

ORIGINAL ARTICLE

Negotiating the boundaries of psychosis: A qualitative study of the service provider perspective on treatment delay in community mental health

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Aim: Evidence shows that many patients are detected and treated late in their course of illness, and that substantial delay occurs even after entry to mental health services. Although several studies have examined the service user and carer perspectives on treatment delay, few have explored the issue from the service provider perspective. The aim of this study was to broaden our understanding of treatment delay by exploring the service provider perspective on reasons for treatment delay in community mental health services.

Methods: A qualitative study using data from focus group interviews with 33 healthcare professionals in community mental health care. Interview data were digitally recorded and transcribed verbatim, and analysed using a grounded theory approach.

Results: Service providers perceived divergent or conflicting perspectives as the main challenge in early psychosis. Clinical negotiation was chosen as the main term describing the interactions between patients and healthcare professionals: This was observed in 3 overlapping areas: (1) Negotiating the patients status as help-seeker; (2) Negotiating the place and conditions of treatment and (3) Negotiating the meaning of distressing experiences and the timing of treatment options.

Conclusions: This study suggests that delay in initiation of treatment for psychosis in community mental health is related to clinical challenges of early disengagement from services and diagnostic uncertainty. Service providers found negotiating the therapeutic relationship and patient-centred flexibility more useful in ensuring engagement than an assertive outreach approach. Diagnostic uncertainty was resolved through watchful waiting using a distress-overload conceptualization in assessing changes in mental state and service needs.

KEYWORDS

community mental health, early psychosis, negotiation, service provider, treatment delay

1 | INTRODUCTION

Many patients with early psychosis are detected and treated late in their course of illness (Marshall et al., 2005). Recent research has shown that almost half of overall delay occurs after referral to specialist mental health services (Bechard-Evans et al., 2007; Birchwood et al., 2013; Boonstra et al., 2012; Brunet, Birchwood, Lester, &

Thornhill, 2007). These studies suggest that inefficiencies on the part of the healthcare providers could be an important determinant of treatment delay.

There are several quantitative studies on the determinants of treatment delay showing a complex interplay of patient (demographic and illness-related factors) and context factors (family-level factors, societal factors and health service/system-level factors; Compton &

Broussard, 2011). Qualitative studies have examined perceived barriers to accessing appropriate treatment from the service user (Jansen, Wøldike, Haahr, & Simonsen, 2015) and carer perspective (Tanskanen et al., 2011). Few studies have addressed the service provider perspective on the challenges of engaging and assessing individuals with early psychosis in community mental health. Including the service provider perspective could be helpful in gaining a broader understanding of treatment delay and to propose effective strategies for reducing duration of untreated psychosis (DUP).

This study was designed to explore the service provider perspective on the reasons for treatment delay in community-based outpatient services. Our basic research question was: "What are the challenges that providers experience in assessing patient status and engaging them during the early phases of psychosis?" We also asked "What are health professionals doing to meet this?"

2 | METHODS

In order to generate theoretical understandings of the topic, we chose a grounded theory approach, influenced primarily by the work of Glaser and Strauss (Glaser, 1978, 1998; Glaser & Strauss, 1967). Grounded theory analysis is "an inductive, theory discovering methodology that allows the researcher to develop a theoretical account of the general feature of a topic while simultaneously grounding the account in empirical observations or data" (Martin & Turner, 1986, p. 141).

2.1 | Setting

Data for this study came from focus group interviews conducted in community mental health centre (CMHC) located in Nordland county in the north of Norway. The setting is a rural area where people live in provincial towns with long distances between towns. The healthcare system is a two-tier public healthcare system where primary care general practitioners and emergency clinics are gatekeepers for all specialized care. A central hospital located at a distance with a catchment area of 240 000 inhabitants, and the 7 CMHC located in the provincial towns comprise the specialized mental healthcare system. All acute and specialized inpatient care is provided by the central hospital, while the CMHC primarily provide outpatient care, with some beds for non-acute psychiatric problems.

2.2 | Participants

Participants were recruited between October 2010 and March 2011. Centre leaders were asked to suggest 6 to 8 participants selected on the basis of their interest and experience with early psychosis patients. In each focus group, variation in gender, age, professional background and whether they primarily worked in adult or child and adolescence mental health was sought. Only 2 of the centres had specialized early intervention teams, the remaining had generic outpatient clinics. Letters with information on the study were distributed to participants, and the focus groups were conducted at the CMHCs.

