the interviews were: (1) Tranquillity, peace, and quietness; (2) the need for information about both psychosis and its treatment; (3) the feeling of being understood; (4) support from loved ones; and (5) practical guidance in reclaiming one's life. Access to mental health support by a dedicated professional was appreciated by those who encountered this. Hospitalization was generally viewed as positive, but the frequent change in staff members during their ward stay was seen as a disadvantage. The tranquillity and quietness that coincided with the hospitalization were appreciated by participants in this study. They felt that this peace and the possibility to sleep as long as needed was an important step towards recovery. As Faulkner and Bee (2017) concluded in their study, the importance of considering sleep within the recovery process should be reinforced. Support from family and close friends was another important contributing factor for recovery, which could have been better supported or implemented during hospitalization. The results of our study replicate the previous results of Addington et al. (2005), who found that families can and do play a major role in the recovery from FEP. The participants in the current study who were not hospitalized did have a single point of contact (a specialized nurse, a doctor, a psychologist, or a social worker) which was helpful in their process of remission.

Information about and more understanding of psychosis were clearly expressed as personal needs. Individuals who experience psychosis for the first time are usually not familiar with the concept of psychosis and often do not know others who have experienced it. Even though the participants were already advanced in the treatment trajectory of a FEP at the time of the interview, they still indicated that many aspects of psychosis and treatment required further clarification (e.g., topics such as the cause of psychosis and why and how long medication must be taken). This finding corroborates a survey among doctors treating people with FEP within the hospital setting, which showed there was no standardized way of providing psychoeducation, and only one-third utilized supplement methods such as flyers, websites, or videos (Belkin et al., 2021). Involving persons right from the start in the treatment strategy may help to address this lack of information, which in return might lead to better outcomes (Guinaudie et al., 2020; Simmons et al., 2021). Using web-based tools to educate individuals as soon as possible will help them to make well-informed shared decisions as early in the treatment as possible which might aid the process of recovery (van der Krieke et al., 2013).

‘Not understanding what was going on’ was a commonly heard remark during the interviews. Although participants in our study stated that more explanatory information about their psychosis would have been welcome, it seemed rather delicate at what time this information should be given and in what way. Information during the period of acute psychosis did not seem to be the right moment for everyone. Later in the process, participants felt more involved when information was shared at a time when they could actually understand and accept the information. The right moment to convey information efficiently, while actively involving the person is not straightforward and needs to be chosen carefully (Farooq et al., 2019; Milton & Mullan, 2014). In addition to a lack of information on psychosis, many participants expressed the need for more information on antipsychotic medication. More information related to medication was a frequently mentioned topic in both the spontaneous recollection phase and the predefined topics.

Where the Camberwell Assessment of Needs (CAN) proposes 22 potentially relevant domains (Phelan et al., 1995), our current study highlights a subset of these topics. This may be of relevance to those seeking to use the CAN to quantify unmet needs in patients with FEP. Within this group, efforts should focus on information and daytime activities. Other domains addressed with the CAN become more relevant when the psychoses recur in time or when people are more advanced in the trajectory of recovery from their FEP. However, CAN is not specially developed for FEP, with limited space for expressing personal experiences (Landolt et al., 2012).

When admitted to a hospital setting, the perceived tranquillity and peace during the phase of the psychosis fading was experienced as beneficial for participants, in the broadest sense. Tranquillity was offered as a safe haven in a ward when the home situation was unsafe, as a place where someone could sleep for as long as needed. Moreover, tranquillity was perceived as the possibility to concentrate on oneself and as a way to re-start daily structure. Among the four persons who had not been admitted, one participant expressed the need that was felt for such a period of rest during this very confusing time for her. Moreover, the fact that one could talk to someone on the ward and felt understood, created comfort as underlined by several responses of participants during the interview. The preference for a treatment period in a hospital, even for persons with a coerced hospitalization, contradicts the trend towards home-based treatment, now popular in many countries as a less expensive alternative to hospital-based treatment (Behan et al., 2015). While it is often assumed that people prefer outpatient care over hospitalization, this was not confirmed in our work.

