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ORIGINAL ARTICLE

Duration of Untreated Psychosis: A Thematic Analysis of service-users' subjective experiences of diagnosis and seeking treatment

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Abstract

The aim of the present study is to investigate the subjective, lived experiences of service users and their families regarding the onset of psychosis and the pathways in seeking appropriate treatment as well as the barriers they may have encountered during this process. Six in-depth individual interviews were conducted (4 service users and 2 mothers). The study took place between May—October 2023 within a Day Centre for Psychosocial Rehabilitation, located in Athens- Greece. Recruitment was purposeful following the snowball sampling technique. Thematic analysis was utilized for the analysis of data produced from narratives. Duration of Untreated Psychosis (DUP) for participants in the present study ranged between 3–9 years. Six themes emerged. All participants experienced trauma in the family prior to the onset of prodromal symptoms. The second theme refers to the first indications that seem to mobilize the family regarding the early onset of psychosis (emergence of positive symptoms, sleep disorders, academic failure and social withdrawal). The third one refers to individual's and family's sensitization and orientation towards psychic life. The role of the therapeutic alliance and stigma also emerges as a critical parameter implicated in early intervention. A prominent theme is the lack of information made available to the wider public regarding the availability and accessibility of services. The present qualitative study identified a number of factors contributing to treatment delay for first episode psychosis, including both intrapsychic and organizational level parameters that are responsible for long DUP in our Greek sample.

Keywords Duration of untreated psychosis · First episode of psychosis · Qualitative · Treatment seeking

Extended author information available on the last page of the article

Introduction and Literature Review

Psychotic disorders, such as schizophrenia, have a profound impact on all aspects of the individual's life and are characterized by persistent symptoms and chronic disability (Fusar-Poli et al., 2017; Howes et al., 2021; Owen et al., 2016; Salazar de Pablo et al., 2024). Hjorthøj et al. (2017) suggest that schizophrenia was associated with a weighted average of 14,5 years of potential life lost and the quality of life of individuals facing psychotic disorders is significantly lower compared to that of the general population (Dong et al., 2019; Rohenkohl et al., 2022).

The interval between the first onset of psychotic symptoms and accessing appropriate treatment, commonly defined as Duration of Untreated Psychosis (DUP) (Cabassa et al., 2018; Polari et al., 2009), is being reported as having a significant impact on treatment outcome and quality of life (Cechnicki et al., 2014; Marshall et al., 2005; Souaiby et al., 2016). Regarding the benefits of timely diagnosis, cohort studies reveal that shorter DUP was associated with several indices of clinical and functional recovery with an enduring, beneficial overall treatment outcome and higher recovery rates at 10 years (Hegelstad et al., 2012; Kamens et al., 2018; Kane et al., 2016), as well as an improved quality of life in the long term (O'Keeffe et al., 2022). Mounting evidence suggests that early intervention leads to improved clinical and functional outcomes for young people experiencing recent onset psychosis (Kamens et al., 2018). Multitude of studies have established a connection between DUP and symptom severity (Salazar de Pablo et al., 2024; Yu et al., 2023). Howes et al. (2021) and Golay et al. (2023) concluded that there is an association between long DUP, severity of both positive and negative symptoms, functional impairment, and low quality of life.

Research has attempted to identify the determinants of DUP, among demographic factors (gender, ethnicity, etc.), onset-related factors, illness-related factors, family-level factors, societal factors, and health services/system-level factors (Apeldoorn et al., 2014; Compton & Broussard, 2011; Melton et al., 2020; Polari et al., 2009). In particular, factors associated with a longer DUP include stigma-related concerns (Franz et al., 2010; Wong, 2007) an insidious mode of onset, and lower social class (Compton et al., 2008; Franz et al., 2010; Paquin-Goulet et al., 2023). Similarly, age at onset, mode of onset (insidious or not), marital status, educational level, employment status and family's lack of mental health literacy have been identified as determinants of DUP (Qiu et al., 2019; Chilale et al., 2014; van Beek et al., 2022). In Greece, Peritogiannis et al. (2025) explored the treatment of FEP across nine Mobile Mental Health Units in rural areas of Greece; overall, 216 patients with an age range 15–55 and a diagnosis of non-affective psychosis participated in the study. The authors reported that the mean DUP was shorter for younger patients (15–25 years old) compared to older ones (25 + years). Nevertheless, younger patients tended to discontinue treatment compared to their older counterparts. Their study also revealed a correlation of DUP with specificity of diagnosis, suggesting shorter duration in cases of schizophrenia, and longer duration in patients with unspecified psychotic disorder (Peritogiannis et al., 2025).

In spite of empirical attempts to comprehend determinants of DUP, research into the lived, subjective experience of service users and their families regarding treatment delays appears to be sparse, while the specific mechanisms that prevent people from seeking timely help are poorly understood (Bay et al., 2016; Kamens et al., 2018; MacDonald et al., 2018). Previous qualitative studies exploring first episode of psychosis (FEP) have indicated that fear of stigma, lack of knowledge about available and affordable services, and symptom normalization commonly operate as barriers to treatment seeking (Allan, 2017; Bay et al., 2016; Cabassa et al., 2018; Ferrari et al., 2015; Jansen et al., 2018; Jansen, et al., 2015; Kamens et al., 2018; Tanskanen et al., 2011). Bergner et al. (2008) report that treatment delay is further mediated by misattribution of symptoms to other stress-related responses, with treatment being sought only when the individual reaches crisis-point. Family members tend to unrealistically view the person as more autonomous and capable, while lack of information regarding the availability and accessibility of services often results in further delays.