2.3 | Data collection

A focus group method was chosen because we wanted to facilitate discussion among participants and explore their collective memory of their daily practice (Krueger & Casey, 2014). The focus groups lasted between 90 and 120 min. Participants were interviewed using an interview guide with several predetermined themes. During the initial focus groups, an open-ended approach was used to explore issues identified as relevant during the evolving conversation. The interview guide was revised in the next focus groups based on what was discovered in previous analysis, and theoretical sampling (Glaser & Strauss, 1967) was used to sample new data that would test or fill out emerging codes and categories. All the focus groups were audio-recorded and transcribed verbatim. All the transcripts were initially coded using the NVivo 9 software.

2.4 | Data analysis

In accordance with grounded theory methodology, data collection and analysis proceeded simultaneously. Initially, open coding was used. This involved line-by-line analysis where indicators for categories were grouped together. Raw data were essentially dissected into small components, and labelled with *in vivo* codes distilled from the participants own words. These concepts were then constantly compared with each other and with new incidents as more data were collected. A core category that explained most of the variation in the participants' main concern was selected during open coding. The next stage of coding, selective coding, involved re-reading the interviews, conducting new interviews and through constant comparison filtering and coding data which were deemed more relevant to the emerging core category. The core category emerged during the first 5 focus groups. Two more focus groups were conducted in the theoretical sampling phase until saturation, where no new data resulted from additional coding or data collection.

The final stage of coding involved theoretical coding or the integration of theoretical codes into a coherent theory. At this stage, memo-making was analytic and focused on defining the core category and its properties. Memos and major categories that had emerged were printed out and hand sorted in visual diagrams, trying out different ways of relating concepts and experimenting with models. The physical sorting of memos and categories ensured that theoretical development was in tune with data. The outcome was a theoretical model that presented the key concepts of the theory and how they related to each other. Two members of the research group analysed the data and consensus discussions were used throughout the data analysis. This collaborative approach was used to ensure that the analysis remained open to the participants own explanations and motives, rather than the researchers preconceptions. Translations of theoretical terms and quotes from the source language to English were done during the late phase of data analysis after discussions in the research team. An external professional was also consulted when working with the final manuscript to avoid subtle meaning differences and to ensure the best English wording in the quotations. An independent study based on the same interview data, but focusing on the ethics of mental health nursing has already been published (Moe, Kvig, Brinchmann, & Brinchmann, 2013).

3 | RESULTS

Each focus group had from 2 to 7 participants. Although the participants often knew each other, the diversity of groups in terms of age, gender, professional background and work place generated important discussions on their experience with this group of patients. See Table 1 for information on participants. Divergent or conflicting perspectives emerged as the main concern in working with young people with early psychosis. The concept of “negotiation” was chosen as the main term describing the basic process involved in the interactions between patients and healthcare professional. This process was observed in 3 overlapping areas: (1) status; (2) place and (3) time. The following quotations have been chosen as representative for each theme.

3.1 | Theme 1: Negotiating status

In reflecting on their experience with patients with an emerging psychosis, the healthcare professionals described the young person as very ambivalent about their role as a help-seeker. One clinician commented:

What we have is a very ambivalent relationship. Do they want help or not? (FG2).

The first step in negotiations is therefore concerned with the patient status as a help-seeker and the healthcare professional status as a helper. The concept of help-seeking implies that a person

TABLE 1 Information about participants in the study (N = 33)

Focus group	N	Mean age	Gender	Professions	Service structure
FG1	5	48.6	M = 3 F = 2	Psychiatrist = 2 Psychiatric nurse = 1 Other = 1	1
FG2	5	42.8	M = 1 F = 4	Psychiatrist = 1 Psychologist = 1 Social worker = 2 Other = 1	3
FG3	4	45	M = 1 F = 3	Psychologist = 1 Psychiatric nurse = 2 Other = 1	2
FG4	7	42.3	M = 2 F = 5	Psychiatrist = 1 Psychologist = 2 Doctor in training = 1 Psychiatric nurse = 2 Other = 1	2
FG5	6	43	M = 2 F = 4	Psychologist = 2 Psychiatric nurse = 3 Other = 2	2
FG6	4	53.8	M = 2 F = 2	Psychiatrist = 2 Psychiatric nurse = 1 Other = 1	1
FG7	2	38.5	M = 0 F = 2	Psychologist = 1 Other = 1	3

1 A generic service with outpatient clinic/inpatient service, with additional dispersed inpatient/d hospitals or day centres for patients with serious mental illness of all ages.

2 A generic service with outpatient clinic/inpatient service, with embedded early psychosis workers.

3 A generic service with outpatient clinic/inpatient service, augmented with a specialist early intervention team.

experiences a problem exceeding personal abilities, and an active or intentional action is made, requesting the assistance from another person. The basic attitude of the healthcare professionals was that this choice had to be made by the young person himself. We characterized this as an enabling attitude.

3.1.1 | Enabling

This attitude is illustrated by the following quotation:

The situation is like this. If it is clearly stated no, then you have to respect that... and ok, but if you change your mind you can contact me again (FG2).

