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How do young adults experience and understand the process of developing a first episode of psychosis? A qualitative exploration

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ABSTRACT

Background: Psychosis is a condition which often starts early in life and leaves a significant mark on a young person's life. It is usually regarded and discussed from a professional point of view. This study sheds light on the lived experiences of young adults who go through a process of developing their first episode of psychosis.

Methods: Interviews were carried out with 10 young adults, aged 19–32 years, 3–12 months after contact with an early detection team for psychosis and were diagnosed as having had a first episode of psychosis. Through a reflexive team-based method, data were put through a preliminary analysis and analyzed line-by-line.

Results: We developed three main themes: 1) "A stressful life situation", which refers to the period before the psychotic experience. 2) "A peculiar feeling" to describe the psychotic experience, and 3) "Redefining the meaning of psychosis", which points to how developing psychosis was understood in hindsight.

Discussion: We discuss how early labeling and stigma may impact the young adults' meaning-making processes. Moreover, we question the conventional psycho-educational approach and call for a more open and dialogical way to interact with young adults who experience and try to make sense of their first episode of psychosis.

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First episode psychosis; early intervention; lived experience

Introduction

Psychosis often starts in a person's teens or early adulthood and affects the person in question as well as their families (Weimand et al., 2011). It may be understood as a state which, more than any other mental disorder, affects the person's sense of self (Davidson, 2020). Professionals have traditionally regarded psychotic disorders as long-lasting or chronic illnesses (Davidson, 2003). During recent decades, however, psychosis has increasingly been understood as a process that evolves in stages, which can be treated at each stage, thus providing greater hope of recovery (Johannessen & Joa, 2021).

Moreover, it has increasingly been seen as a major problem that people often seek help when it is too late (van Schalkwyk et al., 2015), and it is not uncommon for people to experience pre-psychotic or psychotic symptoms for as long as 2–3 years before getting in touch with the health care system (Perkins et al., 2005). Research has suggested that patients have better trajectories and prognoses

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when psychosis is detected and treated at an early stage (Murry & Carpiniello, 2018). Hence, a primary goal of practitioners is to reduce the duration of untreated psychosis (DUP) and provide treatment before it evolves into more severe conditions (McGorry & Mei, 2018). Many countries have therefore implemented early intervention services as part of local or national mental health services (WHO, 2013). Research also suggests that early intervention may prevent suicide related to psychosis (Larsen et al., 2006).

In spite of these benefits, early intervention has been debated. Concerns have been raised about the effects of stigma and early labeling of psychosis (Xu et al., 2016). A qualitative study found that service users perceived early intervention services as more preoccupied with other peoples' concern about their behavioral changes, rather than addressing what they found most pressing, such as their everyday challenges (van Schalkwyk et al., 2015). Moreover, a mixed-method study revealed that young adults participating in early intervention services for psychosis experienced considerable challenges in their social lives before and after the DUP (Kamens et al., 2018).

Geekie and Read (2009) highlighted the need to include personal experiences related to psychosis in the understanding of the psychotic phenomenon. Studies on early intervention services have thus far rested mainly on the professionals' understandings of psychosis, usually focusing on quantitative measures of the DUP and treatment outcomes (Maric et al., 2017). Only a few studies have taken on a first-person perspective exclusively in exploring the lived experience of people going through an episode of psychosis for the first time. A meta-synthesis containing 17 qualitative articles, which focused on experiences related to contact with early intervention services (Hansen et al., 2018), found that before engaging with the services, participants described having a growing feeling of something being wrong. Griffiths et al. (2019) identified both intrapersonal and interpersonal sources of distress in a meta-synthesis of 33 personal accounts. They described multiple, diverse, and nuanced sources – not in line with the signs usually detected by clinicians. Moreover, Vyas et al. (2021) revealed that British South Asian adults experienced stigma from their families and the early intervention services in addition to public stigma. Furthermore, Larsen (2008) explored meaning-making processes based on interviews with 15 service users recruited from a Danish early intervention service. Making sense of the first episode of psychosis usually involves a negotiation process of continuous rejections, acceptances, appropriations, and evaluations – culturally influenced by different social and institutional contexts in society.