Similarly, fear of social stigma associated with a psychiatric diagnosis leads to a raised threshold for treatment initiation (Franz et al., 2010; Hasan, 2018; Kamens et al., 2018). It was also found that low literacy and subjective family beliefs about the cause of mental illness contribute to treatment delays for first episode psychosis (FEP) (Tanskanen et al., 2011). Patients and families' difficulties in recognizing symptoms delay their access to appropriate professional help (Bay et al., 2016; van Beek et al., 2022). Finally, some research suggests that often health-care professionals may have trouble identifying early signs of psychosis or giving this diagnosis to young people (Bay et al., 2016; Cabassa et al., 2018) while other studies highlight the need for specialized interventions to meaningfully reduce DUP (Causier et al., 2024; Dimitrakopoulos et al., 2022; Frischherz et al., 2024).

Bearing in mind that 10 Early Intervention Services for Psychosis (EISP) were newly established within the Greek National Health Services and that one of the main aims of Early Intervention Programs is to reduce the duration of untreated illness (or the time between the onset of prodromal syndromes and treatment), it seems important to understand patients' firsthand experiences around the period that clinicians identify as DUP. Within this context and taking into consideration that this field remains neglected in Greece, following a recovery-oriented approach to research, the present study aimed to investigate the subjective, lived experiences of service- users and their families regarding the onset of psychosis and the pathways in seeking appropriate treatment as well as the barriers they may have encountered during this process. This is the first Greek qualitative study that aims at an in-depth understanding of the specific intrapsychic mechanisms and/or other factors that prevent affected individuals from accessing help, with important implications for prognosis and treatment outcome.

Methodology

Methods

In order to generate rich descriptions of context and first-person perspectives, a thematic analysis approach was considered appropriate for analyzing participant

narratives and in identifying and analyzing repeated emerging patterns (Braun & Clarke, 2006) as well as in interpreting subjective experiences and organizing them in codes and constructed themes (Kiger & Varpio, 2020). The interpretative element was necessary in attempting to understand participants' narratives and their subjective, lived experience. Throughout the study, we employed an open-ended exploratory approach, in which participants were asked to relay in their own words, their specific experiences through in-depth individual interviews, each lasting approximately 90 min (Kamens et al., 2018).

Research Setting and Participants

The present study took place between May—October 2023 within a Day Centre for Psychosocial Rehabilitation, a community mental health unit for adults suffering from serious mental health issues and their families, located in Athens- Greece. The Day Centre offers a wide range of mental health and psychosocial rehabilitation services by a multidisciplinary team consisting of psychiatrists, psychologists, social workers, occupational therapists, and psychiatric nurses. Participants were service users who received mental health services with the Day Centre as well as their parents. Overall, six participants (4 service users and 2 mothers- P4 and P6) took part in the present research. It was decided to include relatives of service users for a more comprehensive perspective on family processes during this critical period. Specifically, the role of family and family processes emerge as a significant determinant of help seeking behavior in the literature and was therefore deemed important to include parents' subjective perspectives in addition to service users' experience. However, only two parents consented to participate. P4 is the mother of P2 and P6 is the mother of P3. DUP for participants in the present study ranged between 3 and 9 years, except for one participant, who developed FEP at the age of 13 and who initially accessed a pediatrician after 2 months from the onset, as reported by his mother.

Inclusion criteria for service users included a) psychosis spectrum disorder diagnosis (F20-F29) according to the International Classification of Diseases, 10 th Version (ICD-10), b) diagnosis given within the last 10 years, c) urban residents during the onset of symptoms and d) absence of a relapse during the past 3 years as well as being stable, as assessed by the mental health professionals involved in their care. Diagnosis given within the last 10 years was set as an inclusion criterion to avoid chronic cases of the disease, whereas urban residency was set taking into consideration the limited access to mental health care in rural areas (Morales et al., 2020). The selection of people residing in the wider urban area of Athens aimed at recruiting larger number of participants and to minimize the risk of stigma often encountered in rural areas of Greece. Absence of relapse during the past 3 years was set as a requirement in order to minimize the possibility of relapse and painful memories emerging as a result of participation. Recruitment was therefore purposeful and targeted, following the snowball sampling technique. Table 1. summarizes the demographic characteristics of participants.

Materials- Interviews

A semi-structured interview guide was developed and revised by the first two authors. The interview guide was followed in a flexible manner, focusing on the following main themes: onset of difficulties and initial symptoms, own, family and professional awareness of initial difficulties as well as their involvement in seeking professional help, course and barriers encountered in seeking appropriate treatment and reflection upon the help seeking process as well as in participating in the present study. Themes were introduced in an open-ended manner, while questions were followed up depending on how much the participant elaborated. The interviews were conducted by the first two authors, with each interview lasting approximately 90 min. The first author was an experienced psychoanalyst and researcher, independent of the Day Centre and the second was an experienced psychologist and member of the broader multidisciplinary team of the Day Centre. The second author was not involved in the participants' individual therapeutic plan. All interviews were conducted in the premises of the Day Centre and were audio recorded and transcribed verbatim.