The data also revealed that healthcare professionals perceived the level of distress and need as considerable in patients with emerging psychosis. One clinician said: “It is chaos. They come in with their life in a plastic bag” (FG1). This state of distress often elicited a response of “keeping the patient in mind,” even though the person declined initial attempts at making contact. This can be illustrated with the comment from 1 informant:

We say that the door is open, and we know the person. Give us a sign, if he or she says they are ready, then we try again (FG2).

The young person’s rejection of initial attempts at making contact was not considered final and perceived distress and suspected psychosis kept the patient in the healthcare professionals mind and often resulted in further efforts to promote help-seeking. One healthcare professional illustrated this by the statement:

We spend a lot of time calling or sending text messages. We spend a lot of time being available, we spend a lot of time inviting... (FG2).

3.1.2 | Personalizing

A possible outcome of negotiation about status is that a person eventually accepts the status as an active help-seeker. This outcome was promoted by several other activities by the healthcare professionals, and we discuss these in terms of personalizing and participating.

Efforts of personalizing the contact with the potential patient involved the healthcare professional moving outside his or her own usual role, for example, by sending texts messages or being available for the patient also out-of-hours. One healthcare professional illustrates this by imagining the patients thinking, and noted:

Here is someone who cares. She has made an extra effort, by sending me a personal message (FG2).

Examples of personalizing also included keeping patient on their lists for a longer than required, thus giving “them a ticket back in.” It was a general attitude that this group of patients required a quite different, or unconventional, approach than the average outpatient. One informant said: “being flexible is our approach, its almost as important as a positive treatment relationship” (FG7).

3.1.3 | Participating

Another important strategy to promote help-seeking generated by the data analysis was engaging the patient in a more practical or concrete way. We term this process participating, and 1 informant expressed this process as a need to “becoming a useful person” for the patient.

It can often be a very good situation. That they experience chaos in their economic situation. Then we can come in... (FG1).

Then you can come in and be the one that helps out. Cleans up a little (FG2).

3.2 | Theme 2: Negotiating place

A major concern for healthcare professionals in more rural areas was that of negotiating the physical location of consultations between healthcare professional and patient. There was a general opinion that the “outpatient approach” was not suited to these patients, and also that their pathology and level of dysfunction required something more.

Many of these young people often fall through the net because they don't turn up. They don't want psychotherapy, they can't make any use of it (FG1).

Some patients will not show up. They don't want to come, they don't want contact with mental health services. And you have the duty of confidentiality. Demands on activity makes it impossible to go home to them (FG3).

The solutions created to solve these issues of negotiating place, will be presented under 2 headlines: conditions of treatment and networking.

3.2.1 | Conditions of treatment

Negotiating the conditions of treatment in terms of proximity and distance is illustrated by the following quotations:

Ok. So you don't want to come here and you don't want me visiting. Ok, but can we e-mail each other then? (FG2).

I will try to text him. Asking if...if I can visit some other time. I will not give up so easily. I need to be a little assertive (FG3).

The use of home visits or ambulatory services was not always appreciated by the young person. Perhaps particularly in very small communities, getting visits from mental healthcare professionals was not wanted because it could provoke gossip and rumours, and in such cases the young person and family members preferred travelling to the local CMHC for consultations. The healthcare professionals were sensitive to the issue of social visibility in rural communities. Physical distance and social proximity are defining characteristics of many rural communities, whereas the opposite socio-spatial relationship

often exists in more urban environments. In Table 2 quotations illustrating how these factors were thought to influence the process of help-seeking are provided.

The process of negotiating place was often time-consuming, but the great efforts the healthcare professionals put into this process, revealed that this was considered important. One informant said:

Its very useful to clarify with patients how can we agree on these important meetings. We can make agreements such as: if you don't show up for a meeting, shall I come home to you, or shall I text the day before, two hour before, one hours before. We spend a lot of time on planning how we shall be able to meet (FG7).

When patients did not want to meet the healthcare professional in person, they would sometimes still provide for the person to have carers around him that may promote and respond to later help-seeking efforts. The process of networking was considered important in this respect.

3.2.2 | Networking

Informal networking concerns supporting people in the natural environment of the patient, whereas formal networking mainly concerns establishing treatment contacts with carers from the various primary care services. One healthcare professional described this activity as:

We often work behind the scenes (FG1).

In this rural context, where some municipalities have only 500 to 1000 inhabitants and the CMHC is located at a distance 3- to 4-h away by car or boat, working indirectly by supporting and supervising the municipal primary care services was sometimes the only option available to the healthcare professionals. One informant explained this approach by noting:

We often travel, but it is often primary carers or the school nurse who meet the patient and they report back to us, and then we supervise. And that is often how we need to work (FG2).