This article contributes to the field by focusing on the lived experiences of 10 young adults who had been in contact with an early detection team in Norway and diagnosed with their first episode of psychosis. Our research question is: How do young adults experience and understand the process of developing a first episode of psychosis?

Method

In this study we applied a mix of phenomenological-hermeneutical epistemology to guide our thinking in the analytical process (Kvale & Brinkmann, 2009). The phenomenological element points to our focus on the young adults' subjective experiences, while the hermeneutical element refers to the researchers' interpretation of their descriptions. As such, our epistemological stance can be seen as a dialogue between the participants' own descriptions (phenomenology) and the researchers' interpretations (hermeneutics) (Binder et al., 2012).

Study settings

We recruited participants from an early detection team, called TOPS, functioning as a low-threshold pathway into the specialist mental health service at Haukeland University Hospital, Bergen, Norway. TOPS primarily serves young people between 13 and 30 years old. They offer voluntary psychosis screening based on the tool "Positive and Negative Syndrome Scale" (PANSS), which is used to assess the scope and severity of psychotic symptomatology (Kay et al., 1987). In addition, family, friends, healthcare professionals, teachers or others can call TOPS for advice if they have concerns about someone they know. The present study reports on data from a larger study focusing on early intervention and recovery processes among young adults dealing with their first episode of psychosis. We have already published an article (Hansen et al., 2020) on how these young adults experienced social relationships inside and outside the services as integral to their recovery processes.

Research team

H.A.H. is an associate professor in mental health care. She has previously worked as a social worker in community health and social services. S.H.S. is a professor in clinical psychology with clinical experience from specialist mental health services. L.D. is a professor of psychiatry and a clinical psychologist with clinical experience working with people with severe mental health issues. E.M.L. is a professor of psychology and a specialist in psychology with clinical experience from specialist mental health and severe mental health issues. Finally, M.V. is a professor and a clinical psychologist with clinical practice from specialist mental health services. Thus, the research team is psychosocially positioned. This in turn has influenced both our data collection and analysis.

Recruitment and participants

Potential participants were first contacted by the clinical team from TOPS. Those who were interested in participating were followed-up by H.A.H. Recruitment was conducted between February 2016 and July 2018. The inclusion criteria and participants have been presented elsewhere (Hansen et al., 2020, pp. 79–80). Participants had to have met with TOPS between the ages of 16 and 30 at the point of contact. They had to be screened for psychotic symptoms (by TOPS) and score four or higher on the following PANSS items (Kay et al., 1987): P1 (delusions), P2 (disorganized thought), P3 (hallucinatory behavior), P4 (excitement), P5 (grandiosity), P6 (suspiciousness), and G9 (unusual thought content).

Ten participants, three men and seven women, gave their informed consent to participate in the study. The interviews were conducted 3–12 months after contact with TOPS, and the participants were aged between 19 and 32 at the time of the interviews. Six participants were students, three were unemployed and one had applied for disability benefits. Two of the participants had not completed high school. Half of them lived with their parents, three lived alone, one participant lived with a partner, and one was homeless.

Data collection

Ten in-depth interviews were conducted 3–12 months after initial contact with TOPS. Our aim was to explore the participants' descriptions and interpretations relating to their experiences with developing and going through a first episode of psychosis. We used a semi-structured interview guide rooted in themes developed by M.V. in dialogue with E.M.L. and later modified by H.A.H. based on feedback from S.H.S. and L.D. To make the interview guide relatable to young adults experiencing their first episode of psychosis, we also obtained feedback from a group of people with personal experience with psychosis. The interview guide addressed the participants' contact with the early detection team and the wider mental health system; their recovery processes; and health and living situation (including lived experience of developing psychosis). This article reports on data related to the latter subject. In addition, demographic information was obtained through a short questionnaire.

H.A.H. conducted the interviews in Norwegian.They were audio recorded and transcribed verbatim in Norwegian by H.A.H. The participants chose the location they were most comfortable with.