Data Analysis

We used thematic analysis with an experiential and realist orientation (Braun & Clarke, 2006) to analyze the data derived from the narratives that emerged within individual interviews. Audio recordings of the focus group were transcribed verbatim, and transcripts were analyzed inductively in order to reflect upon the subjective experience of participants. Transcripts were read and re-read by the two researchers independently at first, in order to generate some initial codes, which were then organized into recurrent patterns or themes. Produced themes were then cross-reviewed by both researchers and refined to ensure that themes cohered meaningfully whilst reflecting distinct and identifiable entities that corresponded to participant narratives. Constructing larger categories of themes through the combination of meaning units was based on similarities within and between interviews; finally, the contents of the main categories were summarized into what was considered the most representative of participant experiences as they emerged within the transcripts.

Ethical considerations

The present study was approved by EPAPSY's Ethics Committee and took place with the informed consent of all participants. The nature and aims of the study were thoroughly explained to participants prior to the onset of the study and written consent was obtained. Participants maintained their right to withdraw from the research process until the point of verbatim transcription of individual interviews. Collected data were coded to secure the anonymity and confidentiality of all participants and were stored electronically in password-protected files only accessible by the researchers; following completion of the research, all data will be permanently

Table 1 Demographic characteristics of participants

	P1	P2	P3	P4	P5	P6
Age	43	25	28	54	39	65
Age at FEP	15	13	20	——	16	——
DUP	9 years	2 months	4 years	——	5 years	——
Gender	Male	Male	Male	Female	Male	Female
Marital state	Single	Single	Single	Widowed	Single	Widowed
Education	Secondary education	Secondary Education	Secondary education	University graduate	Secondary Education	Secondary Education
Residential status	Parental family	Parental family	Parental family	Own family	Parental family	Own family
Occupational status	Postgraduate Student /Receives disability benefits	University Student	Postgraduate Student	Full time employment	Receives disability benefits	Unemployed
Nationality	Greek	Greek	Greek	Greek	Greek	Greek
Mental health history	Yes	Yes	No	Yes	No	Yes

destroyed. Finally, participants were again debriefed about the aims and nature of the study in order to promote transparency and inclusion in the research process (Emerson et al., 1995; Howitt, 2010; Issari & Pourkos, 2015); following completion of the study, results will be disseminated to all participants who enabled its materialization. As the nature of the interview had the potential to evoke painful affect for participants, it was ensured that all participants had immediate psychological and/or psychiatric support by the multidisciplinary team of the research setting; however, this was not deemed necessary.

Results

The following table (Table 2.) summarizes the master themes and subthemes that were produced from the thematic analysis of individual interviews.

1. **Stressful events (prior to the onset of prodromal symptoms):**

   All participants- service users and parents alike- mention significant stressful events in their personal and family history, prior to the onset of the illness. Participants refer to traumatic losses within the family, such as the death of a close relative or frequent separations from loved ones, and the constant need to re-adapt to new environments. Similarly, participants refer to experiences such as systematic bullying or victimization, as well as strained relationships and a lack of communication within the family. Finally, frustrations and disillusionments such as academic failure or romantic rejection are being referred to as examples

Table 2 Master themes and subthemes (from the thematic analysis of individual interviews)

Master Themes	Subthemes
1. Stressful events a. (prior to the onset of prodromal symptoms)	i) Loss ii) Separation iii) Narcissistic injuries
2. Factors facilitating treatment seeking	i) Active symptomatology ii) Academic failure iii) Social withdrawal
3. Service user and family characteristics	i) Capacity for mentalization (meaning making based on external vs. internal factors) ii) Defense mechanisms
4. Therapeutic relationship	i) Service user inclusion ii) Service user exclusion
5. Stigma	i) External/social ii) Introjected
6. Organization and liaison of mental health services and care pathways	i) Lack of information and co-ordination of services ii) Role of psychosocial rehabilitation services

of narcissistic injuries, which seem to contribute to a fragmentation of the Ego and the manifestation of early signs of psychosis. The unrealistically high expectations that service users and their families hold of themselves, stemming from a primitive Ideal Ego, come crushing down when met by reality and its limitations; these dynamics seem to be reflected through the onset of the illness, as emerging from participant narratives.

> *'…there were always difficulties and conflict in my family…my parents were not happy together and there was a total lack of communication…I could see all this…without being able to reach out to someone…I could see my difficulties from early on…' (P1, p.2).*

> *'…my parents have always been overprotective, it was as though I was raised in a glass tower…Everyone, including myself, expected from me to excel in everything, in my University exams, and when I failed, I just collapsed and never attempted to take the exams again…For the next 3 years I was lost in space…I always seem to have a tyrant over my head, judging me…and around that time…it was just like an explosion…I just exploded…' (P5, p.3–7).*

> *'…my husband died in 2009…my son was just 13 and my youngest was just 6 years old…. He just came into the house, had a little water, and just collapsed and died right there in the kitchen…' (P6, p.5)*

'…everything seemed to be perfect during the first year of college…But during the second year, he fell in love with this girl…it was his first time and he was very shy…His friends made fun of him…and when this girl rejected him after a while, he just told me that he was hearing this voice…That was it, this rejection just destroyed him completely…' (P6, p. 2–3)

2. **Factors facilitating treatment seeking**

Amongst the first indications that seem to mobilize the family regarding the early onset of psychosis are the emergence of primarily positive symptoms, difficulties encountered at school or in the individual's academic performance as well as social withdrawal. Participants also refer to a breakdown in communication and relationships with family and friends as well as their withdrawal from previously enjoyed activities such as school or work, which seems to reach crisis point before activating the need for early detection and intervention by mental health professionals.

i) **Active symptomatology**

Active symptomatology, as reported by participants in the study, includes auditory hallucinations, disorganized thought process, poor concentration and difficulties with sleep. The narratives below highlight the early symptomatology that seems to facilitate seeking professional help.