In small municipalities, where a handful of people provide these services, workers from different care levels are well known to each other, and these established team relations become useful in the process of negotiating with the young person about the provision of services. Two quotes by the healthcare professionals illustrate this experience:

We often have to adapt how we do things. I mean we don't need a mobile team, but we need to travel regularly to the different municipalities. And there you set up a team, with one or two who regularly meet, and then you bring in the people you need. Like an ad hoc team (FG4).

It is a good thing that you can use primary care workers. They are often the most important people in terms of building a relationship and motivating the patient (FG2).

TABLE 2 The context of help-seeking in a rural community

		Socio-spatial relationships	
		Physical distance	Social proximity
Help-seeking process	Facilitators to help-seeking	You have to be sort of flexible. Where can we meet? Perhaps we should not meet there, but rather in a larger place where there is nobody paying any notice...nobody from the neighborhood (FG6). Our consultation room is everywhere, so to speak (FG1).	You can get several referrals, from family, neighbors, friends and others... So you get a pretty good overview and get to know the case early on (FG5). We have good opportunities to detect people early, because we do a lot of networking. And we have many informants (FG4).
	Barriers to help-seeking	Even if they have doctors and psychologists at the CMHC, they are still far away, at least on a mental level (FG1). This is our main challenge...this last year it has been difficult to get him to turn up for appointments. That is, organizing the practicalities around transportation (FG4).	I have worked with a young man with psychosis this last year. He does not allow home visits. He absolutely does not want to...but at least he comes to every other appointment, and I work closely with his GP. He does not want to involve the local psychiatric services (FG6). There are so many rumors about people, it must be difficult to have so much indirect knowledge, and perhaps it is not even true. This thing about rumors is pretty difficult...In a small community you get a good overview, but for better or worse, so to speak (FG5)

In summary, although the healthcare professionals in this study found many challenges in working in a rural context, they also saw several advantages of being small communities. This became especially obvious in issues around negotiating place. One noted that:

I think we have many advantages, and particularly with this group of patients, in small communities. Compared to larger cities where people often can hide away in an apartment or withdraw without anybody noticing it. That is difficult when you live on an island with maybe 1000 inhabitants. And it is easier for us to work with primary carers. It is more straightforward and there are fewer people to relate to (FG4).

3.3 | Theme 3: Negotiating time

The third theme emerging from the data was negotiating time. The primary issue in negotiating time was often crisis-management. Several healthcare professionals expressed the view that working with young people with a possible psychotic disorder was like "waiting for a crisis to happen." One informant said:

What do you do when someone comes in with a red flag? What do you do then? (FG2).

Patients with a "red flag" were prioritized, and received prompt attention from the healthcare professionals. There was a sense of urgency with these patients, and they often bypassed the formal pathways to care. One of the healthcare professionals noted:

If there is a strong suspicion of emerging psychosis, the patient is accepted right away, as an emergency patient. Then we have to fix the formal status later (FG3).

At the same time, these patients were also considered notoriously difficult to assess, and a consensual opinion among the

healthcare professionals was that although there was a strong sense of imminent crisis, there was at the same time often considerable diagnostic uncertainty. This uncertainty is illustrated in the following quotes:

This is also a challenge, making assessments. Finding out what is the problem, is it psychosis or is it not. That is very challenging (FG5).

It is not a problem if the patient is obviously psychotic. Then it is not a problem, but when the patient is on the border of....and there are many...he scores on everything and... (FG3).

Negotiating time was about the healthcare professionals coming to terms with the patient on where they are on a trajectory towards psychosis, and what kind of treatment options to use at different points on this trajectory. From the data, it also emerged a common understanding among the healthcare professionals about "crisis as opportunity." One informant noted that:

The ticket in is often a crisis situation where everybody comes together and you can find common ground and create a dialogue, and we can agree on: What is the next step? (FG6).

Imminent crisis, on the boundaries of psychosis, thus became an opportunity for negotiation and mutual discussion between healthcare professionals and patients on how to manage the crisis. In the narratives about negotiating time, 3 sub-themes emerged in the analysis: sensing, strategizing and bridging.

3.3.1 | Sensing

Gauging where a patient is on the trajectory towards a full-blown psychosis relied upon a process we termed "sensing." Healthcare professionals emphasized that through participating in the patients' world in a concrete way, seeing the patient interacting with the world

and other people, the patient's mental state could be assessed. One of the informants said:

You know the person. You can see the changes...the small changes...then you can see that the person is becoming ill (FG1).

In many cases, sensing was monitoring mental status, but also knowing when the patients was so unwell that he or she would be ready to discuss hospital treatment. One healthcare professional noted:

The person is on the borderland. He is not functioning, but he is not so ill that you can admit him to the acute wards. We keep an eye on these patients (FG2).