Regarding the mental health practitioners who provided care, several participants noted having one and the same person to talk to would have been appreciated, as opposed to several different persons. Thus, one spokesperson might become a confidant and they could have brought this information, which would have been trustworthy and could have reduced anxiety and uncertainty. These observations underscore the benefits of working with a case manager who can act as the first point of contact and monitor the client's interests from initial contact to discharge.

Support from family and friends was another important personal need, which was in some cases restricted by hospitalization. Precious relationships with their partner, friends, and family were often subject to distress during a psychosis. Help on how to restore and maintain these relationships would have been of value to many participants, especially in cases where home treatment was the only option and people had to rely on their family and friends for the safe haven they were seeking.

4.1 | Personal advice from participants for individuals with future FEP

Upon request what the participants' tips/advice would be to others in their trajectory to recovery from FEP, some of the personal recommendations were: 'Keep in touch with other people', 'Engage in activities', 'Take your rest', 'Don't take cannabis', 'Focus on other things except the psychosis', and 'Don't make big decisions when recovering from psychosis'.

Although the literature on the needs and preferences of service users during a FEP is scarce, some studies found corroborative evidence. Welsh and Tiffin (2014) came to a similar conclusion regarding the preference for hospital-based treatment when interviewing service users. Others focus more on later life and treatment goals and not on the early-stage preferences and needs of persons with a FEP (Ramsay et al., 2011). Focusing on relationships was mentioned as well as an important need during this later stage. In addition, Ramsay et al. (2011) found that people wanted help with medication. Some wanted help with staying off drugs. These topics were mentioned in our study as well.

4.2 | Strengths and limitations

Although the group of participants was relatively small, the male-female distribution in the study group was almost even. However, in the female group, the mean age was slightly higher, and 3 women were aged 45 years or older at the time of their first psychosis. Women of an older age may have other age-related needs than younger women (Brand et al., 2022; Seeman & Gupta, 2015) and the high hospitalization rate (80%) might reflect a more severe group of people with FEP, thereby impacting the generalizability of our results. Furthermore, during the end of the interviewing timeframe (May 2019–November 2020), $n = 5$ interviews took place via digital platforms, due to the COVID-19 restrictions. This, and the long timeframe in which the interviews took place, might have affected the captured results. Finally, variation in the time interval between FEP remission (3–6 months) may have influenced the memory of participants.

In conclusion, the current exploratory study showed that persons with lived experience were able to indicate their personal needs in the pathway from a first psychotic episode to remission. Personal needs

were not always met. Unfamiliarity with the symptoms because it was the first time underlines the importance of good counselling and education for these people at a vulnerable stage in their lives. More information on psychosis and psychotic medication was an important point of view that was expressed by many service users. Providing a tranquil environment, a dedicated spokesperson, and improved psychoeducation on several topics at the right time might address the unmet needs revealed in our study. Also, the integration of important others (family and close friends) in the care process during hospitalization could be improved. Finally, given that almost all participants experienced the interview in itself as supportive, we recommend including a similar conversation in the treatment program, with the objective of looking back and reflecting on the past treatment trajectory. We propose that these conversations address the personal need of being heard. Our findings reported here suggest that the feeling of being heard and understood is important for people and might help them rebuild their lives again more easily. The findings of this study, though exploratory, are relevant to clinical practice. Future research is needed to gain a better understanding of what specific support is required, as well as the optimal timeline and providers of that type of support, to help people recovering from their first psychosis get back on track with their lives.

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CONFLICT OF INTEREST STATEMENT

The first author, IHH, is part of the HAMLETT research group. She is also an employee at Janssen-Cilag BV, the Netherlands-pharmaceutical company of Johnson and Johnson, yet this work was conducted independently from her employer. The employer did not have any role in the study design, collection of data, in the writing nor the decision to submit this article for publication. Due to the content of this topic, there are no conflicts of interest to declare. JV has served as a consultant for NoBias Therapeutics Inc. and has received speaker fees for Henry Stewart Talks Ltd.

DATA AVAILABILITY STATEMENT

The data, collected through qualitative interviews, that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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