'…I thought I was telepathic at first. That I heard voices because I was telepathic, so I was very happy, as I thought it was my secret talent…But then she was acting strange…she was avoiding me, as though there was no telepathic connection between us, as though this voice was fake…This was very painful for me, because I had this voice telling me that I was special, that I was the son of God… but other people acted indifferently to me…I felt as though I was lost in an endless sea with no sign of salvation…I felt that my life was ruined…' (P3, p.3–5)

'This was quite difficult and confusing…my thoughts were so rapid and intense that my mind was lost…People were asking me a simple question, 'How are you?' and I could not think of the right answer, I would tell them 'Let me think' over and over again as I had to explain everything properly, or I would watch a movie and I would rewind it endlessly so that I understood the true meaning of a single line…My mind would get stuck, and I felt like I was suffocating…' (P5, p.6)

ii) **Academic failure**

All participants describe a gradually increasing difficulty in meeting expectations at school, in their academic or vocational development. As evident in the narratives below, participants found it difficult to attend classes or to engage in activities that were previously enjoyable and meaningful to them, thus demonstrating the detrimental impact of psychosis on social and academic functionality.

'…I was not able to pass my courses at University. That was a major red flag for me…Then, I did not want to go on vacation, I was completely withdrawn into myself…these were important red flags that something is not right, and I needed help…My brother was seeing all these signs and was worried about me, my mother not so much…' (P1, p.4).

'…it manifested through my school performance, my grades just dropped dramatically…I could not structure my thoughts. I used to enjoy studying, and I used to enjoy a lot of other things, like music, languages and all these just…. It was like a straight line that just got interrupted, was cut right in the middle…' (P5, p.5).

iii) **Social withdrawal**

Participants describe a gradual loss of contact with their close ones and the wider society. As indicated in the narrative below, service users found themselves staying at home for lengthy periods of time, having no or little communication with their family and friends, losing friends and choosing to spend endless hours on screens. Indeed, social isolation emerges as a significant indicator of early difficulties that mobilizes families in seeking help.

'…My brother was very upset watching me spend endless hours on my computer…he didn't know how to help me. My father would encourage me to go out, to get a job or to make friends…So my main symptom was apathy, there were no voices or hallucinations except this one time, when I would hear a voice repeatedly again and again, that was just before my admission to the hospital…when again I could not sleep, I could not sleep for 2 days…' (P1, p.9)

'…I would not go out, except for the basic, necessary things…I fell out with my friends, my very close friends…I had many losses during that time…I had nobody for about 4 years…' (P3, p.12)

3. **Service user and family characteristics**

The individual's and family's sensitization and orientation internally, towards psychic life, seem to be a significant factor contributing to the mobilization of the family and the timely pursuit of professional help. In other words, the capacity to comprehend oneself and others and to perceive one's psychic state on the basis of internal processes that lie beyond overt behavior, is emerging from participant narratives as a critical factor for comprehending prodromal symptoms and in pursuing early intervention. Equally, the family's unconscious psychological strategies for managing anxiety and threat seem to have prevented them from assessing accurately the severity of the situation often resulting in a delay in seeking appropriate professional treatment.

i) **Capacity for mentalization (meaning- making on the basis of external vs. internal processes)**

Narratives below highlight that participants' meaning- making of early difficulties seems to take place primarily on the basis of external versus internal events and processes, which in turn seems to affect DUP. In particular, participants in the study, mainly parents, describe how early difficulties of psychosis were initially attributed to external factors or circumstances in their children's life, such as a change of environment, loss of a loved one or lack of motivation and agency.

'…there was this new environment at school with all these new teachers…and I did put a lot of pressure on him…I was quite aggressive in the sense that I would tell him 'Why are you not studying enough, why aren't you moving on, why are you not doing anything?'…I just thought it was the new environment that was responsible for his difficulties… I do wonder if it was my fault that I was putting so much pressure on him…I was wondering why he did not enjoy summer school and why he did not want to go, I just thought he was jealous of his sisters that were at home with me…And then this doctor once told me… 'Have you ever considered that it may just be too much for him?'…and I was totally shocked because no, this had never

crossed my mind, that he could just not bear it, that it was all too much for him…' (P4, p.1 & p.13)

'…after their father's death…my other son…he is just being so negative…I did not understand it at first and I still don't- he seems to have many problems- he doesn't speak to me- he is being so negative…I do not understand why, even though I take good care of him and I give in to all his requests, he is still being like that…I am not perfect, but my other kids, including my son with psychosis, did not respond like that…' (P6, p.22–23)

ii) **Defense mechanisms**

Unconscious psychological strategies mobilized by participants in our study in order to minimize stressful or uncomfortable realizations seem to be implicated in the accurate and timely assessment of early difficulties of psychosis. Defense mechanisms that are employed by service-users themselves and their families (but also by mental health professionals involved in their care) include denial, splitting and displacement and further seem to contribute to inertia, delay in seeking help and ultimately longer DUP.

Denial/Splitting Denial refers to the refusal to accept a painful reality and attributing it instead to something external, such as a physical condition, learning difficulties or romantic frustration or disappointment, as highlighted in participant narratives below.