Three participants chose to be interviewed in their own homes, three chose to meet at an office at Haukeland University Hospital, and four were interviewed at Western Norway University of Applied Sciences. The interviews lasted between 40 and 150 minutes (84 minutes on average). The first author wrote reflexive notes immediately after each interview.

Data analysis

We based our analysis on the guiding steps described by Braun and Clarke (2006, 2019). First, a preliminary, team-based and reflexive, thematic analysis was carried out by H.A.H., S.H.S., and M. V. (Veseth et al., 2017). Secondly, the data material was entered into NVivo 11 and analyzed line-by-line. Based on the analytical focus (participants' experiences of developing psychosis) and the preliminary analysis, H.A.H. reread and coded the data to further identify units of meaning and develop corresponding codes. The different codes were sorted into three overarching themes. The codes were reviewed to check if the extracts formed a coherent pattern in each theme, and validity of the themes was assessed against the data material as a whole. Until this point, the data were processed in Norwegian. Then H.A.H. translated the analyzed findings to English. Finally, each theme was discussed by the analytic team and given a name that reflected the "story" it told. A report was then written in collaboration with the other authors.

Ethical considerations

A debriefing team composed of competent professionals was established in case the interviews should elicit problematic memories or emotions. None of the participants expressed a need for such follow-up. On the contrary, several expressed that they were grateful for the opportunity to tell their story of developing psychosis. Furthermore, the participants were informed about the research project through a short conversation with the TOPS team. H.A.H. also provided them with a written note about the study. Additionally, they were informed about potential pros and cons of their participation during a conversation prior to the interviews. In doing all this, informed consent was given before the interview started.

The research project was approved by the Norwegian Regional Committee of Ethics (2015/1218/REK Vest).

Results

We identified three main themes which resonate with our research question: How do young adults experience and understand the process of developing a first episode of psychosis? The first theme portrays the stressful life situations that the participants described as preceding the psychotic experience. The second theme is about how the participants perceived changes in their everyday functioning, yet without linking them to psychosis at that time. Finally, the third theme points to how the participants came to understand their psychotic experience looking back in retrospect. Most participants seemed to adapt their understanding to the mental health services' explanations, while a few were in opposition to such explanations. The themes can be understood as a process which the participants went through.

A stressful life situation: "it had been a very tough winter"

This theme points to how all the participants described having had especially stressful or difficult life situations before the signs of something being wrong, that were later diagnosed as psychotic symptoms, appeared. They described various situations, such as having gone through a break-up with a violent partner, serving time in prison, being unemployed, failing in the education system, experiencing illnesses and death in their close family, using drugs, etc. All these situations were characterized as stressful, either in isolation or stacked on top of other challenges they experienced in their lives.

One participant (3) described how, after having had a tough time being out of work, breaking up with a violent partner, using drugs (amphetamine) and losing a lot of weight, she had hoped that being put in prison would help her address her struggles and get on with her life. However, she felt like the prison workers did not understand her situation and that they just made her life more miserable. Being imprisoned did not contribute positively to her pre-existing mental health issues. She pointed out that: "It became more of a resting place, and . . . I was very much left alone with my thoughts". She added: "For a long period after that I just slept, and, yeah. I didn't want to face the outside world".

For some, their life situation was not that complex to begin with. Yet, certain events, such as exams or school performances, excessive use of cannabis or other drugs, or having experienced attempted rape, seemed to raise their stress level. For example, one participant (8) pointed out that what he perceived as an insult at work escalated from an unpleasant situation to a more chaotic and unwieldy situation which he felt he could not control: "Then, it had become a lot to juggle at the same time . . . ".

Several had experienced illnesses or the loss of close family members. For some, the loss had happened years ago, but was still influencing their everyday life. Others shared how a recent loss had being weighing on them in the period before the psychotic episode (participant 9):

> It had been a very tough winter. Two ill family members. A few problems at school, and so on. Ehm, so it was like, just a lot that had built up over time. And then, it came, a lot came suddenly around Christmas time. Ehm. I started to struggle more.