The data indicate conflicting views on the issue of admitting patients. In some respects, admission was considered a necessity, the problem being that many patients in severe distress were admitted too late. Two informants commented:

People are not admitted timely, and there is often a delay (FG4).

What happens today is that we wait until a crisis or some other situation occurs (FG4).

But the clinicians also stated the opposite, that outpatient and ambulatory treatment should be made available so that admission to inpatient services could be avoided. One healthcare professional reasoned that:

But there is often a big question regarding these patients, should they be treated as outpatients or should they be admitted. Home-treatment while they are psychotic or admission to inpatient care, what do we think about this issue? I think that there is no right or wrong. I am against all right or wrong answers regarding this group of patients (FG7).

Sensing the patients' level of distress was paralleled by a process we termed "strategizing," describing the healthcare professionals' processes of preparing for possible future events, either mentally or making practical preparations.

3.3.2 | Strategizing

Even though the attitude towards admitting patients varied, the possibility of a need to admit the patient and to prepare the ground for such an outcome emerged as an important issue. The healthcare professionals used strategizing to make sure that the pathways towards hospitalization could proceed without too many obstacles. Often this process would begin in the very early phases of their contact with the patient, one of the healthcare professionals stated that "you have to work well in peacetime to avoid strife later" (FG1). The healthcare professionals described their practice of strategizing as:

I think it is very useful to make these calls early on. To discuss with others if we think that this patient may need to be admitted later (FG2).

When this process of strategizing was followed by transferring the patient to acute or specialized inpatient treatment, this was termed "bridging" by one of the informants:

We build a bridge to inpatient care. To further treatment there (FG1).

3.3.3 | Bridging

The concept of "bridging" implies that the use of inpatient admission is considered as part of an integrated care pathway. Admission to hospital treatment emerged not as a consequence of failure of the local treatment program, but as a planned for intervention managed from the healthcare professional. One informant expressed their rule in this regard as:

Sometimes we try to aim for, how should I put it, more humane admissions. It does not need to happen right away, while the patient is in their nightgown and barefoot... (FG5).

When admission is due, then it should be planned and prepared for. Preferably with a visit to the unit before they are admitted. I think that we often have contributed to this being the case (FG7).

For the healthcare professionals, useful functions for inpatient care are the management of crisis situations. Other functions for inpatient care included assessment, diagnostic work-ups and initiation of medication:

I think that when first episode patients are detected, there needs to be a service for admission, and quick assessment, evaluation and perhaps medication (FG1).

Experiences of admitting to the wards at the hospital could be variable. One concern was that because of the young persons' ambivalence towards admission, once they had motivated the patients to accept an admission, the service response of the wards could be lagging and therefore destroys their motivating efforts:

The ambivalence about this is prominent. If they say yes to admission one day, we should be able to offer it promptly. Then they would accept admission more easily, but if they have to wait maybe two weeks for an available bed, then they may have turned on you and you have to go through the entire process once again (FG7).

4 | DISCUSSION

The clinical encounter is not explicitly or usually defined as conflicted. However, our analysis revealed that service providers perceive divergent or conflicting perspectives as an important clinical challenge in

early psychosis, making clinical negotiation a central process. The themes and subthemes that emerged from this study demonstrate how challenges in engaging and assessing patients with early psychosis could potentially delay initiation of treatment for psychosis.

4.1 | Service engagement and treatment delay

Our analysis revealed that healthcare professionals often experienced early psychosis patients as ambivalent and reluctant at first contact. This is consistent with other studies finding disengagement rates up to 50% among adolescents and young adults in mental health (Lal & Malla, 2015). Our finding that the risk of disengagement is higher when initiating treatment is also consistent with other studies (Wells et al., 2013). The healthcare professionals identified “gossip and rumours” or perceived stigma as an important barrier to help-seeking and engagement. This is in line with previous quantitative and qualitative studies finding an association between perceived stigma and delayed help-seeking (Clement et al., 2015). Furthermore, our participants stated that the characteristics of social proximity and visibility could make stigma an even more prominent concern in rural communities, a finding consistent with other studies documenting high rates of stigma-related barriers in rural areas (Gulliver, Griffiths, & Christensen, 2010). The socio-spatial relationship of rural communities may also shape the help-seeking process and influence the mode of entry to healthcare services. The healthcare professionals in this study indicated that social proximity also had an impact on how the families and social networks of young people interact with the treatment system. Examples included family members and others making informal referrals or acting as informants before initiating help-seeking. Although help-seeking ultimately was perceived as an individual choice by the young person, there was also an awareness that initiation of help-seeking could often be a family decision rather than an individual decision or choice. This is consistent with previous findings of a variety of modes of entry into mental health services, including a pattern where young people have unclear motives and are “muddling through” the healthcare system (Pescosolido, Gardner, & Lubell, 1998). Entry to services either by choice, coercion or “muddling through” is probably determined by both individual (gender, age, perceived stigma and symptoms) and structural (accessibility and social networks) factors (Rickwood, Deane, & Wilson, 2007). The findings in this study highlight the impact of the social context on the help-seeking process.