'…I used to think that my difficulties were due to my scoliosis, that it was physical and that it would be fixed if I had some surgery…Although the surgery went well, it became evident that it was not physical reasons that were the base of my difficulties…So, I was 24 years old before I realized- retrospectively- that I had suffered a psychotic episode…I didn't know who to turn to… not even my parents…but it was eventually my orthopedic who encouraged me to contact a psychologist…' (P1, p.2)

'…My mother thought I was in love…and she thought it was because of that… but when I went to a psychiatrist, he said I had schizophrenia…My mother and my siblings took it really badly…very badly indeed…' (P3, p.5)

'…it was very sudden for me…we didn't have any history in the family…we never had problems like that…and this is why I did not believe it…I did not believe he had a problem because he had met this girl, and I thought it was because he was in love…. And I thought it would just go away after a while…I never thought it would develop into this… Although his siblings used to tell me to take him to the doctor and they were scared of him…I didn't want to…. after all he was not posing a danger to anyone…' (P6, p.1–11)

Ambivalence *Many participants in our sample report struggling with resistance and ambivalence regarding both their diagnosis and treatment, even following a consultation with a mental health professional or even a period of hospitalization, thus demonstrating the potency of defense mechanisms. As highlighted in the quotes below, participants struggled with conflicting emotions or thoughts regarding the reality of their condition, which in turn seemed to result in an increasing DUP.*

'…I was still very reluctant…even after my orthopedic referred me to a psychologist, it still took me a month to contact her for an appointment…Then, I used to miss appointments or turn up late…I had started experiencing some symptoms…characteristics of a psychotic episode…I would hide these from my psychologist…I was trying to hide from her…Eventually I stopped going all together, after about 10 sessions…' (P1, p.2–8)

'…Again… when I was at the hospital's Day Centre, I used to think…. I will just stay for 3 months, and I will stop…I was really negative about getting help and did not want to go… Eventually I stayed for 3 months, then for 6 and I used to think that I wiould not go back… in the end, I stayed for just over a year…' (P2, p.9)

4. **The therapeutic relationship/alliance**

The role of the therapeutic alliance emerges as a critical parameter implicated in early intervention, medication adherence, and commitment to the treatment plan. The quality of the therapeutic alliance is a strong predictor of therapeutic outcome as it promotes service user inclusion, involvement, the capacity to resolve potential conflict with mental health professionals, and ultimately aspects of recovery. On its negative side, participant narratives suggest that difficulties in establishing a respectful relationship with professionals and a mechanistic attitude to recovery, including mere adherence to medication, do not seem helpful for service users' psychosocial rehabilitation. Participant narratives further highlight examples of a paternalistic attitude towards service users by mental health professionals that deprives them of the right to consent and participate in issues around diagnosis, medication, and prognosis.

i) **Service user exclusion**

Service user exclusion from their own treatment can have detrimental effects both emotionally and practically, such as a sense of powerlessness and frustration, decreased engagement and compliance, damaged trust, including avoiding help seeking behavior in the future.

'…I did not get any information around my condition…My brother again was the catalyst…he observed that I had some tremors, and he asked the doctors…And it was then that they told him about the medication I had been given and the potential side effects…I was not really taking any initiative to ask about these things myself…I was not informed about the kind of medication I was being given,

whether they were antidepressants, vitamins or antipsychotics, or they never mentioned the injectable kind of administration…They explained all these and the benefits of injectable treatments, i.e. that they are better absorbed by the body, a lot later, when I was discharged from hospital.' (P1, p.11)

'…I had asked the doctor whether I had schizophrenia, and he said no, you just had a crisis…but it is true, it is a chronic condition, and I have been having it for years… Every doctor has their own strategy for dealing with you…that first one, was trying to get me to take the medication, he would just agree with me so that he doesn't get me upset and he was just trying to convince me to take my medication…' (P3, p.3–13)

'…We went to this doctor, and he prescribed a medication for him… he was very scared of medication…and so the doctor told him that he would not have to take any medication…but then we used to put it in his drink in various ways, and this went on for about six months, until he eventually found out…Then we were able to convince him that he was better off with his medication, he was calmer…' (P6, p.8)

ii) **Service user inclusion**

On the other hand, including service users in their own treatment increases engagement and motivation as well as the restoration of a sense of control over one's life, which is crucial in recovery. As indicated in the narrative below, service users experience self-awareness and growth and a greater sense of autonomy and dignity.

'…. The doctors explained to me what that meant and what symptoms it included and they made me understand what was happening to me…It was very helpful…to be able to understand…Sometimes I feel that I have more clarity on the situation, and I understand what is happening to me from a greater perspective…And that is down to the professionals involved, to make it clear to me… ' (P5, p.17–23)

5. **Stigma as a deterring factor for seeking treatment**

The role of stigma emerges as an important factor contributing to delays in seeking appropriate treatment. Stereotypes regarding mental health that are associated with shame, guilt, and a judgmental attitude, are often perceived as resting in the social context as it appears in participant narratives, while other times they seem introjected, emerging internally within service users and families themselves. What seems prominent, however, in the transcripts, is that the role of stigma seems to be easily discussed by mental health professionals, albeit in a mechanistic manner, lacking empathy and sometimes without the capacity to offer empowerment and guidance to service users and their families.

i) **External/social**

Social stigma refers to the negative attitudes and beliefs often prominent within society that lead to discrimination, social isolation and shame, as highlighted in the quote below.