A peculiar feeling: "I was not in tune with myself"

A common theme in the participants' stories was that they had noticed some changes in their everyday functioning. Yet, at the time they did not think of this change as signs or symptoms of psychosis. Several described how they had slept poorly and/or had little appetite, they thought too much (it was hard to switch off), they talked more or less than usual, and/or they had a peculiar and undefinable feeling. This can be neatly summed up in a quote from one of the participants (3): "I was not in tune with myself".

Typically, the participants described an ambivalence towards the meaning of their experiences. On the one hand, they had a gut feeling that this was something they would need professional help to get through. Most of the participants had already been receiving help in the mental health system, but for problems other than psychosis. On the other hand, they talked themselves into believing that this was nothing serious. For instance, one participant (2), who struggled with hearing voices described how she used to rationalize her experiences:

> "Yes, actually, when I had auditory hallucinations, I thought that it was just a part of another sound, as if my brain just tacked it on and made it into what I was hearing". She continued: "So, I just in a way explained it logically. And tried to explain it with, 'that's just the wind', or 'that's just creaking in the house', or . . . or that kind of thing".

Another aspect of this theme was that the peculiar or unfamiliar feeling seemed to increase with time. The participants described this period as lasting from a few weeks to several years. It was not easy to define exactly when it started or even how long this phase had lasted. In contrast, one participant (6), a young man who described himself as a long-term drug addict, explained how he went into psychosis for exactly 16 days, something he blamed the mental health services for, as they prevented him from taking several barbiturates he had been using for years. He described this experience as mostly involving overly suspicious and scary thoughts.

However, most participants talked about how they felt increasingly chaotic and disturbed, sometimes this was connected to feeling paranoid and/or anxious or scared. For some, this escalated to a point where it became difficult to remember and describe exactly what had happened. Others had a more distinct recollection of how they felt. For example, one participant (7), who had just arrived from studies abroad, described her frustration at the time she decided to seek help in the Norwegian health system:

> Yes, I was very … the reason why I in a way held back from making contact when I came here, was that it was hard for me to assess whether it was just sort of a 'oh, poor me' experience, and if I should just pull myself together, eh, and stuff. So, when I went to the Personal Crisis Support Team, then I was very much, su-, or yes, suicidal idealization, so to say. That I, the best thing was to die, that I wanted, eh, to, like die.

The same participant continued to describe how she felt after a while: " … eh, I wasn't able to do anything. I wasn't able to decide whether I should eat or brush my teeth or cry or, it was just like, I went [round] in a circle".

Redefining the meaning of psychosis: "there are so many layers in life, right?"

The participants' experiences of what they later learned to understand as psychotic symptoms did not match their prior ideas of what psychosis entailed. The psychosis diagnosis in itself was viewed as a frightening event, and it was seen as the very last psychiatric diagnosis they wanted to get. Moreover, people with psychosis were thought of as seriously mentally ill, someone who really had lost their grip on reality – or even crazy mass murderers like they saw in movies. They described their own experiences, when looking back at it, as far less serious than what they had imagined psychosis to be. In fact, they did not understand the difficulties they had experienced as psychosis before engaging with early intervention services.

One participant (3) described how she had changed her understanding of her own psychotic episode after receiving help:

> Yes, so I don't think much about the kind of diagnosis. But in a way, it seems, well, they say that psychosis is a lack of reality. And it is perhaps that lack of reality that has taken quite a while for me to recognize, kind of, in a way. There are so many layers in life, right? And you must find yourself in all these layers, and it can be a bit hard to sort out.

She pointed out that it was hard to understand what was going on while being in the middle of it:

> It is a bit like, you're walking around in kind of a fog, right? And you know that there are people out there who look at you from the outside, so you become a bit like a wounded bird running from place to place, trying to fix her wing.

She added: "But when looking back, I feel I might have been psychotic for several years. Maybe at a milder degree then, but that it increased after a while".