Initial service disengagement was particularly related to problems of non-attendance and treatment drop-out. The participants described several strategies to meet the challenge of early disengagement, and these were often other than those recommended in national treatment guidelines and academic research. The assertive community approach has been a model for many early intervention teams (Nordentoft, Rasmussen, Melau, Hjorthøj, & Thorup, 2014), and proponents of this approach have suggested that problems with disengagement should be met with increased assertiveness among referrers and early intervention services (Nordentoft et al., 2011). Our findings show that this criterion of assertiveness was perceived as difficult to enforce in initial engagement with patients. The service providers in this study maintained that patient choice and patient-

centred flexibility were more important to ensure continued engagement with services. Rather than using an assertive approach, our informants found a negotiation approach to service engagement more useful. These negotiations often concerned divergent perspectives between service providers and patients regarding the reasons that individuals present to mental health services. Identifying and clarifying the individuals perceived needs, and becoming a useful person was considered important in the early phases of engaging patients. This is consistent with the findings in other qualitative studies that patients often disengage from services because there are disagreements on service needs and relationships issues (Smith, Easter, Pollock, Pope, & Wisdom, 2013). Our results suggest that rather than engaging early psychosis patients assertively, a model focusing on negotiating the therapeutic relationship and patient-centred flexibility could be a more appropriate model for early intervention services.

4.2 | Diagnostic uncertainty and treatment delay

Negotiating time emerged in the analysis as a description of the process of resolving the conflict between the sense of urgency invoked by suspected psychosis and awaiting greater diagnostic clarity or allowing more time to let the relationship develop. Consistent with recent studies on the initial complaints of first-episode patients (Falkenberg et al., 2015), our participants found that patients often presented with ambiguous symptoms or “symptoms of everything.” Symptoms themselves became a subject of negotiations, and uncertainty often revolved around when to regard distressing experiences as non-specific symptoms, prodromal signs or psychotic symptoms. These difficulties in defining the boundaries of psychosis are also discussed in the academic research literature (Heinimaa & Larsen, 2002), as well as in clinical settings (Handest & Nordgaard Frederiksen, 2013). A recent study found that among first contact patients reporting at least 1 psychotic symptom, the majority still received a non-psychotic diagnosis (Boonstra, Wunderink, Sytema, & Wiersma, 2008). It has therefore been suggested that professionals often adopt a passive “wait-and-see” approach when confronted with diagnostic uncertainty, thus prolonging treatment delay (Singh, 2005). In contrast, our participants response could rather be described as “watchful waiting” approach. Rather than discharging reluctant patients with an ambiguous first presentation, they were often scheduled for follow-up assessments and the terms sensing, strategizing and bridging emerged in the analysis as a description of this active approach in resolving diagnostic uncertainty. The emphasis on sensing level of distress also suggests that in addition to using the traditional diagnostic or “criteriological” model on detecting psychosis, our participants also implicitly used a distress-overload conceptualization in assessing mental state and service needs (Wells & Brook, 1989). Clinical guidelines for detecting early psychosis have an almost exclusive focus on positive psychotic symptoms (ie, delusions and hallucinations; Preti, Cella, & Raballo, 2014). However, several studies have documented that a break in the functional curve often precede overt symptoms in the majority of patients (Addington, Penn, Woods, Addington, & Perkins, 2008; Häfner et al., 2003; Parnas, Schulsinger, Schulsinger, Mednick, & Teasdale, 1982; Woodberry et al., 2014). A pattern of sudden change in several areas, including academic, social, affective and

existential change, will often suggest development of psychosis rather than any other mental disorder (Møller & Husby, 2000). It has been argued that an unintended consequence on the strong focus on positive psychotic symptoms, and the relative neglect of functional decline, negative symptoms and existential change, is that many patients with symptom-poor or unconventional presentations are detected late (Jones & Shattell, 2016; Preti et al., 2014). Our finding on watchful waiting suggests that early detection could benefit from a broader and more global approach to assessment of psychosis, including aspects of the psychosocial context and level of distress as additional indicators of psychosis.