'…It was really bad… There is this stereotype about people with mental illness that they are dangerous to others…and I was thinking 'oh my god, am I in the same category now…? My family was treating me as though I was dangerous, and that was a very strange thing to me…' (P3, p. 8)

ii) **Introjected**

Equally, introjected stigma involves an identification with societal misperceptions and misrepresentations of mental illness. Introjected stigma seems to affect both service users, family members, as well as mental health professionals themselves, as indicated in the narratives below.

'…There was this doctor once who advised us to discuss this issue openly and to disclose my son's diagnosis (schizophrenia) to people because this issue must be addressed and absolved of all the guilt it carries…And I thought that was so shortsighted…and I told her 'excuse me, do you think society at this point is ready to…if you had a child with this diagnosis, would you openly discuss it with everyone? People do not know what to say…they will just ostracize us from our community…' (P4, p.10)

'…my daughter insisted that I call the police to have him sectioned… How could I do such a thing…I did not want my neighbors to know…that would embarrass him so much that it would make everything worse…I didn't know what to do…So we lived like this for about two years, two years of tension and anxiety for him but also for my other kids…' (P6, p.3)

6. **Organization and liaison of mental health services and care pathways**

i) **Lack of information and co-ordination of services**

The lack of information made available to the wider public but also to mental health professionals themselves regarding the availability and accessibility of services is a prominent theme in participant narratives that results in a delay in treatment seeking and in longer DUP. The lack of organization and co-ordination of mental health services in Greece contributes to the prominence of stigma around mental illness and limits service users' opportunities for meaningful psychosocial rehabilitation and inclusion in their treatment plan. Appropriate referrals seem to depend on individual professionals alone, rather than constituting part of standard practice while seeking appropriate treatment burdens the family itself. Therefore, the lack of co-ordination and continuity of care in psychiatric services often contributes to large gaps in the provision of care, resulting in delays in accessing appropriate treatment and ultimately longer DUP.

'…I just thought that I was losing my child…that all that is left for me is to lock him up in a clinic…that he will not be able to be a part of society… There was no information provided around causation,

prognosis or anything like that …until I just started reading on it myself…' (P4, p. 3–4)

'…There is no way I was ever going to find out about the Day Centre and the work that is being done in the community…If that one particular doctor had not mentioned it, I would have never known… And this is where my son received a lot of help…If it were not for that one particular doctor, who made this one phone call and made that referral, I would have never known…' (P4, p. 7)

'…It was quite difficult to access the appropriate services primarily due to a lack of clarity in the information provided but also mistaken information altogether…Information came mostly from other service users so it largely depended on their experience, which can be misleading…It took me over a year to find out about community Day Centres…And even longer to find out about disability benefits and pension, professional rehabilitation options…as well as peer organizations for the promotion of service user rights and working against stigma…' (P1, p.15–16)

ii) **The role of community psychosocial rehabilitation services**

Community psychosocial rehabilitation services play a vital role in assisting service users rebuild social and professional skills, develop support systems and foster their social inclusion.

'…My greatest motive for joining the Day Centre was basketball… that was a great motive for me…At the beginning it was quite difficult for me to adapt… but I did eventually meet new friends…and we enjoy doing many things together… The Day Centre helped me more than the time I spent in the hospital…In the hospital options were quite limited whereas in the Day Centre we are free to join groups and activities both in the Centre but also in the community…' (P2, p.5)

'…I changed a lot of medication, but what has helped me most is the Day Centre…This is where I started making friends and started communicating properly…At the beginning I would not talk to anyone…but I gradually started socializing…I used to be just like a wild animal locked in my house, before that…' (P3, p.7)

'…:It gave me a great motive to get out of bed…to get out of the house, to see people…and this gives meaning to my life…The care that I received all these years truly reduced in the minimum the time that I would have spent in the hospital…There were times that I was locked up in the house and wanted to hurt myself, and I would have done so and have been admitted to the hospital…I think that treatment in the community and the way I experienced it was really critical for me…All the professionals involved, the groups and the people that I met…being referred to the Day Centre was critical for me…' (P5, p. 14–25)

Discussion

The aim of the present study was an in-depth exploration of the subjective experiences of the process of treatment seeking amongst service users and their families residing in Athens- Greece during the early stages of psychosis. Overall, results emerging from participant narratives seem to be consistent with existing literature on factors contributing to DUP (Allan, 2017; Bay et al., 2016; Bergner et al., 2008; Cabassa et al., 2018; Chilale et al., 2014; Ferrari et al., 2015; Jansen et al., 2018; Jansen et al., 2015; Kamens et al., 2018; Qiu et al., 2019; Tanskanen et al., 2011; van Beek et al., 2022).

Firstly, our results call attention to the existence of parameters that pre-exist the onset of psychosis, which nevertheless seem to influence treatment seeking and ultimately DUP. These parameters include premorbid aspects such as the experience of trauma in the family prior to the onset of the illness, inherent personality characteristics of the individual as well as characteristics of the family system; such aspects are not easily assessed in studies exploring DUP. Nevertheless, they seem to have a significant impact upon help-seeking behavior from the part of the family or carers and most importantly these aspects are associated with the denial or misattribution of symptoms, particularly in the case of an insidious mode of onset (Qiu et al., 2019; Salazar de Pablo et al., 2024; Souaiby et al., 2016).