The participants also expressed that they were concerned about getting an "answer" to or explanation for what they were experiencing. Several participants seemed to accept and take onboard the mental health services' explanation. For example, one participant (4) explained:

> Yes, I have learned to understand the symptoms much better. That I am able to, for example when I was at the rehearsals [for a university] during the weekend, then it was, the ones around me, was … When I experience stress, I get very insecure, then I start to believe that others think the same about the thing I am uncertain of … think that others think it too. Before I got help, I didn't understand that … [that others do not have the same thoughts as her in their minds].

However, some were unsatisfied with the answer they had received – or they felt they had found no answers at all. For example, one participant (1) explained:

> I just became irritated, actually. First, they put me on something, a very serious admission [to a mental health hospital]. With people who weren't anything near my, so to say … they went around and hit themselves against

> the wall and . . . that was not me. But actually, the only problem . . . they didn't understand what my problem was. They did not understand anything. They just spent so much time trying to find out if there was something wrong with me. For a very long time, they used, and then they found nothing, in the end . . . and then, I just left. And said, we're done.

Based on the stigma related to psychosis, this was a diagnosis they particularly wanted to avoid. They described different life situations and somewhat diverse psychotic experiences. However, most participants found their own experience less severe than what they had imagined beforehand.

Discussion

We have explored the experiences of ten young adults who had been in contact with an early intervention team and diagnosed with a first episode of psychosis. Through our analysis, we developed three themes: "A stressful life situation", "A peculiar feeling" and "Redefining the meaning of psychosis". These themes illuminate how the participants experience and understand the process of developing a first episode of psychosis.

Firstly, according to our findings, the participants were concerned about getting an answer as to how they should understand the difficulties they were experiencing. Understandably, going through a process of developing and experiencing a first episode of psychosis is not likely to go unnoticed. Hence, being offered an explanation in which symptoms and a diagnosis were at the forefront, may provide some comfort and sense of tangibility. According to Pitt et al. (2009) "naming the problem" was usually experienced as helpful, as it often felt like a relief to get an answer to what was wrong. However, diagnostic labels were also perceived as a source of social stigma and social exclusion. Research on stigma also suggests that such a label may be a burden for an individual's social life in the long run (Gronholm et al., 2017).

Our findings also pointed to another issue related to stigma associated with psychosis in early intervention contexts: Most participants assessed their own experience as "less serious" than what they expected psychosis to be. They saw psychosis as a serious mental illness associated with mass murderers and dangerous people, not something they identified with. The notion of psychosis as a very serious and scary condition might partly explain why participants did not initially relate their own experiences to psychosis. Common explanations for this have been that the person lacks insight into their illness (McCormack et al., 2014), or that they will not acknowledge it as a defense mechanism (Anglin et al., 2014). In many English-speaking countries, efforts have been made to reduce public stigma by replacing "schizophrenia" with "psychosis" (Lasalvia et al., 2015). Yet, Passerello et al. (2019) found a significantly higher number of tweets with negative connotations related to "psychosis"/"psychotic" than "schizophrenia"/"schizophrenic". This was the opposite of what was expected based on the assumption that schizophrenia would be the more stigmatized term of the two. Noiriel et al. (2020) highlight the need to base the terminology more on patients' needs and understandings, and less on the services' needs for labels and categories. At a minimum, services should spend more time on listening to young adults' own subjective experiences and understandings, rather than "automatically" applying a traditional psychoeducational stance. This is also in line with the findings in a bottom-up co-written review of the lived experience of psychosis (Fusar-Poli et al., 2022). Fusar-Poli et al. (2022) conclude that the psychotic experience is idiosyncratic in nature, and cannot necessarily be transferred into the formal clinical frameworks used by professionals.