4.3 | Limitations

This study had several limitations that should be acknowledged. First, the participants in our study worked in rural context, which may limit generalizability. Second, service disengagement and diagnostic delay are only 2 of the many variables that potentially influence treatment delay, and these findings should not be considered a comprehensive model of treatment delay. Third, the grounded theory model generated in this study should be interpreted with caution. The study was retrospective and vulnerable to recall bias. However, the findings on potential sources of treatment delay in community mental health are in accordance with other studies, and serve to validate these. Finally, in accordance with grounded theory methodology, it would have been interesting to explore the patients experience with the health-care system to complete and contrast the service provider perspective. In retrospect, this would certainly be the lacuna that we would like to fill.

4.4 | Implications

This study highlights the dual aim of early intervention services to reducing treatment delay and promoting the use of non-coercive pathways. Our findings show that achieving both outcomes is often a balancing act between the sense of urgency in reducing DUP and developing a helping relationship with the patient. Rather than resolving problems of disengagement and non-attendance with a more assertive approach, our findings suggest that developing guidelines based on a model of clinical negotiation may be a viable option (Eisenthal, Emery, Lazare, & Udin, 1979). Our analysis also revealed that the balancing act between the urgency of reducing DUP and waiting for diagnostic clarity can often be difficult in community care. Symptoms are expressed in a dialogical encounter between patients and healthcare professionals. It is only through a negotiation of meaning that often indistinct experiences become recognized as indicators of psychosis. Our analysis suggests that in real-world settings, a global evaluation patients and the broader psychosocial context are viewed as important for recognition and early detection of psychosis.

5 | CONCLUSION

Few studies have examined treatment delay in community mental health from the perspective of service providers. Although our

participants found that disengagement from services and diagnostic uncertainty to be common and associated with treatment delay, the results from this study also revealed important insight on how to meet these clinical challenges. An approach based on negotiating the boundaries of psychosis was proposed as a viable model for early intervention practice. This study suggests that the concept of treatment delay is complex, and a broader understanding of this concept should involve several perspectives, including that of the service providers. The findings on the value of a clinical negotiation approach could inform future research and possibly be integrated in new models of care.

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REFERENCES

- Addington, J., Penn, D., Woods, S. W., Addington, D., & Perkins, D. O. (2008). Social functioning in individuals at clinical high risk for psychosis. *Schizophrenia Research*, 99, 119–124.
- Bechara-Evans, L., Schmitz, N., Abadi, S., Joober, R., King, S., & Malla, A. (2007). Determinants of help-seeking and system related components of delay in the treatment of first-episode psychosis. *Schizophrenia Research*, 96, 206–214.
- Birchwood, M., Connor, C., Lester, H., Patterson, P., Freemantle, N., Marshall, M., ... Singh, S. P. (2013). Reducing duration of untreated psychosis: Care pathways to early intervention in psychosis services. *The British Journal of Psychiatry*, 203, 58–64.
- Boonstra, N., Sterk, B., Wunderink, L., Sytema, S., De Haan, L., & Wiersma, D. (2012). Association of treatment delay, migration and urbanicity in psychosis. *European Psychiatry*, 27, 500–505.
- Boonstra, N., Wunderink, L., Sytema, S., & Wiersma, D. (2008). Detection of psychosis by mental health care services: A naturalistic cohort study. *Clinical Practice & Epidemiology in Mental Health*, 4, 29.
- Brunet, K., Birchwood, M., Lester, H., & Thornhill, K. (2007). Delays in mental health services and duration of untreated psychosis. *Psychiatric Bulletin*, 31, 408–410.
- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., ... Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*, 45, 11–27.
- Compton, M. T., & Broussard, B. (2011). Conceptualizing the multifaceted determinants of the duration of untreated psychosis. *Current Psychiatry Reviews*, 7, 1–11.
- Eisenthal, S., Emery, R., Lazare, A., & Udin, H. (1979). "Adherence" and the negotiated approach to patienthood. *Archives of General Psychiatry*, 36, 393–398.
- Falkenberg, I., Valmaggia, L., Byrnes, M., Frascarelli, M., Jones, C., Rocchetti, M., ... Fusar-Poli, P. (2015). Why are help-seeking subjects at ultra-high risk for psychosis help-seeking? *Psychiatry Research*, 228, 808–815.
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Aldine Pub Co: New Brunswick, Canada.

- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: A systematic review. *BMC Psychiatry*, *10*, 113.
- Häfner, H., Maurer, K., Löffler, W., an der Heiden, W., Hambrecht, M., & Schultze-Lutter, F. (2003). Modeling the early course of schizophrenia. *Schizophrenia Bulletin*, *29*, 325–340.
- Handest, P., & Nordgaard Frederiksen, J. (2013). Why is it so difficult to diagnose schizophrenia? *Ugeskrift for Laeger*, *175*, 2748–2749.
- Heinimaa, M., & Larsen, T. K. (2002). Psychosis: Conceptual and ethical aspects of early diagnosis and intervention. *Current Opinion in Psychiatry*, *15*, 533–541.
- Jansen, J. E., Wøldike, P. M., Haahr, U. H., & Simonsen, E. (2015). Service user perspectives on the experience of illness and pathway to care in first-episode psychosis: A qualitative study within the TOP project. *The Psychiatric Quarterly*, *86*, 83–94.
- Jones, N., & Shattell, M. (2016). Not what the textbooks describe: Challenging clinical conventions about psychosis. *Issues in Mental Health Nursing*, *37*, 769–772.
- Krueger, R. A., & Casey, M. A. (2014). *Focus groups: A practical guide for applied research*. Thousand Oaks, CA: Sage Publications.
- Lal, S., & Malla, A. (2015). Service engagement in first-episode psychosis: Current issues and future directions. *Canadian Journal of Psychiatry*, *60*, 341–345.
- Marshall, M., Lewis, S., Lockwood, A., Drake, R., Jones, P., & Croudace, T. (2005). Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: A systematic review. *Archives of General Psychiatry*, *62*, 975–983.
- Martin, P. Y., & Turner, B. A. (1986). Grounded theory and organizational research. *The Journal of Applied Behavioral Science*, *22*, 141–157.
- Moe, C., Kvig, E. I., Brinchmann, B., & Brinchmann, B. S. (2013). Working behind the scenes: An ethical view of mental health nursing and first-episode psychosis. *Nursing Ethics*, *20*, 517–527.
- Møller, P., & Husby, R. (2000). The initial prodrome in schizophrenia: Searching for naturalistic core dimensions of experience and behavior. *Schizophrenia Bulletin*, *26*, 217.
- Nordentoft, M., Austin, S., Bertelsen, M., Jeppesen, P., Jørgensen, P., Melau, M., ... Thorup, A. (2011). Treatment of first-episode psychosis patient, psychosocial aspects. *Drug Discovery Today: Therapeutic Strategies*, *8*, 37–41.
- Nordentoft, M., Rasmussen, J. O., Melau, M., Hjorthøj, C. R., & Thorup, A. A. E. (2014). How successful are first episode programs? A review of the evidence for specialized assertive early intervention. *Current Opinion in Psychiatry*, *27*, 167–172.
- Parnas, J., Schulsinger, F., Schulsinger, H., Mednick, S. A., & Teasdale, T. W. (1982). Behavioral precursors of schizophrenia spectrum. *Archives of General Psychiatry*, *39*, 658–664.
- Pescosolido, B. A., Gardner, C. B., & Lubell, K. M. (1998). How people get into mental health services: Stories of choice, coercion and “muddling through” from “first-timers”. *Social Science & Medicine* (1982), *46*, 275–286.
- Preti, A., Cella, M., & Raballo, A. (2014). Preventing or masking psychosis? Possible unintended consequences of the ultra high-risk strategy. *Schizophrenia Research*, *153*, 241–242.
- Rickwood, D. J., Deane, F. P., & Wilson, C. J. (2007). When and how do young people seek professional help for mental health problems? *The Medical Journal of Australia*, *187*, S35–S39.
- Singh, S. P. (2005). Early intervention in psychosis: Obstacles and opportunities. *Advances in Psychiatric Treatment*, *11*, 71–78.
- Smith, T. E., Easter, A., Pollock, M., Pope, L. G., & Wisdom, J. P. (2013). Disengagement from care: Perspectives of individuals with serious mental illness and of service providers. *Psychiatric Services*, *64*, 770–775.
- Tanskanen, S., Morant, N., Hinton, M., Lloyd-Evans, B., Crosby, M., Killaspy, H., ... Johnson, S. (2011). Service user and carer experiences of seeking help for a first episode of psychosis: A UK qualitative study. *BMC Psychiatry*, *11*, 157.
- Wells, J. E., Browne, M. O., Aguilar-Gaxiola, S., Al-Hamzawi, A., Alonso, J., Angermeyer, M. C., ... Kessler, R. C. (2013). Drop out from out-patient mental healthcare in the World Health Organization, World Mental Health Survey initiative. *The British Journal of Psychiatry*, *202*, 42–49.
- Wells, K. B., & Brook, R. H. (1989). The quality of mental health services: Past, present, and future. In J. L. Taube, D. Mechanic, & A. A. Hohman (Eds.), *The future of mental health services research* (pp. 203–224). Rockville, MD: US Department of Health and Human Services, NIMH.
- Woodberry, K. A., Serur, R. A., Hallinan, S. B., Mesholam-Gately, R. I., Giuliano, A. J., Wojcik, J. D., ... Seidman, L. J. (2014). Frequency and pattern of childhood symptom onset reported by first episode schizophrenia and clinical high risk youth. *Schizophrenia Research*, *158*, 45–51.

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