Early trauma seems to impact the persons' capacity to perceive and manage threatening or difficult experiences, through the development of defense mechanisms that often distort a person's perception of reality or disorganize one's capacity for mentalization, meaning making, and resilience, through the undertaking of appropriate action. Such mechanisms appear to determine the extent to which early signs of mental illness are being perceived, registered, and detected as opposed to being denied or displaced onto another object, such as external circumstances or even one's body, thus resulting in a delay in accurate diagnosis and treatment. Ambivalence (both on the part of the service user as well as their family) may further contribute to delays in seeking appropriate treatment, while denial and splitting in the perception of prodromal symptoms seem to lead to longer DUP. Indeed, van Beek et al. (2022) report the denial or minimization of symptom severity by family members in their UK study and suggest that overtly socially unacceptable behavior is often the catalyst to seeking help.

Consistently with our results, a multitude of studies in the literature report that some of the factors increasing DUP include a denial of the illness by the family or caregivers and the attribution of early difficulties to parameters that are circumstantial or external to the person, resulting in significant delays in accessing appropriate treatment (Qiu et al., 2019; Souaiby et al., 2016; van Beek et al., 2022). Indeed, despite considerable prior distress, help is often not being sought until crisis point, whilst service users themselves are often the last to acknowledge their symptoms as mental illness; such findings are also reported by participants in the present study (Tanskanen et al., 2011; van Beek et al., 2022). Paranoid views and a pervasive mistrust in the mental health system may further be fueled by such premorbid parameters as well as the perpetuation of stigma around mental illness, which is often

introjected by service users, families and mental health professionals themselves, in addition to being perpetuated by the wider social context.

The present study highlights the family's close involvement in decision-making and thus the duration of untreated psychosis and is consistent with existing literature. Indeed, research suggests that families and service users' immediate support network and the quality of these relationships play a major role in help-seeking behaviour, treatment initiation, and continuation (Tanskanen et al., 2011; van Beek et al., 2022). For example, perceptions of a positive and warm family environment among patients with FEP were associated with a lower risk of patient relapse (Lee et al., 2014) whilst caregiver perceptions of family support were related to shorter DUP among patients with FEP (Compton et al., 2009; Goulding et al., 2008; Mo'tamedi et al., 2014). Similarly, Hernandez et al. (2019) report that patients with stronger family relations had shorter DUP compared to individuals who had a more troubled relationship with their families; open and honest communication amongst family members was further identified as a key component of strong family relationships. Overall, research highlights the role of family members as critical in the initiation and decision-making regarding treatment and that family factors must be targeted more specifically in order to develop more nuanced interventions, during the early period in which neurobiological deficit processes in schizophrenia are most active (Hernandez et al., 2019; Souaiby et al., 2016; Tanskanen et al., 2011; van Beek et al., 2022). Considering the paramount significance of family involvement in early detection and intervention in individuals with high risk for psychosis, it seems important that information and educational campaigns around prodromal signs of psychosis are delivered in ways that accommodate caregivers' personality characteristics and social needs (Melton et al., 2020; Salazar de Pablo et al., 2024) this seems particularly important for cultures with a strong family orientation such as Greece.

In addition to intrapsychic characteristics that may burden early detection and intervention on behalf of family members that need to be taken into account, our results further highlight the lack of information, co-ordination and organization of mental health services in Greece, in ways that would enable timely access to appropriate treatment (Causier et al., 2024; Dimitrakopoulos et al., 2022; Frischherz et al., 2024). Almost all participants in the present study report lacking basic information around early signs of psychosis as well as information about the rehabilitation process and the options that are available to them, other than accessing a psychiatrist, most often on a private basis. Even when participants accessed a psychiatrist, it seems that early interventions were sparse -without regular follow up- and revolved largely around medication prescription often without the knowledge or consent of the service user; most importantly neither service users nor their families reported being provided with information around symptomatology, medication side-effects, prognosis, and rehabilitation options.

The majority of mental health professionals are being reported by participants in the study as keeping the patient in their medical care, without making timely and appropriate referrals to other services (i.e., home and/or community mental health services) that would address other aspects of psychosocial rehabilitation and would provide appropriate support for families; many mental health professionals themselves are being reported as either being unaware of these options or as indifferent

towards other parameters of rehabilitation other than the pharmacological (Birchwood et al., 2013; Cabassa et al., 2018). Appropriate referrals to community mental health services are being reported as taking place sparsely, not as part of standard practice following recommended pathways to care but by sole mental health professionals that happened to be better informed around the availability of services or more aware of the importance of aspects of the therapeutic relationship. These professionals on the other hand are being reported as honouring a humanistic approach to mental health, as relaying information and support to service users and their families around the process of psychosocial rehabilitation and as adhering to a recovery-based approach to mental health, as opposed to mere compliance with medication. Indeed, service users in our sample report that eventually coming into contact with the right mental health professionals and appropriate services made a huge difference not only on a symptoms level but also on aspects of their quality of life such as re-entering education, employment and socialization.

Cabassa et al. (2018) report that quality of contact with the health care system constitutes a critical juncture in pathways to care that can either reduce or increase delay entry into Early Intervention Services, while negative interactions with mental health professionals ultimately contribute to longer DUP. Interpersonal connections made with mental health providers and the quality of care received were reported as significantly impacting subsequent help-seeking behaviors for five out of six participants; positive experiences with mental health professionals were reported as leading to treatment engagement and are consistent with findings of the present study regarding the quality of the therapeutic relationship at the first point of contact. On the contrary, negative experiences such as lack of clear information and communication around treatment options, medication side effects and/or not getting appropriate referrals to specialized services, all seemed to contribute to further delays in care-seeking behaviors for FEP (Cabassa et al., 2018).