Secondly, we found a discrepancy between the participants' reported lived experience of what we have described as "a peculiar feeling", and what they later learned to be the conventional conceptualization of psychosis, which correlates with descriptions in earlier research on lived experience of psychosis (Hamm et al., 2018; Møller & Husby, 2000). In our view, this discrepancy may indicate that the participants were not given active roles throughout the process of interpreting and making sense of the difficulties they had gone through. To start with, all participants reported having endured particularly stressful life situations, such as serving time in prison, losing a close relative, or drug use, either as a single event or a string of multiple events. Explaining psychosis as a consequence of multiple distressing life events was found to be a key element in a study focusing on personal meaning-making processes, using in-depth life-story interviews about 20 years after participants first received mental health treatment for psychosis (Bergström et al., 2019). Although the participants in our study did not directly state that they understood their psychotic experience as resulting from several stressful life events, they revealed how their life situations lead up to and culminated in what they later understood to be psychosis.

Moreover, our findings indicate that the participants learned to redefine the meaning of psychosis to be broadly in line with the conventional understanding of the term. Most of them accepted the explanation they were provided without questioning the meaning of this conceptualization of psychosis, which resonates well with the findings of Friesen et al. (2021). Only two participants in our study rejected or questioned the services' explanation, one claiming he got no answer, the other did not get the answer he wanted. The participants who did not agree with the services experienced little room for negotiation. The point here is that meaning-making processes seemingly needed to be in accordance with the services answer to what psychosis "is" to be included in the young adults' meaning-making processes. This is in accordance with what Larsen (2008) found in an ethnographic study on finding meaning in a first episode of psychosis. According to Ritunnano et al. (2021), the role of self-interpretation and meaning-making processes have been under-investigated relative to clinical and biological predictors of the onset of psychosis. Based on qualitative data and psychotherapeutic experience, Geekie (2013), also underlines the importance of clients having the opportunity to discuss their own explanatory models related to their psychotic experience.

Our findings tap into a larger and more profound debate about how useful traditional psychiatric diagnoses really are for those in need of help related to a first episode of psychosis or other serious mental illnesses (Irarrázaval, 2022; Kinghorn, 2020). According to Hari (2018), psychiatric diagnoses can be regarded as checkbox thinking, where the person's stories and meaning-making experiences become secondary to diagnostic assessments. Through psycho-educational training, young adults may learn how to recognize signs of new episodes (Matoba et al., 2016). However, such a focus may also leave them constantly "on watch", preventing them from living a full life. An alternative psychological model is the "Power Threat Meaning Framework" (PTM) (Johnstone & Boyle, 2018). This model promotes constructing a narrative of the reasons behind the person's difficulties and is seen as a collaborative and ongoing process in which relational context, social circumstances and life events are taken into consideration. Seery et al. (2021) investigated effects of psychiatric diagnosis versus a psychological formulation on stigma. They found a significantly higher desire for social distance when a person was presented in psychiatric terms as opposed to personal accounts. However, knowledge in this area is limited, and further evaluation is needed.

Methodological considerations

Reflexive notes were used throughout the interview process to enhance awareness of how the first author's background as a social worker, without professional experience from specialist mental health services, might have influenced her interpretations and the follow-up questions. Additionally, a reflexive team-based analysis method was applied to ensure the data were looked at from more than one researcher's angle. However, all researchers are mainly psychosocially aligned, and thus influenced both the interpretation of the data and our point of departure for the discussion.

The findings from this study are based on 10 in-depth interviews and are therefore limited in generalizability. In addition, the interviews occurred three to twelve months after contact with the early detection team, which may have resulted in them finding themselves in different conditions and circumstances in which to express their experience.

Conclusion

In this study, we asked “How do young adults experience and understand the process of developing a first episode of psychosis?” In summary, the first theme, “A stressful life situation”, illustrates various challenging life circumstances which preceded the psychotic experience, as described by the participants. The second theme, “A peculiar feeling”, concerns changes in the participants’ everyday functioning, which they did not associate with psychosis at the time of those changes. The third theme, “Redefining the meaning of psychosis”, pertains to how most participants came to understand their experience as psychosis after contact with the services. The majority seemed to find that their understanding of psychosis was in line with the mental health services’ explanations, while a few disagreed with these explanations.

We call for more research into young adults’ subjective experiences in this regard in order to provide services with richer understandings of what going through a process of developing a first episode of psychosis feels like.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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