Birchwood et al. (2013) further report that delays within mental health services and care pathways significantly impact subsequent help-seeking delays to a greater extent than the characteristics of patients with extremely long DUP. It is being reported that the type of service received at first contact is a critical predictor of DUP, while delays in appropriate referrals to specialized EIS, following entry into the mental health system further contribute to long DUP (Causier et al., 2024). To sum up, research suggests that when patients access a non-specialized, non-crisis type of psychiatric service, DUP can actually be longer, with detrimental effect on prognosis and overall functionality (Birchwood et al., 2013; Frischherz et al., 2024).

Consistent with existing literature, our findings highlight the importance of quality of care when defining the notion of 'untreated psychosis', namely whether psychosis treatment refers to pharmacological interventions or whether it also involves aspects of rehabilitation. All participants in our study report initially accessing psychiatric treatment nevertheless without appropriate referrals to community or home-based mental health services that reportedly made a difference to their quality of life (Birchwood et al., 2013). This lack of referrals emerging from the present research could indeed call attention to the fragmentation of the (mental) health system in Greece and the unavailability of services (Dimitrakopoulos et al., 2022). In any case,

it may allow us to revisit the notion of treatment and definitions of DUP in the field of psychosis research.

Again, our results are consistent with existing literature; van Beek et al. (2022) report that especially in low- and middle-income countries (such as Greece), health systems are inadequately designed to manage mental health difficulties, with an alarming 76%–85% of people with severe mental disorders not having access to properly organized mental health care; indeed, in Greece the health care system is fragmented and underequipped to operate in an organized and efficient manner that would enable timely access to appropriate treatment, thus reducing DUP, particularly amongst young people with FEP (Dimitrakopoulos et al., 2022). Rather, poor intra- and inter- organizational communication between services places the burden to individual families of service users to navigate their way towards accessing appropriate treatment. Similarly, unhelpful service responses and the role of mental health professionals (lack of skills in recognizing early signs of psychosis or an apathetic attitude towards patients) are being reported by Tanskanen et al. (2011) as significant barriers to prompt treatment and as factors increasing DUP (Birchwood et al., 2013; Cabassa et al., 2018).

The present study is not without limitations. The sample size was particularly small (N = 6), whilst recruitment from a single setting prevented generalization of the findings to other mental health community Centres and broader early psychosis populations. Recruitment of more family members as well as mental health professionals would have enriched our findings and would enable better comparisons between service user, family and clinical conceptualizations of DUP (Bay et al., 2016; Tanskanen et al., 2011). Finally, the study utilized retrospective interviews that may produce a significant recall bias, however even such distortions constitute part of participants' psychic apparatus and were thus deemed to be part of the subjective experiences explored. Therefore, a replication of the present study with a larger, more diverse sample would certainly increase the confidence and generalizability of our results.

Conclusions

Despite the above-mentioned limitations, the present qualitative study is significant for the Greek literature as it is possibly the only one that explores service user and family subjective experiences of DUP. A number of factors contributing to treatment delay for first episode psychosis, including both intrapsychic and organizational level parameters that are responsible for long DUP in our Greek sample were identified. An important finding that seems to be universal is the central role of family involvement in identifying early signs of psychosis but also in the initiation of treatment; the study also highlights how the family system may indeed either encourage or deter help-seeking in FEP. As far as the Greek experience is concerned, the lack of organization and co-ordination of mental health services in Greece contributes to the prominence of stigma around mental illness and the prolongation of DUP.

Bearing in mind that one of the main aims of Early Intervention Units is to reduce the duration of untreated illness, it seems important to understand patients' and families' firsthand experiences around the period that clinicians identify as DUP as well as possible difficulties around that time. Research suggests that despite exposure to targeted information campaigns, service users and family members often still face difficulties in recognizing or understanding the severity of symptoms and in seeking appropriate treatment. Early Intervention Services therefore need to be carefully designed to relay information and support to family members who may not only lack the ability to correctly identify emerging symptoms of psychosis but who may also be unwilling to do so (Bay et al., 2016; Kamens et al., 2018; van Beek et al., 2022). It is suggested that initiatives to reduce DUP are home-based and multi-focused, targeting not only young people and (mental) health professionals but also parents, teachers, and broader social networks including community and online forum that young people utilize.

It seems important for information campaigns to relay firsthand experiences of people facing psychosis in order to normalize such experiences and to reduce social as well as introjected stigma; this is particularly true for FEP amongst young people, where appropriate and timely interventions may be invaluable due to the capacities of adolescence and early adulthood as a developmental period. It is needless to re-iterate that a full psychiatric reform with standardized pathways to care and efficient liaison between different services is long called for in the field of mental health in Greece.

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Data Availability The present qualitative study was conducted in greek and the original narratives were subsequently translated in English for the purpose of this publication. The original interviews (in greek) are available on request.

Declarations

Ethics Approval The study was conducted in accordance with the Declaration of Helsinki ethical principles. Approval was obtained from the ethics committee of Association for Regional Development and Mental Health.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Consent to Publish Participants consented to the submission of their narratives to the journal.

Conflict of interest The authors declare that they have no conflict of interest.

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